

# **PSYKOLOGISK FAKULTET**

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Exploring the Experience of Having an Eating Disorder and Blogging about the Illness.

An Interpretative Phenomenological Analysis.

# HOVEDOPPGAVE

Profesjonsstudiet i Psykologi

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Høst 2011

Supervisor Norman Anderssen I think it was just that I knew that there was always someone there who watched me, who managed to read my thoughts and managed to take part in my misery.

#### Abstract

Eating disorders are serious and stigmatized illnesses, that may cause profound damages to the people afflicted. Many people with eating disorders turn to the Internet in order to meet likeminded and obtain support, for instance through blogs. Blogging has become an important arena for social participation for many people. The aim of this qualitative study is to explore the experience of having an eating disorder and blogging about the illness. The study consists of nine in-depth interviews with patients diagnosed with an eating disorder who have experiences with therapy, and with blogging about their illness. By using an Interpretative Phenomenological Approach (IPA), we wanted to capture the patients' unique experience of the phenomenon. An inductive analysis resulted in seven categories of meaning, which illustrate important aspects of the participants' experience; 1) Sense of community, 2) The power of the audience, 3) Self-representation online: is this the real me?, 4) The experience of writing, 5) The mutual relationship between blog activity and psychological state, 6) Writing as therapy and 7) Blogging in relation to the mental health care: skepticism and acceptance. The results may be relevant to the mental health care when meeting patients who blog.

#### Sammendrag

Spiseforstyrrelser er alvorlige og stigmatiserte lidelser som kan ha alvorlige skadevirkninger for de som er rammet. Mange mennesker med spiseforstyrrelser benytter Internett for å møte likesinnede og oppnå støtte, for eksempel gjennom blogger. Blogging har for mange mennesker blitt en viktig arena for sosial deltakelse. Denne kvalitative studien har som mål å utforske opplevelsen av å ha en spiseforstyrrelse og blogge om lidelsen. Studien består av ni dybdeintervjuer med pasienter som lider av spiseforstyrrelser. De har erfaringer med terapi, og med å blogge om sin sykdom. Gjennom en fortolkende fenomenologisk tilnærming (IPA), belyses pasientenes unike opplevelse av fenomenet. En induktiv analyse av intervjuene ledet til syv meningsbærende kategorier som illustrerer viktige aspekt ved deltakernes opplevelse; 1) Følelse av tilhørighet, 2) Publikums betydning, 3) Selvrepresentasjon på internett: er dette den virkelige meg?, 4) Opplevelsen av skriving, 5) Det gjensidige forholdet mellom bloggaktivitet og psykisk tilstand, 6) Skriving som terapi og 7) Blogging i forhold tilbehandlingsbehandling: skepsis og aksept. Resultatene kan være relevante for helsevesenets praksis i møte med bloggende pasienter.

#### Acknowledgements

This study is the result of a chance encounter, which led to a following collaboration. In the fall of 2009, we presented a poster on the "pro-ana" trend on the Internet at a conference for social psychology at the University of Bergen. We were approached by professor Ole Dreyer, who encouraged us to contact his colleague, professor Finn Skårderud who became our research partner. We will therefore start by thanking Ole Dreyer for introducing us, and consequently making this study possible.

Further, we would like to thank our supervisor, professor Norman Anderssen, for valuable guidance and suggestions, especially on critical thinking and methodological issues. We would like to thank our research partner, professor Finn Skårderud, for his help with practical arrangements concerning the recruitment of participants and the execution of the interviews. Additionally, we would like to thank him for valuable input derived from his theoretical and clinical expertise, and his willingness to share his personal experiences within this field.

We would like to give special acknowledgement to our informants. Their courage to open up, and willingness to describe, interpret and reflect upon their experiences have been invaluable for the results. This may have been challenging for them, as they have also explored and shared the less positive aspects of their blogging activities. We are very grateful for their participation.

We are thankful to Ella Mannes Johansen and Erlend Rørvik for their helpful comments and assistance in proofreading the thesis. Further, we thank all of our friends and family members who have listened to and shown an interest in our project, which has been inspiring in our work.

Finally, we would like to emphasize our ability to cooperate and work well together. All three of us have participated in every step of the process; planning and designing the project, carrying it out and analyzing the results. We would thus like to thank each other for making this process a fun and interesting endeavor.

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# **Table of contents**

Abstract
SammendragIl
AcknowledgementsIII
Introduction1
The Internet and blogging1
Motivation to blog
Impression management and self-representation
Self-disclosure, authenticity and forming relationships online5
Disclosure of a "true self"?6
Identity online7
Ingroup formation7
Eating disorders8
Eating disorders, identity and group-affiliation
Eating disorders, shame and stigma12
Social support online and other positive effects of Internet use
Potential negative consequences of Internet use among patients with EDs14
Writing as therapy
Eating disorders and therapy through writing
Self-disclosure through blogging
Summary and aim20
Method21
Methodological Approach21
Design
Recruitment
The participants
The Interviews
Transcription25
Data Analysis25
Validity, generalizability and reflexivity
Validity27

Generalizability	
Reflexivity	
Ethical Concerns	
Results	
Sense of community	
Online community providing a sense of belonging	
Inspiration to recover	
Establishment of friendships	
Belonging to a group and compliance to norms	
Forum as a closed community	
The power of the audience	
Recognition, support and containment	
Vulnerability to feedback from the audience	
Not knowing who the audience is	
Being valuable – inspiring others and sharing one's knowledge	40
Avoiding misunderstandings and forestalling the audience	41
Expectations from readers causing pressure	42
Self-representation online: is this the real me?	
Authenticity and self-representation	
Exposing versus protecting oneself	
On anonymity	
The blog posts as snapshots	
The experience of writing	
The writing process	
Different venues for writing	
Writing versus face-to-face interaction	
The mutual relationship between blog activity and psychological state	
Triggering	
Their own negative experience of being triggered	
The effects of keeping an optimistic versus a pessimistic focus	
Variation in writing due to psychological state	
The importance of the blog related to the strength of the ED	
The development of the blog's content	

Writing as therapy	56
Changing one's view of the ED through blogging	56
Reducing shame	57
"Getting it out"	58
The blog as a means to improve, remember and stay focused	59
Blogging as a supplement to traditional therapy	59
Blogging in relation to the mental health care: skepticism and acceptance	60
Experiences with the mental health care	61
Blogging while being hospitalized	61
Therapists as readers	62
Blogging behind others' backs	62
Advice for the mental health care	63
Discussion	64
Motivations to blog	65
Advantages concerning the social interaction online	
Friendship formation	
Self-representation; real me = "the blogged me"?	66
Coming out to friends and family	67
Feeling competent	68
Possible disadvantages concerning the social interaction online	69
Negative focus	69
Disinhibition	70
Ingroup and extreme community	70
Immersing oneself in the world of EDs	72
The blog activity as therapeutic	73
Writing as therapy	73
Alexithymia	74
Blogging and the mental health care	75
Methodological issues	76
Future research	78
Conclusion	79
References	81

Appendix A: Invitational letter	94
Appendix B: Interview guide	96
Appendix C: Overview of nodes	106
Appendix D: Excerpts of analysis	
Appendix E: Translation of quotations	110
Appendix F: REK approval	111

Table 1: An overview of the cal	egories and subcategories	
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#### Introduction

Eating disorders are serious and potentially lethal conditions affecting many people in the world. They are often associated with massive emotional pain. This pain often becomes evident through the way the afflicted relate to their bodies. Eating disorders are subject to much attention within the health professions, and there have been numerous attempts to understand and explain these conditions since they were first described. This thesis will examine a relatively new phenomenon: patients' blogging about their eating disorders on the Internet. In this introduction, we will present the theoretical framework in three parts; the Internet and blogging; Eating disorders; and Writing as therapy. We will start by describing the practice of blogging and exploring the various possibilities that the Internet in general provides regarding self-representation, identity formation and establishment of relationships. Further, we will address eating disorders and how they can sometimes become a part of identity, as well as how blogging and Internet use may contribute to this. Here, we will also address the stigma related to eating disorders and the potential consequences of this stigma. Finally, we will describe studies on writing as a therapeutic tool, both in the normal population and in patients suffering from eating disorders.

# The Internet and Blogging

The Internet has become an important venue for social interaction, especially among young people. People are sharing aspects of their daily lives, talking about their interests with likeminded others, and keeping in touch with family and friends through e-mail, chat rooms, instant messaging and other means (McKenna, Green, & Gleason, 2002). Referring to Internet home pages, John Seabrook stated the following in 1995: "a home in the real world is, among other things, a way of keeping the world out [...] An online home, on the other hand, is a little hole you drill in the wall of your real home to let the world in" (as cited in Chandler, 1998). A relatively recent phenomenon is called weblogs, or *blogs* (Herring,

1

Scheidt, Bonus, & Wright, 2004). The blog is seen as a continuation of the home page, and contains posts that the owner of the blog has written (Farrell & Drezner, 2008). What is recognized as the present-day format of blogging first appeared in 1996, and the term weblog was first applied to it in 1997. Herring et al. (2004) formally define blogs as frequently modified web pages, in which dated entries are listed in reverse chronological sequences.

Blogs can serve different purposes. A blog can for instance function as a personal diary, as a web page for sports commentary, a place for fashion updates, celebrity gossip, political commentary, or it can have several functions simultaneously (Farrell & Drezner, 2008). The blog is public for everyone who wants to read, and the readers of the blogs can comment on the posts right after they are released online (McNeill, 2003). The comment link is often placed under each blog post and readers affiliate with the author by commenting on a post (Lenhart, 2005).

The number of blogs increased dramatically in the beginning of the third millennium, from less than fifty in 1999 (Mead, 2000, cited in Farrell & Drezner, 2008, p. 5) to between 2.4 and 2.9 million active blogs in 2003 (Wolff, 2003, June 23). The Pew Internet & American Life Project reported in 2005 that 7 % of Internet users, or close to 9 million adults over 18 years old, kept their own blog at the time of the study, whereas 19 % of U.S. adolescent Internet users (4 million teens) reported having ever kept a blog (Lenhart, 2005). In November 2011, "blogpulse.com" indicated that there were 176 million identified blogs in the blogosphere ("BlogPulse," 2011, November 11). Because of their popularity, blogs are now recognized as a form of news media. However, unlike traditional news media, most blogs are created by ordinary people (Liao, Liu, & Pi, 2011). The readers of blogs are also ordinary people, and Lenhart (2005) finds that in the U.S., 27 % of adult Internet users and 38 % of adolescent Internet users read some blogs. A topic of interest is the underlying motivation for this activity. **Motivation to Blog.** The Pew Internet Project blogger survey found that the American blogosphere is dominated by those who use their blogs as personal journals (Lenhart & Fox, 2006). Two groups emerge from the survey; those who view their blog as a personal and private hobby, and a smaller group who view their blog as a more timeconsuming and public endeavor, comparable to journalism. For both groups, the primary motivation to blog seems to be the need to express themselves creatively and to record their personal experiences (Lenhart & Fox, 2006).

On the other hand, Nardi, Schiano, Gumbrecht, and Swartz (2004) describe five major motivations for blogging: documenting one's life; providing commentary and opinions; expressing deeply felt emotions; articulating ideas through writing; and forming and maintaining community forums. For instance, documenting one's life helps one keep family and friends abreast of life events. Nardi et al. (2004) claim that expressing deeply felt emotions through blog posts may cause a feeling of catharsis: A blog might serve as a relief valve. Some people are motivated to blog because it allows them to test out their ideas on an audience, and for some people who feel that they were never heard while growing up, even a small audience can be meaningful. Finally, Nardi et al. state that blogs give people a place to "shout" or express their opinions. Sometimes, this is done by writing to an audience of total strangers, and sometimes the purpose is to communicate to friends and family.

**Impression management and self-representation.** "Impression management" is a phenomenon that was first described by Goffman (1959). He explains how people actively attempt to present themselves to others in a specific way, thereby influencing others' impression of them (Goffman, 1959). According to him, people play different roles in life, as if on a stage. The way we present ourselves to others contributes in creating one's "on stage" personality, or "persona".

According to Goffman (1959), people use verbal and non-verbal communication to express their identity. As bloggers are presenting personal material, one could say that they are engaging in a form of self-representation. Self-representation seems to be facilitated by the Internet, as one is not restricted by characteristics that might reveal parts of one's "offstage" self, such as body language, appearance, ethnicity or age (Valcheva, 2009).The Internet thus offers a unique possibility when it comes to choosing how one wants to appear. Turkle (1995) was the first to describe how the World Wide Web, with its relative anonymity and different fields of social interaction creates a virtual laboratory, where participants can explore and experiment with different aspects of their selves. By creating online selfrepresentations, one has the opportunity to choose which aspects of one's personality to represent and emphasize (Turkle, 1995). Users of the social networks are more in control when it comes to presenting themselves in a certain way online than when they are in face-toface communication (Krämer & Winter, 2008).

McKenna and Bargh (1999) claim that online communication lacks the "gating features" of face-to-face interaction, which means that body language, physical appearance, tone of voice, and other attributes that would be detectable in normal interaction are absent. Skårderud (2003) highlights the importance of the possibility to hide one's body when communicating online. It is argued that the Internet releases people from the expectations and limitations of their physical environment, and the costs and risks of being judged for their statements or identities are strongly reduced. This is especially evident when these identities are not shared by the rest of society (Bargh, McKenna, & Fitzsimons, 2002).

Some studies point to the fact that many of those who use the Internet as a social arena experience a tension between pressures to exercise impression management and a desire to present an authentic sense of self (Ellison, Heino, & Gibbs, 2006). However, it has been demonstrated that most online self-representations are surprisingly accurate and users

claim not to engage in "playing with identities" (Machilek, Schütz & Marcus, 2004, as cited in Krämer & Winter, 2008)

Self-disclosure, authenticity and forming relationships online. The "gating features" that affect normal social interaction may inhibit people who are less attractive or socially skilled when developing close friendships where one engages in self-disclosure (McKenna & Bargh, 1999). Self-disclosure can be described as sharing intimate information about oneself to another person, such as thoughts, feelings and experiences (Derlega, Metts, Petronio, & Margulis, 1993). Derlega et al. (1993) state that self-disclosure is important in relationship development, as well as in relationship maintenance. Another aspect of selfdisclosure is social validation; receiving validating feedback regarding one's thoughts and feelings. Derlega and Chaikin (1977) note that people sometimes engage in a greater degree of self-disclosure with strangers than with people they know relatively well. This may be explained by the stranger's lack of access to one's social circle, which reduces the risk of other relationships being violated.

One may question whether real and profound relationships can occur when socializing online. Cummings, Butler, and Kraut (2002) state that online social interaction does have some value, but that relationships sustained by primarily online interaction do not become as close as those sustained by other means. Contrary to this, McKenna et al. (2002) report that profound and meaningful relationships do form on the Internet, and that these relationships appear to be stable over time. These authors also argue that when people meet on the Internet, in the absence of gating features, they like each other more than if they had initially met face-to-face. A parallel can be drawn to an older study by Gergen, Gergen, and Barton (1973) who reported that people who initially met in the dark not only engaged in more self-disclosure, but also liked each other more than people meeting in a room that was brightly lit. Skårderud (2003) claims that online interaction is related to reduced thresholds for disclosure, and that

this can be especially useful for persons struggling with shame, secrets and isolation.

**Disclosure of a "true self"?** McKenna et al. (2002) discuss what is revealed during self-disclosure. According to the authors, a "real me" is sometimes disclosed, which is the version of the self that a person believes to be true. This self is allegedly not presented to others in most situations (McKenna et al., 2002).

Larsen (2007) however, argues that social activity online can be seen as a continuation of people's offline lives, and that most people strive to be as sincere as possible. She claims that critics of social networking sites lack the understanding of what they are really about. A study by Valentine and Holloway (2002) demonstrated that children's online and offline worlds are not oppositional or unconnected, but rather mutually constituting. They hold that the social and the technical always co-develop, and that the children's online identities and relationships are no less "real" than those encountered offline. Further, Valentine and Holloway's (2002) study indicated that online activity does not harm offline friendships. Instead, it pointed to examples of children who re-establish friendships with friends they have lost contact with by catching up online. Along the same line of research, several studies have demonstrated that the boundary between the two spheres is blurred (boyd, 2006; Larsen, 2007).

Suler (2004) has described an "online disinhibition effect". He uses this term to explain how many people loosen up, feel less restrained, and express themselves more openly when online. Thus, people are more likely to engage in self-disclosing when interacting on the Internet. Suler (2004) claims that rather than revealing an underlying "true self", the disinhibition can be seen as a shift to another constellation within self-structures. Suler argues that several factors are involved in the "disinhibition effect". Among other things, he claims that anonymity makes people feel less vulnerable about self-disclosure and acting out, and that being invisible gives people courage to visit places and do things that they would not otherwise do.

**Identity online.** Thomas Erickson (1996) claims that personal home pages are not only being used to publish information, they are also being used to construct identity. One of the authors of home pages interviewed by Chandler (1998) stated that posting on his page helps him define who he is. Another author stated that publishing his feelings helps him validate them.

The Internet and blogging offer a possibility of receiving responses from others about one's self-representation in a direct manner. Already in 1902, Cooley described this process happening in the physical environment, and labeled it "the looking-glass self" (Cooley, 1964). According to him, the way others respond to a person affects how he or she subsequently represents and perceives him- or herself. This phenomenon can also be applied when considering identity and self-representation online: One's identity can be created on the basis of responses from others. When reading these responses by others, a reflexive creation of "cyber-me" is taking place (Robinson, 2007). If one adopts the view on self-development of the symbolic interactionists, this cyber-self can thus be said to be constructed on the same principle as the self in face-to-face interactions (Valcheva, 2009).

Larsen (2007) argues that adolescents deliberately use each other as co-constructors of identity online, by mentioning each other and commenting on each other's Internet activity. Talking about each other in a positive manner allegedly assists in enhancing each other's self-esteem and a positive identity.

**Ingroup formation.** Bloggers can narrow down their preferred communication network by joining what is called a "blogring" (Mantella, 2007). By joining such a ring, the network becomes limited to a group of individuals who share a specific interest or focus. The name of the blogring will appear on the individual's blog. According to Turner, a group exists "when two or more individuals perceive themselves to be members of the same social category" (as cited in Brown, 2000, p. 3). Furthermore, when an individual identifies with a group, the group becomes an ingroup for that person (Tajfel & Turner, 1986). Thus, when a blogger joins a blogring, the ring can be considered an "ingroup" for him/her. One may have several ingroups simultaneously. Having ingroups, however, also implies the existence of outgroups. An outgroup is any group of which a person does not consider him- or herself a member. The concepts "ingroup" and "outgroup" are usually used in the context of intergroup relations and conflicts. Tajfel and Turner (1986) stated that intergroup behavior occurs in interactions where one's actions are governed primarily by group memberships and not by individual qualities. The groups formed on the Internet may have the same effect.

Belonging to a group has implications for the way a person views him- or herself (Brown, 2000). The person is likely to include group membership as an important part of his or her identity, which in turn may have positive or negative consequences for self-esteem. All groups evolve norms that are descriptive for acceptable and unacceptable behavior. These norms help the individual group members predict their environment, and serve as standards for behavior (Brown, 2000).

Blogs are potentially open to dimensions of positive interaction, social support, and even friendships. Feedback from the audience may confirm or acknowledge the bloggers' cognitions, emotions and sense of self (Snider, 2003) In conclusion, it appears that the Internet is a powerful arena for social exchange, one that may affect psychological functioning. It is therefore a topic of interest in the field of psychology.

# **Eating Disorders**

Eating disorders, hereafter called EDs, is a denotation for several conditions, where those affected display an over-concern with body weight and shape (Skårderud, 2007a). Different types of EDs include anorexia nervosa (AN), bulimia nervosa (BN), eating disorder not otherwise specified (EDNOS) and binge-eating disorder (BED), although the latter is not yet included in the diagnostic manuals (American Psychiatric Association, 1994; World Health Organization, 2000). EDs vary in how they are manifested in individuals. Conflicts and uncertainties towards identity, self-image and emotional reactions are usually present long before symptoms of disordered eating become evident (Buhl, 2002). The body may come to represent the concrete manifestation of their dissatisfaction (Skårderud, 2007a), making it a symbolic instrument for change in order to obtain a sense of mastery and control (Seierstad, Langengen, Nylund, Reinar, & Jamtvedt, 2004).

According to the Norwegian Institute of Public Health, the prevalence for women in the age group 15-44 is 0.3 % for AN, 2 % for BN and 3 % for BED (Rosenvinge & Götestam, 2002). Because these estimates are based on both national and international studies, it is difficult to determine the exact prevalence. An estimated 2-5 times as many people exhibit some symptoms, without meeting the full diagnostic criteria (Newton & Ciliska, 2006; Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011). Additionally, only 30 % and 6 % of those who struggle with AN and BN, respectively, will receive help from the mental health care (Statens helsetilsyn, 2000). Women are far more likely to be diagnosed with an ED compared to men (Kjelsås, Bjørnstrøm, & Götestam, 2004; Núñez-Navarro et al., 2011; Seierstad et al., 2004). EDs usually appear during adolescence, and the causes for the different disorders are the subject of much research and debate. There seems to be a complex etiology, where combinations of biological, social and psychological factors play a part in disposing, triggering and maintaining the disorder (Buhl, 2002; Vestergaard, Sørensen, Kjølby, & Videbech, 2008).

Scandinavian studies show that among people with EDs, the prevalence is higher for other psychological problems, compared to the general population (Vestergaard et al., 2008). Among people with AN there is an elevated prevalence of depression and anxiety disorders, like generalized anxiety, symptoms of obsessive-compulsive disorder and social anxiety. Among people suffering from BN or BED, there is a higher prevalence of anxiety disorders, depression, substance abuse and personality disorders (Klump, Bulik, Kaye, Treasure, & Tyson, 2009).

Studies show that individuals diagnosed with AN are prone to suppress negative emotions and bodily signals (Schmidt & Treasure, 2006). Buhl (2002) claims that the capacity to use adequate concepts and words in describing internal needs and emotions seems to be insufficiently developed in patients with EDs. The ability to reflect upon and mentalize the inner world of both oneself and others provides the individual with the understanding and organization necessary for meaningful intra- and interpersonal communication (Allen, Fonagy, & Bateman, 2010). When the inner world is poorly integrated and the ability to mentalize is impaired, the result may be a fragmented understanding of the self, hence making the body the concretization of mental life (Skårderud, 2007a). Patients diagnosed with EDs often show ambivalence towards the condition. Studies show that patients with AN often experience safety in having the disease. The anorexic behavior is sometimes attributed to positive qualities such as mental strength, self-esteem and identity (Nordbø, Espeset, Gulliksen, Skårderud, & Holte, 2006). Women suffering from AN interviewed by Rich (2006) reported a constant negotiation of contradictory feelings about their disease: feeling both empowered by it, but also having an awareness of it being destructive. These attributes may contribute to how treatment is experienced as unsatisfactory for both patients and the mental health workers (Nordbø et al., 2006; Schmidt & Treasure, 2006), at least in early stages of the condition (Dias, 2003).

**Eating disorders, identity and group-affiliation.** EDs are commonly perceived as medical diseases. Rich (2006) claims that a medicalised construction of the condition usually dominates the discourse, thereby reducing the condition and excluding the various social and moral aspects of it. In Rich's study, the participants interviewed told of experiences of having

their health and wellbeing reduced to a matter of weight loss or gain (Rich, 2006). However, as stated above, many people suffering from AN think of it as a productive and empowering condition of distinction, especially in the early phases of the disorder (Warin, 2004). There are few other chronic diseases where affected people actually seek or want the condition (Rich, 2006). Sometimes having an ED becomes a part of a person's identity. This is evident in pro-anorexic websites on the Internet, called "pro-ana" websites (Dias, 2003; Gavin, Rodham, & Poyer, 2008). The Internet has emerged as an important context for construction of identities, also related to EDs (Rich, 2006), and the pro-ana sites can be understood in light of this. On these sites, people with EDs share their stories with other likeminded, and they often perceive the condition as a life style choice, as opposed to a disease. As an illustration of this, Gavin et al. (2008) found in their study that people with AN reframe their symptoms as signs of success on pro-ana sites. The posts on the sites also demonstrate a desire to retain the disorder, as well as becoming a "better" anorexic (Rich, 2006). Further, their posts show a clear tendency of in- and outgroup formation, where the ingroup consists of people with EDs and the outgroup consists of all so called "normals" – people without EDs (Gavin et al., 2008; Giles, 2006). Cochran's study (2009) is limited in its scope, but presents interesting hypotheses. She described how having an ED can become the most important part of a person's life in that he/she must monitor the food consumption, the body weight and hide the condition from others. Also, Gavin et al. found that there are two important themes in the "pro-anorexia" identity; the feeling abnormal – different from the rest of the population – and the hiding of the condition from friends and family. EDs often have secretive and even deceitful properties, possibly due to the threat of others trying to "fix" the persons affected, and this may cause a feeling of loneliness and isolation (Gavin et al., 2008). Indeed, in the study by Rich (2006), all the women interviewed reported feeling misunderstood and isolated, as well as alienated or disconnected from family and friends, health professionals

and even their own bodies (Rich, 2006). This may help explain why the formation of in- and outgroups occurs on the pro-ana Internet sites. It is possible that this helps to restore a sense of belonging that people with EDs may otherwise be deprived of (Gavin et al., 2008), much because of the shame and stigma associated with the conditions.

Eating disorders, shame and stigma. Shame is considered a central affect in relation to EDs, and it is described as both a cause and a consequence of the disorder (Skårderud, 2003), motivating the person to try to change him/herself. Further, in addition to experiencing body shame, many patients feel shameful of their eating disordered behavior, and for not being able to eat in a natural way (Skårderud, 2003). People with EDs appear to possess both internal shame and external shame (Goss & Gilbert, 2002). While the internal shame is related to a sense of personal unattractiveness and is often associated with intense self-criticism for certain attributes or even self-hatred, the external shame is concerned with the fear of being disregarded or looked down upon by others (Gilbert, 2002). The feeling of shame is often connected to silence and refraining from putting one's feelings and thoughts into words (Skårderud, 2007b).

A phenomenon related to the feeling of shame, is stigma. Goffman (1963) defines stigma as a form of social rejection, where the stigmatized individual is reduced from a whole person to a tainted one. EDs are stigmatized in Western society (Haas, Irr, Jennings, & Wagner, 2010; Mond, Robertson-Smith, & Vetere, 2006), and the stigma may be even greater for those who perceive these conditions as a life style choice (Gavin et al., 2008). Frable (1993) differentiates between identities that are concealable (e.g. homosexuality) and those that are conspicuous (e.g. obesity). People who possess qualities that are conspicuous can find similar others in the environment, and hence feel less isolated (McKenna & Bargh, 1998). McKenna and Bargh (1998) claim that people who have concealable, marginalized identities have fewer venues to express their opinions, which makes them more likely to

identify with and participate in online groups. Also, they tend to value the membership of these groups more than people with conspicuous stigmatized or mainstream identities. Further, the authors find that responses to posts on the groups are more important for those with concealable marginalized identities than for the two other groups. The more important the marginalized identity is to the person, the more self-acceptance the person feels after participating in an online group.

The group participation further leads to a higher likelihood of revealing the identity to family and friends and to feeling less estranged from society. Thus, according to McKenna and Bargh (1998), participating in an online group may enhance self-acceptance, self-esteem and sense of belonging for people with stigmatized identities, especially when this identity is normally concealed. This could be an important reason why many people with EDs seek similar others online. As McKenna and Bargh (1998) revealed, participation in a virtual group may also affect behavior in other arenas, such as disclosure to family and friends. However, Gavin et al. (2008) found the reverse pattern: The more meaningful the stigmatized identity (pro-anorexia) was to the participants, the less likely they were to "come out" to friends and family. It is of interest whether *blogging* activities by persons with an ED affect their behavior and decisions in daily life when meeting with family and friends.

Social support online and other positive effects of Internet use. Cochran (2009) hypothesizes that there are several possible positive effects of blogging about one's ED. It allows one to look at problems, reflect and ventilate emotions, and to receive honest feedback and support from others who understand the blogger's frustration and suffering. Cochran (2009) also hypothesizes that the combination of catharsis, reflection and supportive feedback may only be possible through blogging. Gavin et al. (2008) found that pro-ana forums provide users with much needed support and understanding. This may be unavailable to them in real life due to fear of the responses from others if the users "come out" (Gavin et al.,

2008). The anonymity that the Internet provides may enable people with EDs to talk freely about their condition and to gain sympathy and support online before they feel ready to disclose to family and friends (Gavin et al., 2008). It is possible that blogging and participating in online groups constitute a step in the process of coming out and seeking treatment. One may consider this in light of the transtheoretical model of behavior change (Prochaska, DiClemente, & Norcross, 1992), where one recognizes that a person may move through different stages of readiness, as well as moving back and forth. Once a person gets to the stage where he/she weighs the benefits of change higher than the costs, change may occur. Dias (2003) argues that treatment is often unsuccessful until a person moves to a stage closer to readiness to change.

Social support online may be useful to people who are still in an early stage of readiness to change, where one receives support and understanding while still maintaining secrecy and isolation (Gavin et al., 2008). What people struggling with EDs are not ready to say to family, friends or professionals, they may be able to express in a safer, less confronting sphere of cyberspace (Dias, 2003). In addition, it has been argued that social support is more likely to be effective when it is provided by others who are in socially similar situations, facing the same stressors and doing so in a calmer manner than the individual in distress (Haas et al., 2010).

## Potential negative consequences of Internet use among patients with EDs.

Cochran (2009) also presents possible negative effects of blogging about EDs. A focus on eating and weight may be a sustaining factor. The bloggers in Cochran's study kept track of calorie intake and took pictures of food, a focus one might want to avoid when trying to recover. Further, Gavin et al. (2008) describe a tendency for participants of pro-ana Internet sites to offer inappropriate support, such as supporting the anorexic behavior and a selfdeprecating discourse. When a person posts negative comments about her/himself, the other

participants reply in a supportive and positive manner in order to contradict this negativity. It seems that to be self-critical and self-abusive is an important way to elicit support. This may hold true for bloggers who write about their ED as well, in which case it is possible that the person gets stuck in a negative manner of thinking and writing about him/herself. Consequently, this may influence the healing process. Further, these authors hypothesize that the effect of this kind of support will depend on which stage of readiness to change the person is in (Gavin et al., 2008). There is also a possibility that the personal stories of one's disease may have a reinforcing or triggering effect on people who are in similar situations (Guardiola-Wanden-Berghe, Sanz-Valero, & Wanden-Berghe, 2010).

The Internet is filled with information about every imaginable topic, and users often go searching for knowledge online. This also includes seeking information about health. It is estimated that 5 % of web-searches are health-related, although the information online is varying in quality (Bell, 2007). Information about EDs is not always accurate and the effect of misleading information about health in general, and EDs in particular, is not fully understood.

There is also a potential for extreme communities to develop, due to the difficulty of censoring information online. The extreme communities often reframe mental health issues entirely, which makes the sites of interest to mental health professionals (Bell, 2007). The pro-ana sites already described are one of the most discussed forms of extreme communities online. One of the concerns surrounding these sites is that they offer support for an anti-medical model that is believed to decrease recovery rates and possibly cause injury or death (Bell, 2007). This view is now challenged by studies demonstrating that pro-ana sites are complex, and that the effects of these sites are not yet fully understood (Mulveen & Hepworth, 2006).

15

In addition to Internet sites, there are many blogs containing pro-anorexic writing. Mantella (2007) examined nine different motives among a certain blogging society for people with pro-anorexic tendencies, called "pro-ana" blogs. The motives examined were: blogging to form and maintain community forums; blogging to document one's life; blogging for catharsis; blogging to obtain and provide social/emotional support; blogging to obtain and provide information; blogging due to ego-protection; and blogging related to identity. The participants in the study rated the nine motivation factors from 1-5, based on how much they felt it matched their reasons for blogging. The most important motivation factor seems to be to obtain emotional support (59 % of the participants), followed by community motives (29, 1%) and motives to reach goals (23, 1%). Although the pro-ana blogs provide the members with advice on how to get thinner, this is among the least important motivation factors: 0 % for providing and 12, 7 % for obtaining information. It is clear that it is important to consider social support when judging the effects of pro-ana Internet sites and blogs, as well as blogs about EDs not defined as pro-anorexic (Mantella, 2007).

As we have seen, EDs are serious and stigmatized conditions where the people afflicted are often isolated and lonely. The Internet provides an opportunity for these people to express their thoughts and feelings in a safe and less confronting sphere, and this activity may have both positive and negative effects.

## Writing as Therapy

A topic of interest is whether writing in itself can be viewed as something helpful for the mentally ill individual. Pennebaker (1997) has explored therapeutic writing as a part of psychological treatment. Several studies have demonstrated that to systematically write about one's suffering can have a positive effect on physical and mental health (measured by the number of medical visits, school grades, sick leaves and subjective wellbeing) (Birkeland, Rimehaug, Arefjord, & Jøraas, 2009; Pennebaker, 1990, 1997; Pennebaker & Chung, 2010).

It is claimed that some factors must be present in order for the writing to have the desired effect. One of these factors is that the participants should write about topics that touch them emotionally, which is called *emotional writing* (Pennebaker, 1997). The standard laboratory writing technique repeatedly used by Pennebaker (1997) involves randomly assigning participants (students) to one of two or more groups. All the participants are asked to write about an assigned topic for three to five consecutive days, 15-30 minutes without pause each day. The control groups are asked to write about a superficial topic, whereas the participants in the experimental group are asked to write about emotional topics, such as relationships, the future or who they believe they are. The results from Pennebaker's different studies, summarized in his review article from 1997, indicate that students who write about emotional topics have larger health gains than those who write about superficial topics. It is also found that using many positive emotion-words is related to increased health, whereas both a very low level and a very high level of negative emotion-words is related to deterioration of health. By using many positive emotion-words and reflecting on the text one writes, one will presumably move towards writing more coherent and complete texts (Pennebaker, 1997). It is demonstrated that the more the writers have reflected on a topic, the more the writing affects health positively (Pennebaker & Chung, 2010). For the writing to have the desired effect, it should continue for some time, preferably several weeks (Smyth, 1998). An interesting finding in the literature is that the health effects that result from writing occur both when the text will be read by someone else, and when nobody but the writer will read it, as would be the case with a personal diary (Pennebaker & Chung, 2010).

In the review article by Pennebaker (1997), he tries to explain the effect that writing seems to have on health. One theory is that holding back emotional information is a way of inhibiting oneself, and that inhibition is a physiological stressor. This stress may create psychosomatic processes that increase the risk of getting sick and having other stress related

problems (Pennebaker, 1997). However, it has not been confirmed that disclosing one's problems has a direct positive effect on inhibition-stress, although inhibition does seem to have a long-term negative effect on health (Pennebaker & Chung, 2010). Baker and Moore (2008) claim that releasing stress through writing will likely enhance a blogger's perception of self-worth and his or her problem solving abilities.

Narrative theory posits that people use narrative analysis in their daily lives, as a primary instrument for the creation of meaning (White, 2011). Within narrative therapy, the focal point is how the patient constructs the world and sees him- or herself in this world. People generate several stories simultaneously, and some specific stories dominate our experience of ourselves. Writing down one's lived experiences and reading it later might facilitate reflections upon the stories' perspective and their interpretation (Speedy, 2000). Reorganizing and integrating cognitive and emotional components of stressful events into a more coherent narrative is assumed to be related to health gain (Graybeal, Sexton, & Pennebaker, 2002; Schmidt, Bone, Hems, Lessem, & Treasure, 2002). The written text is considered more valid than the verbal; it has a permanent characteristic that surpasses the oral speech. A story that has been silenced earlier can be experienced as more tangible and real (Speedy, 2000).

White (2011) claims that the identity account inherent in constructed stories often take form as problem-saturated narratives. These experiences of identity are often in accordance with perceptions by people in the individual's environment. To counteract accounts that produce negative identity conclusions, Morgan (2000) states that it might be constructive to engage in a retelling of stories, where neglected events and alternative stories are promoted to question the dominant ones.

**Eating disorders and therapy through writing**. Schmidt et al. (2002) use Pennebaker's paradigm when treating patients with EDs. They argue that patients with EDs

gain less from traditional psychotherapy compared to other patients, due to an avoidant emotional style, so called *experiential avoidant*. This style is related to a reluctance to dwell on various experiences, thoughts, feelings and bodily reactions, as well as an unwillingness to change these patterns and the contexts in which they occur (Schmidt et al., 2002). It is also claimed that these patients are often alexithymic – having problems recognizing and describing emotional conditions (Buhl, 2002; Páez, Velasco, & González, 1999). This might cause problems in a therapeutic setting where doing so is a central focus. Further, it is argued that people with EDs have reduced abilities to produce specific memories, and have a more generalized autobiographic memory than most people. Anorexic patients tend to be shy, inhibited and careful, and 3/4 report a history with trauma. All of these factors can contribute to challenges in traditional therapy (Schmidt et al., 2002).

Schmidt et al. (2002) thus argue that writing can be helpful for patients with EDs. They point to research suggesting that writing has the most health gain for those who are alexithymic (Páez et al., 1999), have less opportunity to confide in others, or who belong to a stigmatized social group (Richards, Beal, Seagal, & Pennebaker, 2000). All of these factors can be applied when an ED is present, and it is therefore believed that this group can benefit from writing as a therapeutic tool (Gowers & Shore, 1999, cited in Schmidt et al., 2002, p. 305).

**Self-disclosure through blogging.** A study by Ko and Pu (2011) demonstrated that self-disclosure through blogging may improve the blogger's social connections, promote self-understanding, elicit positive feedback on the published information and increase resilience. These results were in line with findings by Miura and Yamashita (2007), who additionally claim that writing on blogs can boost information-processing abilities and increase psychological satisfaction. Furthermore Ko and Pu (2011) point to social support as an especially important factor in the facilitation of resilience. As self-disclosure on blogs can

give social benefits to the bloggers, this may help construct protective mechanisms, and promote resilience (Ko & Pu, 2011).

In sum, the act of writing seems to have a therapeutic effect under certain circumstances. The possibility of using this approach in meeting patients with EDs is interesting, especially since this group of patients may have more difficulties with opening up and talking about their condition than other patient groups.

#### **Summary and Aim**

As we have seen, the Internet is a powerful arena for social activities. People exercise impression management and preferred amounts of self-disclosure, and find others with similar attitudes, thoughts and problems. One may establish relationships with people one would otherwise never meet. Through these relationships one may build and modify one's identity and experience support and a sense of belonging. This may be especially important and helpful for people who possess marginalized and stigmatized identities, such as people with EDs. The increasing number of Internet sites and blogs dedicated to this specific topic is an indication of this. Further, the act of writing about one's problems, and one's thoughts and feelings surrounding these problems, may have a positive health-gain. In our study we were interested in how these issues come together.

In this study, we interviewed patients with EDs about their blogging activities. We were interested in examining their reasons for blogging; how they wish to portray themselves on the blog; why they write to an audience as opposed to keeping a personal journal; how their ED is affected by the blogging; and what reactions their blogging activity has elicited from mental health care professionals.

The aim of this study is to explore the experience of having an eating disorder and blogging about the illness.

#### Method

The present study is based on interviews with nine patients who all have a diagnosis within the ED range, and who have an Internet blog where they write about their illness. The transcribed interviews constitute the data material in this study, and by using an Interpretative Phenomenological Analysis we seek to explore the life worlds of these patients.

## **Methodological Approach**

Following an Interpretative Phenomenological Analysis (hereafter called IPA), we wanted to explore the unique experience of blogging about one's ED. IPA derives from a merger of phenomenology, hermeneutics and idiography. The approach enables the researchers to learn from the insights of the experts, namely the research participants (Reid, Flowers, & Larkin, 2005). IPA has its theoretical origins from phenomenology and hermeneutics, with key ideas derived from Husserl, Heidegger, Merleau-Ponty and Gadamer (Laverty, 2003; Smith, Flowers, & Larkin, 2010). However, it is distinct from phenomenological psychology in that it relies on the combination of the lived experience, the situated meaning, and the idiographic components that constitute a phenomenon (Laverty, 2003).

The approach is *phenomenological* in that it seeks to capture the psychological essence of a particular phenomenon in a specific context (Giorgi & Giorgi, 2003). Through an inductive process, one focuses on the examination of the participants' lived experience in detail, as an attempt to make sense of their personal and social worlds (Reid et al., 2005; Smith et al., 2010). Based on the ideas of Husserl, one seeks to illuminate the human experience of the participants' 'life world', e.g. the framework of beliefs that constitute the world for a person (Laverty, 2003).

The understanding of another person's situated experience of the world requires an *interpretation*, thus making hermeneutics an important part of the approach. In Heidegger's

view, our experience of the world depends on our historicality, consisting of cultural, social and historical contexts (Laverty, 2003). People attribute meaning to events, which subsequently shapes their interpretation and experience of these events. Further, the meaning derives from the interaction with others in the social world (Willig, 2008). The approach is idiographic in terms of its focus on the distinctive interplay in an individual (Ashworth, 2003). The interplay stems from the various factors influencing a person (such as physical, social, cultural, symbolic, psychological), and how these relate to context (Willig, 2008). The idiographic focus enables a detailed analysis of experience. To maintain an idiographic focus, a maximum sample of ten participants is recommended (Reid et al., 2005). In this study we have chosen to deviate from the idiographic focus, in order to maintain anonymity: We will present the results as categories of meaning, on which some, most or all participants may agree. The distinct opinion of a single participant will not be emphasized, and we will not present the participants by using numbers or pseudonyms. The blogging community is small in the sense that many of the different bloggers know each other. Consequently, they may be able to trace the source of a single statement if this is deviant from the current opinion of the blogring as such. Our aim is to understand the meaning of the phenomenon, rather than to measure its frequency. This method is not preoccupied with the exact number of participants reporting certain matters.

IPA allows and even requires the researcher to participate in the interpretation of the phenomenon. While trying to decipher the inside experience and understanding of the world as a blogger, the researchers get involved in a double hermeneutic; trying to make sense of the participant trying to make sense of their world. Further, it is important to have in mind that the participants might struggle to express what they are thinking and feeling. Some may not wish to self-disclose, leaving the researchers in need of interpreting and deriving the

participants' mental and emotional state from what they actually say (Smith & Osborn, 2003).

#### Design

**Recruitment.** There are many blogs on the Internet focusing on EDs. However, we wanted to explore the meaning and importance of blogging for those who also have experiences with therapy. EDs are often associated with stigma and shame, and the population is commonly looked upon as a marginalized group. This makes the population less accessible. However, our research partner has access to this population through his workplace, and after establishing procedures accepted by REK (see below), invitations (see appendix A) were distributed to potential participants. The bloggers who wished to participate contacted us by e-mail without having to inform their therapist, and individual arrangements were made. Out of 15 invitations, we received nine positive responses.

The participants. The inclusion criteria were the following: 1) having a diagnosis within the ED parameter 2) undergoing, or having previously undergone psychotherapy, 3) keeping a blog with a focus on the ED, and 4) being over 18 years old. The sample consisted of exclusively women in the age range of 19 to 34. They are ethnic Norwegians coming from different parts of Norway. Most of the women have dropped out of school or higher education programs, while a few have completed a higher education. The participants vary in terms of how long they have been ill. Two of them developed an ED when they were approximately ten years old, six of them were in the age 13-18, and one participant got sick in her early twenties. The participants also differ in the amount of treatment that they have received. Some of them have been admitted in hospitals for several years, while others have only undergone therapy sessions for the last two years. At the time of the interviews two participants were currently admitted in an inpatient clinic specializing in EDs, one was waitlisted and one had recently been discharged from a clinic. In addition, three participants

were outpatients, and the remaining two received no professional help at the time of the interview.

The patients' backgrounds with psychological problems are severe, and they all have comorbid psychological diagnoses. Several of them have a history of deliberate self-harm, depression and/or social anxiety. Two of the participants are diagnosed with emotionally unstable personality disorder, and one of these is also diagnosed with a posttraumatic stress disorder (PTSD). Another two have a diagnosis of bipolar disorder, and three participants have previously tried to commit suicide. In addition, some of the participants have incurred physical damage or syndromes due to their ED. Examples of this include hemorrhagic gastritis, electrolyte imbalance, damaged digestive system, amenorrhea, dental problems and epilepsy.

The scope of the participants' blog practices varies in terms of duration, publishing frequency, and number of readers. The average time period of blogging is three years, ranging from one and a half to six years. They all have open blogs, where readers have access to the blogger's full name. However, two of the participants started out blogging anonymously, and one has also kept a pro-ana home page. Most of the participants publish one to four blog posts every week. However, one of the participants publishes two blog posts every day, while another participant can go several weeks without publishing. The number of readers, measured in unique IP-addresses, ranges from 100 to 2 000 per day, and occasionally some of the blogs have as many as 20 000 readers per day.

**The Interviews.** We used semi-structured in-depth interviews in order to facilitate an open dialogue and in-depth exploration of the participants' experience with and reflections on blogging about their condition. The interview guide (see appendix B) was structured into five topics, based on a literature review and the clinical experience of our research collaborator. The five topics were: blog practice; the history with an ED; writing as therapy;

stigmatization; and professional help. Before beginning the interview, the participants were informed of the aim of the study. They were also briefed on the technical and ethical aspects of the study; namely that their participation was confidential and that the interview would be recorded and later transcribed, and that the recorded interviews and transcriptions would be kept confidential and safely stored, see below. The mean duration of the interviews was 1 hour and 45 minutes. One interview was conducted over two consecutive days. HW conducted all of the interviews. Six of them were carried out at different hospitals, one was conducted at a private practice office, and two were held through a videoconference using the software application Skype.

**Transcription.** The interviews were recorded and then transcribed. SAR transcribed five interviews and HHP transcribed the remaining four. During the transcription, identifiable information (such as names, cities and clinic names) was excluded. All three authors read through the transcripts. This way, at the first and second read through, one of us had conducted the interview, one had transcribed, and the last author had just read the transcript. We transcribed the interviews verbatim, and non-verbal aspects of the communication, like pauses and laughter, were included.

## **Data Analysis**

The nine transcribed interviews constitute the data material. Using IPA, we followed four stages in order to deduce the unique experience of our participants (Smith et al., 2010; Smith & Osborn, 2003; Willig, 2008). First, following an idiographic approach, we laboriously read through each transcript. While reading, we did exploratory noting, such as writing down associations, questions, comments, summary statements and descriptive labels along the margins. Our individual notes were then compared and the emergent patterns were discussed. Second, with the assistance of NVivo 9 software (QSR, 2011) which is based on the making of categories or 'nodes', text excerpts were coded into the database and labeled

according to their content of meaning. For example, all statements that included experiences related to the audience were subcategorized in nodes such as "Recognition and validation", "Vulnerability related to exposure and feedback from the audience" and "Being valuable – inspiring others" (see Appendix C). The various text excerpts may represent more than one category of meaning. In line with IPA, the quotations were selected to reflect both the typical and atypical reflections and recurrent themes of the experience, in order to illustrate the complexity of the phenomenon (Smith et al., 2010). During this step, there was also a gradual recognition of some professional and personal preconceptions about blogging and EDs. In addition, we became conscious of how entering the unique life world of our participants influenced us. The latter will be addressed in the discussion section.

Third, the nodes of meaning were compared and categorized to a higher level of abstraction. In other words, the nodes were clustered together on the basis of their meaning inherent to the participants' experience. We clustered a total of 74 nodes (see appendix C) into seven super-ordinate themes. The themes were given tentative names and descriptions, which were continuously adjusted during the progression of the analysis.

The final step consisted of a write-up of the themes, where they were explained, nuanced, and illustrated by quotations (Smith & Osborn, 2003). During this step, we translated the quotations from Norwegian to English. This process may have caused some of the meaning of the original quotations to be altered or lost. See appendix E for an example of the translation of a quotation. The final step also included exploring the interrelationships and shared connectedness between the different themes.

#### Validity, generalizability and reflexivity

Questions concerning the validity and reliability are important to address in order to enhance the integrity of the research. Awareness regarding reflexivity is also a means to increase the quality of qualitative research. Yardley (2000) presents four principles for assessing the validity and reliability of qualitative research; 1) Sensibility to the context, 2) Commitment and rigor, 3) Transparency and coherence, and 4) Impact and importance. The following sections are an account of the measures applied to improve the study's quality.

**Validity**. In qualitative research, validity concerns the various ways of ensuring that the sample and analysis of the research data address and answer the intended questions (Kvale, 2004; Smith, 2003; Willig, 2008). Researchers are therefore in constant need of evaluating the quality of every step in the research process. Although methodological rules constitute the foundation of research, subjectivity is an inevitable part of it. In other words, the researchers bring into the equation their own experiences, emotions, values, biases and personal agendas (Maso, 2003). Further, in-depth interviews are not objective means of collecting data. The socio-cultural milieu creates a backdrop for the involved parties, and the immediate interaction during the interview may influence the outcome (Smith, 2003). A semi-structured interview guide provides the interviewer with fixed guidelines concerning the research situation. However, it should also be easily adapted to the individual participant and the immediate situation in order to provide flexibility. This might increase the likelihood of gaining access to the experience and life world of our participants, which may in turn increase the validity of the study.

Communicative validity depends on the dialogue between individuals within the research community, as well as the use of the hermeneutic circle and taking on the role of the devil's advocate when analyzing the data material (Kvale, 2004). The discussions throughout the analysis between the three authors, are thus a part of the validation process. In addition, notes and inputs from our supervisor and research partner provided us with new outlooks, and served to increase the communicative validity. By doing so, inter-rater reliability is also increased. However, reliability in its traditional sense loses some of it applicability in qualitative research (Yardley, 2000). Furthermore, by writing a detailed account of the

different stages of our research process, we aim to adhere to the principle of openness and transparency. Through the inclusion of detailed extracts from the transcripts, we aim to illustrate the coherent chain of interpretation (see Appendix D). A part of reliability concerns the social value of the study, and whether the results are applicable to clinical practice. We believe that the results of our study meet this criterion.

**Generalizability**. Generalizability is secondary to our aim; to explore the unique experience of a specific phenomenon. As this is a qualitative study, we cannot automatically generalize the findings to another population. However, the phenomenon in question is most likely relevant to people beyond the participants in our study. As Kippax with collaborators (as cited inWillig, 2008, p. 17) claim; "each individual mode of appropriation of the social ... is potentially generalizable". We do not know how many people share our participants' particular experiences, but one can assume that our findings apply to other individuals in the same context.

**Reflexivity**. Reflexivity is another way to improve the quality of qualitative research. Our preconceptions have affected every step of the process, i.e. when designing the interview guide, during the interviews, in the analysis of the data and the presentation of it. Finlay (2003) describes reflexivity as "the process of continually reflecting upon our own experience and the phenomenon being studied, so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes" (p. 108). The researchers' preoccupations with their own emotions and experiences can pull the research in an unfortunate direction. It is therefore important that one should strive to sustain a minimum of what is "lost in translation" (Willig, 2008). We have tried to adhere to the principle of reflexivity.

### **Ethical Concerns**

In accordance with the Law of health research of 2008 (Helse- og omsorgsdepartementet) the study was approved by the Regional Committee of Medical and Health Research Ethics (Region West), see Appendix F.

To secure the patients' voluntary consent and to avoid making them feel pressured into participating in the study, they were recruited through an invitational letter in a sealed envelope, distributed by a collaborating research partner. Thus, the patients were free to contact us and subsequently make individual arrangements. Those responsible for the recruitment do not know who eventually decided to participate in the study. Only the authors have access to the participants' names and belonging transcripts. After further anonymisation, our supervisor and collaborating research partners got additional access to the transcripts. Identifiable information was removed and some false information added. In this way, the transcribed interviews should be near impossible to trace back to the individual participant.

Before the interview began, the participants were informed about the framework of the study. They were also informed that their participation and the information given could at any time be withdrawn from the project with no consequences. Furthermore, to secure the wellbeing of the participants, the interviewer was alert to signs of distress. If such non-verbal signs occurred throughout the interview, the interviewer would change to a more supportive questioning style or change the subject.

# Results

The results of the interviews are clustered into seven categories of meaning that we find to illustrate important aspects of the participants' experience of blogging about EDs. We will use quotations from the interviews to present the data material, as well as to illustrate specific aspects of the categories of meaning. We intend to highlight the topics from as many points of views as possible, using quotations from all the participants. The same participant will not be quoted in the same section of quotations. We wish to provide as much insight into

our participants' experience as possible, but due to limitations in space available, it has been necessary to limit the amount of quotations in the text. In addition, some words and sentences are left out when this does not alter the meaning of the quotations. The missing parts are illustrated by the use of three and four dots when words and whole sentences respectively are left out. Some quotations may be relevant to more than one category, and were therefore originally categorized in several nodes. This is due to the fact that the bloggers' life worlds are not organized into fixed categories, but rather as a complete experience of life. Nevertheless, we have strived to present distinct and independent categories of meaning.

We start out by presenting the categories that specifically concern social aspects of blogging: The experienced community among the bloggers, and the importance of the audience. Then we will describe how the bloggers try to represent themselves. Further, we will focus on the blogging in itself, and how it relates to the bloggers' psychological state. Towards the end of the results, we will present the bloggers' thoughts on the therapeutic effects that blogging might have, and their experiences and considerations regarding how the mental health care should meet patients who blog. An overview of the categories and subcategories are presented in table 1.

# Sense of Community

It appears that being a member of a specific community – belonging to a group, establishing friendships, and obtaining support and inspiration towards recovery – is of tremendous value to the bloggers interviewed. Thus, obtaining a sense of community is a central motivation for their blog activity:

"I think it was just that I knew that there was always someone there who watched me, who managed to read my thoughts and managed to take part in my misery."

**Online community providing a sense of belonging.** All of the participants describe the blog as a means to obtain a sense of belonging and community. This is achieved when

many different people struggling with similar problems follow and support each other

through regular commenting on each other's blog.

The participants explain how feeling accepted and supported is a central part of the online community. An important feature of the support is that it is provided by likeminded people who experience the same or at least similar problems:

".... In a way it's a very nice feeling to be able to talk to someone who understands, who feels, shares the same opinions as you. So I think that is a relief, and I feel that it's very strenuous to talk and communicate with someone who doesn't know how it feels."

The support and community also lead to a concern for other bloggers. When another

blogger goes through a bad period regarding her ED, the participants may read this blog more

often, in order to keep updated on the situation. Some of the participants find this somewhat

strenuous.

Inspiration to recover. The bloggers use each other's experiences as guidance and

inspiration. Seeing others recovering is a motivating force for the bloggers in their own

struggle:

"It is often in other blogs that I find inspiration to.. if I'm struggling for a while, then I can go online and read other blogs and think "oh if that person has come this far in the process, almost recovered", then I can read and think "yes, I want that too", so there is much support there."

"Interviewer: the fact that you are all in treatment to get well, do you follow each other, or do you know of others who are more or less ill than yourself? Do you know where they are in the process?

Blogger: I think it's both.. both better and worse. But it's nice to see that we're on our way, everyone is on their way, among those [blogs] that I follow. And I think that's nice, it would be difficult to keep track of someone who was a lot worse. Like where I was a couple of years back maybe. That could have pulled me down maybe, I don't know, that the disease would be affected by it."

"But I think that when it [the ED] was at its worst, I needed it, I needed to understand more of what was happening to me, and I think I needed to accept that I was sick. I like had some problems accepting the diagnosis, and it got easier when I realized that I had the same symptoms as many others with the diagnosis." As we see in these quotations, by being each other's role models and letting each

other know that they are not alone, the bloggers inspire each other in the process of getting

better. Another form of such inspiration is evident when the readers comment on blog posts,

encouraging the bloggers to keep going and trying to get well, as illustrated by this quotation:

"And I think it's very much like that for me, that it was important that others could validate that it was right for me to keep working against the eating disorder, instead of keep living with it."

One of the bloggers actually says that at one point in time the blog and the feedback

she received was the only thing motivating her to keep on trying to recover.

Establishment of friendships. Some participants say that they have met people

online who they have become close friends with, even though they have never met in person:

"I've met many people who also blog and whom I've become close friends with, [friends] that I think I'll have for the rest of my life. So it's very much like a community, and it's fun to follow others."

However, some participants emphasize the difference between their friends online and

the friends they have in "real life". It is as though the friends online are less real and less

important than the ones they actually meet. It seems like the online friends serve a different

purpose:

"But I separate the friends I have online and those that I have outside the Internet, who may be more important to me in my position.. you know what I mean? I don't want to disappear into the computer and become like, you know... It sounds mean, but I think that as long as it doesn't take up too much of my time and I don't get too hooked on it, I think it's nice to have sporadic contact, but I'm more concerned with getting back to my own life."

The bloggers often start to communicate through other Internet forums as well, like

MSN, Facebook or Skype, and sometimes they even meet in person. Several of the

participants describe very genuine and rewarding encounters with likeminded others, whom

they have already become friends with through the Internet.

Belonging to a group and compliance to norms. The community that exists online seems to function as an ingroup for the participants, and many of them appear to take part in the same blogring. The bloggers explain that they feel understood and accepted by the blog community, or the blogring, as opposed to how they feel facing the rest of society. They emphasize that it is only those who have actually experienced the same situation that can relate to it and understand it completely. Many of the participants seem to identify with the blogring. This becomes evident by their way of using words such as "we" when talking about blogging.

A consequence of group formation is the development of norms. Several bloggers talk about different norms for blog activity that are more or less evident and explicitly expressed. Indeed, the whole concept of keeping a blog about mental health problems seems to be part of a larger normative understanding. One participant states the following:

"There has developed, I don't know how to explain it, but among the known "bloggers of mental health"; everyone knows about each other, and there is a group for bloggers about mental health on Facebook, where everyone who does it is a member and, yes, it is like blog friends. And to criticize each other, I think that is out of the question."

Several bloggers talk about ways of interacting on the blog that have normative qualities, such as commenting on other blogs and expecting comments on their own blog from a specific number of people. One norm that seems to be quite common and accepted by the participants is that the content on the blog must never be too pessimistic, detailed or specific. A reason for this is that they want to be a positive influence on their readers, and inspire others to keep trying to recover. In addition, they are afraid of actually influencing others in a negative direction (called triggering; this will be discussed later). Some of the participants also mention that they don't want to worry their readers. To counteract the pessimistic tone in their postings, they usually include a positive ending: A posting may be dark and somber, as long as it ends with a sentence or two about a better day tomorrow etc.

#### **BLOGGING AND EATING DISORDERS**

Often the bloggers hold back and portray the situation as better than their true experience of it. One participant states: "Sometimes I feel more hopeless than what I express there." Thus, it seems like a norm has developed within this blogring to always include a positive ending. One of the bloggers explains that if she does not include the ending, the readers will do it for her, in the commentary field:

"Then I feel that they provide the ending. That what I haven't written, for instance that it is all worth it, that you cannot give up, keep fighting and then, then I get it [from the readers], instead of writing it myself. So, it's kind of nice, because maybe I don't feel like that. Maybe I get a little more hope when they write like that."

The bloggers talk derogatory about the kind of blogs that focus on negative issues and that are too specific about calorie intake, weight or self-harm, and they often think of the owners of these blogs as young, immature and more ill. It seems that there are rules for what is accepted content on the blogs. However, there seem to be some differences among the bloggers in how the norms are perceived. This is evident when bloggers talk about what specific content is accepted. Some participants include content on their blog that other bloggers in the study find too triggering.

**Forum as a closed community.** The differences in understanding of the norms for content are even more evident when the participants talk about various venues for meeting bloggers and discussing their EDs. During the study, some bloggers revealed that there exists a closed forum online where only people with EDs are allowed to attend. Four participants stated openly that they were members. However, it is uncertain how many of the remaining participants are members, as we became aware of the existence of the forum after several interviews had already been conducted. The criteria for being included in the forum are strict. For instance, it is mostly people the bloggers know of and whose blogs they have read that can be accepted as a member. The reason for this is that the forum is supposed to be a safe place, where the participants can discuss their condition even more freely than on their blogs.

#### **BLOGGING AND EATING DISORDERS**

One can see this in light of the positivity norm and fear of triggering that the bloggers have concerning blog posts. The participants explain that the forum is a place where they don't have to worry about influencing young readers in a vulnerable situation. In addition, they can express minor frustrations or discuss hobbies in a personal journal on the forum; content that they think of as too trivial or uninteresting to post on their blog. The participants don't think of the writing on the forum as more honest, rather they see the forum as a place where they can include certain details that they withhold from the blog posts, making it more revealing. However, it seems that the participants have difficulties deciding on this, as some also state that the forum is the only place where they can be completely honest.

This forum is also governed by certain norms and rules. There are certain topics that aren't allowed, such as drug use, overdoses or self-harm. When it comes to which topics related to the ED are accepted, the participants differ in their opinions. Some of them explain that they have to stay positive and exclude details about weight, working out, calorie intake or pictures of their bodies. Others point out that one can leave a warning that one's current journal post may be triggering to others, thereby reducing one's responsibility. Some participants exemplify triggering content in blog posts at one point in the interview and then later mention the same content as examples of what they post on the forum. It seems that the forum is a place where the eating disordered thinking is more evident, and where the bloggers are more influenced by their own need to express this than by the fear of triggering others. Some of the participants express ambivalence towards the activity on the forum, saying that they don't know if they will still be a member if they recover completely. One of them, however, states that she fears getting excluded from the blog community if she does not support the forum:

"Interviewer: Can you talk a little about your activity on the closed forum? Blogger: It is a place.. I go when I'm doing worse. I was invited by someone.... I know her from her blog, where she doesn't write anything triggering at all. So I thought "ok, I'm sure it's nice with a forum like that", I didn't know what I was getting into. I saw the tone when I got in there, and saw that people published pictures of themselves, wrote about calorie intake and things like that, so I have also done that in there. Not too much, I try to stay away really. But at the same time I'm scared to be excluded, in a way, from the blog community, by not supporting the forum."

The participants explain that there actually exist two different forums, and that one of

them displays more triggering information than the other, due to fewer rules for content. One

participant also talks about gatherings in real life for members of the latter forum, where the

eating disordered behavior is shared and turned into a social activity. She speaks of so called

BP's; binge and purge-meetings, where a group of bloggers meet in restaurants or at home,

and binge eat and purge together. Some of the bloggers feel skeptical toward getting too

involved in the blog community, as exemplified by the following quotation:

"Blogger: There is a good saying that to assemble two lonely people does not make the two lonely people feel better, there are just twice as many lonely people in a room. Uhm, and that's how I feel there, that we're talking about a lot of lonely people, but one does not get less lonely by being together. Because one does not, [pauses] loneliness is something that is situated inside a person.

Interviewer: So being in the community does not represent something positive or?

Blogger: Yes, I'm sure there are a lot of positive things, but every time I hear them talking about the positive, it's that "we can be ourselves". And then I say "ok but what are you then?" "We can talk about disease and stuff like that". And then I say "but is that you? It isn't, that's the thing standing in your way, preventing you from being who you're supposed to be". But then they've already degraded themselves into their own symptoms, that they can only be themselves if they are their symptoms. It makes me sad."

One of the bloggers speaks of a blog friend who quit blogging and left the forum

when she was close to recovering from her ED, and states that she might follow her example:

"She didn't want to leave us, because we are her friends. But she said that "if I want to recover completely, I can't be with people who always focus on and talk about the illness" .... And I do understand her. I think I need to cut off some of my friends too, stop reading some blogs and leave the forum."

The closed forums provide a feeling of belonging, and an opportunity to share more detailed information than on the blog. Nevertheless, it appears that several of the participants are aware that being a member of such forums can affect them and their ED negatively.

# The Power of the Audience

The audience plays a major part in the bloggers' lives, both by providing support, and by being receivers of the bloggers' urge to share and help others who are struggling. However, the audience also represents possible pitfalls.

**Recognition, support and containment.** The participants all find the audience to be an important part of the blog experience. They explain that if it weren't for the audience, they could have just kept a personal journal instead (some of the participants actually do both), and one states:

"If nobody had read it, it would be like standing in the woods, screaming without anyone listening."

When it comes to explaining what the audience actually means to them, the bloggers mention several elements. One element is the understanding and acceptance from other bloggers that is described in the section concerning community among bloggers. There is also the support from other readers, both known and unknown, who do not take part in the blogging community, but leave comments. The support can make the bloggers feel more at ease with themselves, as they internalize the acceptance and feel less shameful. Some of the bloggers say that this is related to a feeling of validation and recognition, and that by accepting and recognizing the blog post's content, the readers help them feel valuable and worthy:

"I think it has a lot to do with recognition, feedback, you sort of get addicted to it. Getting positive responses and things like that."

The bloggers explain that the readers often give them advice, motivate them to keep going and provide positive feedback when they have written something sensitive and intimate. It seems as if the bloggers let out their feelings to someone who in turn can help them deal with them. This can appear as a kind of containment. The following quotations illustrate the power of support by the audience:

"Interviewer: What do the readers mean to you?

Blogger: Oh, they've meant very much. They've given so much support during times when I didn't have any myself. And they've sort of been there all the way, and followed me all the way, and they've cheered and believed in me and sort of.. many have given advice, without me asking for it. And it's quite amazing that there's someone out there who is actually interested in following you and your story. And sort of getting a lot of confirmation that what you're doing is right."

"But I think there can be very good medicine in blogging. It.. us eating disordered are often sick for attention, uhm people who have either become sick from getting the wrong kind of attention or too little attention. And attention-sickness should really, it should really be a part of ICD-10 and all of those, because I think it's a real disease. To get sick either from the wrong kind of attention or too little attention. And that getting attention can actually be pure medicine. And of course then it has to be positive attention. And if they manage to write so that they get positive feedback, then I think that is a very good medicine."

Vulnerability to feedback from the audience. Although the bloggers explain that

feedback and support from the readers is invaluable to them, they also experience a profound

vulnerability concerning the reception of their blog posts. Some of them describe a feeling of

intense anxiety after posting something, especially if the post's content is controversial or

deeply personal to them.

"Blogger: It's very much like "oh my God, what am I saying?", and it haunts me a lot, the thing that has made me sick, this intense self-criticism. Uhm. I think "what do they think now?" I'm afraid to offend someone, especially when it's a sensitive topic....

Interviewer: ....Do you remember how you felt after posting that [specific posting]?

Blogger: Uhm, I think I felt terrible. But at the same time it was a total kick to dare to do something like that. It's, but I, yeah.. I should just quit blogging, because of the nerves I have every time I post something."

This anxiety is striking considering the fact that most of the bloggers receive very

little negative feedback on to their blog. In fact, some of them say that they have never

received any negative comments at all. Others say that they have received countless positive

comments and very few negative. Paradoxically, they still say that the negative comments are the ones they remember, often even by heart:

"Interviewer: have you had any negative [comments]?

Blogger: not negative maybe, but I have one. I had a question-and-answer session a while ago, and then there was one person who made a comment about my body, but then I thought "it's a good thing I have a good day today". If not, I think that would have affected me a little."

"I've had almost 14 000 comments during the time I've had the blog, and it's, I think I've got 10 negative. But I can almost remember them word by word (laughs). It's pretty crazy."

The few negative comments may also affect the bloggers, in that they internalize the

criticism, or as one bloggers states; confirm her own doubts.

Not knowing who the audience is. As described, it seems like the bloggers receive a

lot of positive feedback and support. Still, they feel anxious and vulnerable when publishing,

in case of any negative feedback they might get. One participant relates this to the anonymity

of the audience, as it is easier for the reader to write something offensive while being

anonymous. The fact that the bloggers share personal information with a great number of

unknown readers can also have an anxiety provoking effect. Some of the participants say that

they try not to think about the unknown readers at all, while others get affected when taking

them into account. The following quotation illustrates the latter:

"I think about it [the unknown audience] at times. When I don't know why I do it [blog]. And then days or a week can pass by without me writing anything... I consider whether I should continue or not. But I keep coming back."

Others say they worry about who is reading their blog, such as neighbors and colleagues, especially when there is someone in their life that they don't get along with. Still, most of them feel proud of their blog, and consider the faceless audience as a natural part of blogging. One blogger states the following:

"I don't think about it very much. In the beginning I thought about it a lot, "who are these people, oh my God, what do they think when reading this?" I found it very unpleasant and scary. Now I've sort of gotten used to it, and I don't think about it so much."

### Being valuable - inspiring others and sharing one's knowledge. All the

participants say that the audience offers them an opportunity to feel valuable and important to others. Some of the participants repeat that this aspect of blogging makes it all "worth it". They say that if the blog can help someone, then it takes very little effort for them to share their story. The bloggers experience that when writing about getting better, others can become motivated to recover from their own ED. They feel valuable when being able to help others in this process, and one participant states: "I want to express that it's so worth it; fighting this disorder." They receive many e-mails from readers who tell them that the blog has had a positive effect on their lives, either because they feel better after reading about the bloggers' struggles and successes, or because they have learned something by reading the blog.

"I often receive e-mails from people saying that they've read and understand things better now, or someone saying that they relate to it and feel less alone. But like the best mails I get are the ones where people say that they've.. that I've inspired them to sort of seek help, or start fighting their own battles. Then I feel that it's worth it, if I can just share my words like that, like that costs me nothing at all and if that is positive for someone else, then it feels as if I make a difference and that what I write means something to someone else."

The participants explain that by sharing their story about having an ED, they get the chance to disseminate knowledge. This may provide health professionals with an understanding that can facilitate and improve their relationship with ED patients. They all have a history of being a patient in the health care system, and seem to feel competent on what works and what does not. The bloggers also get to explain to young and vulnerable girls that EDs are dangerous and detrimental to well-being. This especially applies for the girls who ask them for advice on losing weight. They hope that they can influence the girls to

# **BLOGGING AND EATING DISORDERS**

change their focus and to seek help if this is needed. Also, by sharing their experiences, the

bloggers can give advice on useful measures when battling an ED:

"The last post that is directly related to the eating disorder, is one called "recovery". Where I.. I received a question from a reader asking if I had any tips on how to proceed if one had acknowledged being sick, and she also wondered how to move forward. And then I presented my "ten steps to get well", where I highlighted what I find important and essential in a recovery process."

Among the participants, there is also a wish to explain to the general population what

having an ED feels like, and to break down myths and stereotypes:

"But one of the reasons why I started blogging, that I forgot to tell you about..is that I've been so provoked... I think there are so many who believe that eating disorders are about dieting, or that you're shallow or that you don't want to grow up, or that you're stubborn and want attention, or all the different things like that. And I felt that if I am to tell everyone that I've been ill, then I'd like to explain that it's not like that. I don't want anyone thinking I've spent ten years of my life, and really wasted everything that mattered to me, because I really wanted to wear a bikini."

It appears that some of the bloggers take on a role as a health professionals, in that

they are asked for advice on EDs. This is something that they gladly provide. However,

others express distinctly that this is not something they have the professional competency to

do.

# Avoiding misunderstandings and forestalling the audience. Several of the

participants emphasize a fear of being misunderstood by the readers, and that they put much effort into expressing themselves in a straightforward manner. This includes leaving out certain topics, using less humor or irony, and spending much time formulating the posts:

"But if I am to write about something that I find complicated or difficult, about thoughts and feelings and sort of try to make it understandable to others, then I can easily spend a couple of hours a day writing it. To find the perfect words and proofread so that it gets.. and so that it can't be misunderstood in the wrong ways."

Sometimes the bloggers feel rejected and pre-judged by people who have not read their blog or understood what they wish to convey. They mention people who think the bloggers glorify EDs, affect other people in a negative way, write mostly to get attention etc.

### **BLOGGING AND EATING DISORDERS**

The bloggers underline that they try to avoid this kind of writing, and it seems that the prejudgment is hard to accept in light of this.

"People generalize, thinking "oh my God, if you blog about eating disorders, you are triggering. But it.. I sort of think, if people have an opinion, where they sort of judge without having.. knowing what they judge, then I just think it's ridiculous of them... Then I sort of mostly get irritated because I think it's so ridiculous. I get provoked, because I don't think they should have an opinion about something they haven't studied."

The bloggers seem to try to avoid misunderstandings by providing the audience with forestalling information, possibly because they expect a specific reaction to what is posted. Another aspect of this is that some of them want to be their own advisor, so they provide the solutions to their problems before anyone else gets the chance to do so. It could be seen as a preservation of autonomy in the recovery process, while still needing the support and validation from the audience. One of the bloggers states the following:

"I kind of write advice to myself. So that it won't be open for everybody to tell me what to do and what not to do. But sometimes, people have a need to help..... Just that the person cares, ok that's like nice. I get the advice from my therapist and the ones who are supposed to do that part, and of course [from] myself."

Expectations from readers causing pressure. The participants have slowly obtained

more readers on their blog over time, and some have very large blogs on a Norwegian scale. In order to keep the readers interested, the bloggers feel the need to publish posts on a regular basis, as well as writing in the way that the readers are used to. For instance, some participants have humor as a trade mark, while one mentions being the positive one who is always looking on the bright side. These expectations of how to write can be tiring when the bloggers feel less cheerful. Other participants explain that they have more readers when they are doing worse. Their explanation for this is that the readers are either worried about them or that they like tabloid writing, as it is more entertaining: "The worse I feel the more readers I have. And I'm like, is it because they care or is it because some love to read about others' tragedy? That it becomes a kind of soap opera that people cannot miss?"

Either way, the assumed expectations from the audience can lead to a pressure that

the bloggers sometimes experience as challenging.

### Self-representation Online: Is This the Real Me?

When interviewing the bloggers, we were interested in whether they try to portray the

person they see themselves as, or if they try to manipulate the self that they represent. It

appears that the participants in our study differ regarding this.

Authenticity and self-representation. When blogging, one has the possibility of

choosing how to represent oneself. Many of the participants state that they portray themselves quite authentically. They feel that instead of wearing a mask when blogging, they take it off, and dare to be their true selves, as illustrated by the following quotation:

"I feel that I take it [the mask] off. Until people learn [about my situation], then the mask is on. But online, or on the blog, it is like off. Then it is up to me.. to write. I like writing. And then, then it goes off."

The participants feel freer to express their opinions and share their most private thoughts and feelings on the blog than they do in face-to-face interaction, and hence they feel more authentic online. However, other participants express feeling that they do wear a mask, or play a role when blogging. They consider it important not to present a too negative picture of themselves, even if they feel bad while writing. They experience that avoiding to do so can affect themselves in a positive way, as they assimilate this self-portrayal. This is illustrated by the following quotation:

"It is very important, actually, to appear different from how I am, because I am.. or at times when I'm very sad and things like that, you can fool yourself a bit by not focusing on the sad things.... I use it to motivate myself, you might say. So.. not different from who I am, but different from how I feel, maybe....I am a lot braver and much more positive and much more, uhm.. more of everything when I write.... I can't motivate myself by writing negatively. Even though that might be closer to how I feel.

But I don't want to feel the way I feel. And so I can't write how I feel, I have to write the way I want to feel."

From this, we know that some of the bloggers feel that they engage in role playing, in order to motivate themselves to change feelings or thoughts. For some, role playing also involves maintaining a writing style they have started out with. As described in "the power of the audience", the bloggers often feel that the readers expect a certain focus in the blog, and they try to meet these spoken or unspoken expectations. One blogger says the following about taking on an expected role:

"I think the negative thing is that you may feel obligated or..You get the role as a sick [person], a person who hurts herself, who eats little, who writes post after post about how tired she is or how dizzy she feels or how many stitches she sewed. And then it can be difficult to write that things are better, difficult to improve or change because it has sort of become your identity."

Exposing versus protecting oneself. The bloggers are asked about the effects of

exposing themselves to the audience. Some of them find it frightening, while others underline

that opening up and being personal is what is the most rewarding. One blogger states:

"I had to make a choice, if I should be completely honest and open, or be superficial, [writing] about what I did today...and I figured that I either had to be completely.. open, or else it wouldn't matter, because it's difficult doing something in between."

It appears that for some bloggers, revealing information to friends and family is

experienced as more threatening than having an audience that mainly consists of strangers:

"If there is someone I don't want [to read the blog], I think it must be, it is rather the close ones than strangers. Strangers are fine by me, I don't care too much about them. And at first I found it a bit strange, that friends who had an impression of me as a normal person would read it and think "oh my God, that's tragic, poor girl", and think, think something negative about me."

The participants claim that they are careful when it comes to publishing material they consider too private. Most of them say that they keep certain things to themselves, that they only share the most private things with their therapist or write it in a diary. Nevertheless, this can be challenging, and they express that one has to be quite mindful in order to avoid

revealing too much. The following quotations are examples of what the participants said about this:

"I feel quite open, but there are also things that I don't publish. But sometimes I feel that "oh, have I published too much?" but then I just know that I haven't."

"If I read through very revealing posts before publishing them, I won't publish them. Then I feel very open and vulnerable, and I think "no" (laughs)."

**On anonymity.** In anonymous blogs, the bloggers do not use their real names or post pictures of themselves. This way, they are in a position where they don't have to feel responsible if they are portray themselves different from their offline self, unlike the bloggers who are open about who they are. In addition, being anonymous often makes people write with fewer restraints, through the disinhibition effect described in the introduction. When it comes to blogging about EDs , it seems like anonymous bloggers feel less responsible for their readers, and often publish more triggering information than the ones who blog openly. Further, they may blog in a more negative fashion.

None of the participants presently keep an anonymous blog, although some of them did earlier. In general, they are skeptical of the concept of writing anonymously. It seems that this is due both to triggering and to the lack of recovery possibilities that an open blog offers:

"In my opinion, the blog, when writing anonymously, becomes more destructive."

"Being anonymous.. I am very skeptical considering how healthy that is in such a context. A lot of your filter is removed, regarding what you publish and where your focus lies. If I were to write from the anorexia's point of view, I would have published a living hell. And if I were anonymous, I might not care that much. Uhm, when I write based on who I am, and have to face people with it for the rest of my life, for what I've written, I think twice before I publish."

The blog posts as snapshots. The continuing changes in psychological states constitute an interesting aspect when it comes to blogging about mental illnesses. Publishing a blog post preserves the blogger's state of mind in the moment of writing. This is challenging for some participants, as they feel less authentic if what they write is not

#### **BLOGGING AND EATING DISORDERS**

illustrative of how they generally feel. Others, on the other hand, see it as a way to preserve a

good feeling:

"What I find challenging, is that you get caught in a moment. If you have one day with a lot of panic and anxiety, and you portray yourself as quite sick, while two hours later, you may feel much stronger. It is a bit difficult, finding that balance."

"Last Friday, I managed to do something that was like a victory to me, and then I felt that I had to put it into words, even though it was just a small thing.... The next day it gets blurry, and kind of not a big deal. Maybe that's true as well, but when I recognize that feeling [happiness], I have to write straight away, so that I don't lose it. So that I, if the next day isn't that good, then I can read it one more time and kind of remember that this was how it felt."

Since the blog posts are somewhat permanent, they can be seen as preserved

snapshots of the blogger's thoughts and life. They remain constant, even though the blogger changes the way she thinks or feels.

Altogether, it seems that the bloggers differ in their thoughts on whether or not to represent themselves in a completely authentic way. While some value honesty, others see it as important not to appear too negative or reveal too much, both for the audience's and their own sake. However, some bloggers see this not as less honest, but rather as less revealing.

# The Experience of Writing

Writing is the main component of blogging. The bloggers choose the topics they want to write about, what genres to write in, and other measures to underline what they want to convey. Most of them use other arenas for writing in addition to blogging, nevertheless they consider blogging as unique.

The writing process. Even though the participants write about similar topics, they differ in the writing process, i.e. how they go about writing their blog posts. A few of them state that they always have several possible blog topics in mind, and that they can just pick any one and start writing. One blogger explains that she has up to fifteen specific topics ready at all times, while another one says that the ideas for the blog posts often come to her at

nighttime. However, most of the participants state that they do not have a clear idea about a topic before sitting down to write. One participant describes the writing process in the following quotation:

"I start to write and then my thoughts shape themselves – I 'think-write'."

**Different venues for writing.** All the participants have other venues where they write about their EDs. Many of them keep a private diary in addition to having a blog, and some have journals on the previously mentioned closed forum. Their private diaries have several distinguishing features compared to the blog. In the diary, they can write without selfcensorship, and they use less well formulated sentences. One of the bloggers describes her diary as a place where her thoughts and feelings fuse in a mix of random babble. On the blog, however, they often write about one specific topic, and they describe the blog post as a short story with a beginning and an end. Further, the emotional tone in the diary is often more negative than in the blog posts:

"The difference is that I write more negatively in my diary.. fixed thoughts that I write down without even thinking. It's like.. I don't even try to find a solution. I rather write down everything that's wrong and any without hope. But it is almost the opposite when I write on my blog."

Writing versus face-to-face interaction. The participants claim that writing is quite different from talking about a difficult subject such as EDs. According to the participants, the blog gives them an opportunity to think through what they want to express, and they do not have to take the immediate reaction from the receiver into account. One participant explains it like this:

"I think it has to do with the peace and quietness around you; writing provides you with the time to hear your own thoughts. Because.. stress can easily disrupt and prevent me from speaking at all. So, I like it when I have the time to think things through before I say anything ... Especially when it comes to talking about feelings, which I don't really know. And if I have to get in touch with and describe a feeling.. I

don't really know what I feel. So for example in group therapy, I lose grasp of everything .... "

The bloggers appreciate the lack of direct contact, and feel that being with their online friends is less demanding of them. For some of the participants, the blog becomes their main venue for social interaction. Especially for those who are most severely affected by the ED, the blog becomes an important aid for communication, both with friends and family and with the audience:

This is illustrated by the following quotations:

"What I notice the most is that social things, being with other people, it is very quickly about food. You're supposed to enjoy food with good friends and in family gatherings and such. So I've noticed the last few years that I.. I guess I'm very isolated, I withdraw a lot. And I think that is also, also the reason for me to keep blogging, that I stay in contact with the world in a different way. When I don't manage to meet people because they're always eating (laughs). Or because I feel so enormous that I don't dare to leave the house."

"I didn't manage it, really..I had..wanted to be in touch with the outside world. Uhm.. The computer was all I had.... I had many friends. I didn't have the capacity to meet them."

"That is why I like the Internet so much; I can be alone, and at the same time be with other people."

The participants state that if they go through a bad period, they sometimes write

poetry or cryptic stories, with the hope that their close ones will decipher the message.

When writing a blog post, one does not need to look into the eyes of the receiving part. The bloggers can "hide behind the screen", as one puts it. As the "gating features" described in the introduction are absent, one does not have to consider appearance or nonverbal signals, neither one's own, nor the reader's. Also, as opposed to normal face-toface interaction, there is a time lag between the posting, the reading, and the possible commenting by the reader. Many of the bloggers find it more comfortable opening up and being personal when having the opportunity to hide behind the screen. They may feel less invaded and vulnerable when talking about intimate experiences online. For those who find

#### **BLOGGING AND EATING DISORDERS**

face-to-face interactions uncomfortable, the Internet may serve as a crutch in the process of

self-disclosure:

"I think it makes it a lot easier to open up. You don't have to look anyone in the eyes. For me, I feel somewhat relieved of the shame .... It makes it easier to tell people the things I find difficult to talk about, as opposed to sitting in front of the person."

"Many people are like "you are so open, and you are so articulate". Uhm, and then I usually reply "I am not articulate; I am able to write well when I'm all alone. I sit and speak through my hands to a computer.. If you had been sitting in front of me at this very moment, and I was supposed to use my words and my breath and like be present with both my face and body, I'm not sure I would manage to utter any of the words I'm writing now."

Furthermore, writing gives the bloggers a sense of control over what they present. As

discussed earlier, the participants describe a fear of being misunderstood, and some state that writing helps them prevent this from happening. As described above, they get the chance to carefully formulate and edit their blog posts. They are also in charge of how much they want to expose themselves, as described by one blogger in this quotation:

"When talking to a person face-to-face; I easily get nervous, and then I might share more than I'm comfortable with. But when I write; I can save it, edit, think about what I want to say, analyze it again and be certain that this is something I want to share. So I feel that this is a great way to control the exposure."

Some of the participants state that they have become more confident in face-to-face interaction since they started blogging. However, some of the participants claim that blogging may represent a hinder for two-way communication. One participant states that she now has less to talk about with her friends, and her friends might forget to ask her about things that they have already read on the blog. Further, her friends know a lot more about her life than she does about theirs. The equilibrium in the friendship gets disturbed, as illustrated by the following quotation:

"They are my friends, so.. I want to know things about them as well. To keep the dynamic in the friendship in order.. to keep a sort of equilibrium."

The participants seem mindful of the different features of blogging; how they write their blog posts, where and what to write, and how having a blog might affect interaction with their offline friends.

# The Mutual Relationship between Blog Activity and Psychological State

For many of the bloggers we have interviewed, it seems like there is a close link between the blog activity and how they feel. These aspects appear to operate under constant influence of each other. Also, the focus of the blog determines how the writing affects the individual. Even though most of the participants express a positive attitude when it comes to the effect blogging can have on their ED, some question whether it can also have a detrimental effect, and that one does not necessarily get better from blogging about the topic. The following quotation illustrates this skepticism:

"If you only write about sickness, if you only focus on food and body and weight, I definitely think it [blogging] can have the opposite effect, because it can cause you to avoid working on the things you bring with you from therapy, and rather make you work with, continue to work with the eating disorder instead of against it."

**Triggering.** One of the negative effects that can come from blogging and Internet activity is triggering. Triggering as a phenomenon is already mentioned in the thesis, and we will now take a closer look at it. From our understanding, triggering occurs when someone gets affected in a negative way by reading articles, newspapers or other blogs about topics such as food, dieting, body image and working out. This can potentially lead to an increase in eating disordered thinking. Some act upon these temptations, while others experience psychological distress. In this study, all the participants have similar ideas of how triggering operates, and they all agree that it should be avoided. This is what two of the bloggers say about getting triggered:

"Maybe I should stop reading some blogs. Or sign out of the forum.... I don't really want to break it off with anyone, but maybe I'll have to with some of them. In order to avoid being triggered. Or being held back, not getting anywhere." "That is the disadvantage concerning our disorders, that they are so-called social disorders. And they [people with ED] pick up tips. And they weren't necessarily meant as tips by the publisher, but that is what they're used as. And that is really sad. And they say "they can just choose not to read", but that is not how it works."

All the bloggers claim that they try not to trigger others, and they speak derogatory

about those who do. As discussed in "Sense of community", there seem to be somewhat clear

rules, or norms, among the bloggers when it comes to triggering:

"I try to be aware not to trigger anyone.. Others who struggle can copy what I do, in a negative way. I think setting limits helps me too. To think that what I don't want to expose anyone else to, I would perhaps not want to expose myself to either."

"Interviewer: You said that even if you sometimes don't feel that things will get better, you have to write it [that it will].

Blogger: I think it is important, that others don't lose hope, even if I do.... It can easily be contagious, negative things on a blog."

It seems, however, that the norms that have developed within this blogging society do

allow some triggering content. For instance, one blogger avoids writing the exact amount of

time spent jogging, as she considers this triggering. However, the mere reading about others

jogging might be triggering for vulnerable readers. In other words, the understanding of

norms for triggering is not clear-cut.

Several of the participants state that triggering is a greater problem on the forums,

than on the blogs. On the forums, more triggering statements are accepted:

"I write less censored [on the forum]....It is more like, being completely honest, or writing honestly....But that is the thing about affecting, or triggering, at least it did that to me."

"You can write more.. personal stuff that maybe you can't write on your blog, because it might trigger others. You can say how things really are. Uhm.. "Today, someone said that, and I am exhausted and ate so and so much of that."

When it comes to triggering, the participants are more critical of celebrities writing about their scarce food consumption and work out regimes, and magazines that focus on dieting, than they are of blogging. Some of them consider the blogs as the opposite to this type of publishing. They claim that presenting their lives, damaged by their EDs, should inspire people to health rather than sickness. This is what one of the bloggers says about this:

"I think it [blogging] can have a counter effect. I don't think it's triggering, at least not more triggering than many other things. Seeing celebrities in bikinis in a magazine should be more triggering than reading about a person who vomits or hates herself or feels fat even though she's not."

#### Their own negative experience of being triggered. The bloggers interviewed have

all been triggered when reading information online, either by picking up specific tips or by becoming emotionally affected, and subsequently changing behavior. To be triggered is an entirely negative experience for them, illustrated by the following quotation:

"It is very exhausting, trying to get well and still getting even more alternatives presented.... For each alternative you get presented.. you have to make one more choice. And I get exhausted from making those choices all the time."

Many of the participants mention pro-ana sites. They all claim that they are presently not seeking any of the existing sites, but several of them reveal that they have done so earlier. By reading about e.g. ways to reduce weight, they used the sites as a way to maintain and further develop the ED. Today, the bloggers interviewed display negative attitudes towards the pro-ana sites.

# The effects of keeping an optimistic versus a pessimistic focus. According to the

participants, writing about the ED can be very helpful when trying to recover. However, this depends on the focus of the writing. Several of the participants differentiate between "negative blogs" and "positive blogs" within the ED blogosphere. If one is writing in a negative fashion – not focusing on getting better – one might reduce the chances of recovery. On the other hand, writing in a positive fashion might increase the chances of actually feeling more positive, and in turn becoming more motivated to recover:

"It all depends on the way you write about the topics. I think, if you write in a negative manner, it has a negative effect. If you write down what you have eaten, what you will eat, how many calories and things like that, every day, it will be an

encouragement to the eating disorder.... But if you turn it the other way, and write about gaining weight.... it might motivate and.. getting out of the eating disorder, using it that way. It has a direct negative effect I think, if you just keep on staying in the past. And write negatively about yourself. Uhm, then I think it has the completely opposite effect to the treatment."

"For a long time, I had written that "my goal is to reach 40 kilos" and all that, and then I wrote "today I reached my goal". And I didn't mean "wuhu", I could have smashed my head into the computer, but I wrote "weee, I've reached my goal". And people became super happy, [and said] "that's great, wow", and then you get a little "wow, maybe it is good, yes, you're right about that". You hear other voices than your own."

Thus, writing positively and receiving encouraging feedback on this can make

difficult tasks (such as gaining weight) more manageable.

According to the participants, anonymous bloggers often write in a negative fashion,

as they do not have to face the consequences of it. When reading these blogs, one is at a

higher risk of being triggered compared to when reading positive blogs, which is the category

in which the participants place themselves. Even though they write about the daily hassles of

having the disorder, they wish to recover, and this is the underlying focus in the blogs. This is

what two of the bloggers state about blogging in a negative manner:

"I think blogging negatively, if I can call it that, won't make things any better.... The way I see things, the brain sort of does what you tell it to do, so if you write what you're about to do, it kind of gets into your sub-consciousness, affecting your eating disorder in a negative direction."

"I think they can become more captured by their eating disorder, by doing that [writing a negative blog]."

Variation in writing due to psychological state. The participants agree that writing is a powerful tool, with the strength to affect bo1th the bloggers and the readers. The bloggers write more negatively when they go through a bad period regarding the ED. Others say that they only blog when they feel the need to, while refraining from it when they feel better. The participants are conscious about what and when they publish. For example, some say that they do not want to blog when they feel very sick and destructive. This can affect the readers

### **BLOGGING AND EATING DISORDERS**

in a negative manner, but also themselves, as they believe that the writing in itself is

powerful. These are some of the bloggers' statements regarding this:

"And there are times where I don't manage to write anything. Or I feel everything is negative, so that there is nothing constructive to write about.... So what I've learned is that I'll wait; when I am, or when everything is at its darkest, I'll wait a little longer [before writing]....During the times when I'm captured in it [the ED], the posts are very one-dimensional and very few. Because I can't [write constructively], I'm so entangled in the eating disorder."

"Interviewer: That distinction, between the negative and the positive blogs .... is that a flexible distinction? Are there times where the positive, with quotation marks, turn more negative, and then back?

Blogger: Yes, that happens. I think I have crossed that line too, when I've been very sick, and written about it. Then I might have triggered somebody."

"I don't think I write much when I'm happy, that's a bit odd. But then I'm just happy."

# The importance of the blog related to the strength of the ED. The participants

have different feelings toward how important their blog is to them. We were interested in

assessing how they would feel if they were no longer allowed to blog. Some say that to stop

blogging would be like removing a part of them, while others claim that it would not be a

problem to stop:

"I think I would have felt misunderstood, and extremely lonely, not having anyone to tell me "I understand how you feel". I wouldn't have anyone to talk to or.. I think I would have become extremely frustrated.... I have a hard time talking to people about this [the ED] face-to-face."

"I've been wondering "do I still need the blog as much?", in a way. But then it's, I want to be a role model, in a way, for everyone who has followed me and read when things have been shitty, to put it that way (laughs), [show them] that it can get better."

Some of the participants underline that the blog is not as big a part of their lives as it used to be. For the ones who feel that they have come a long way considering their ED, it seems particularly important not to let it remain a central aspect of their lives. Thus, the blog appears to be experienced as a helpful tool for recovery that the bloggers feel less dependent upon when they get healthier. "It is only 20 % of my life [on the blog], there is so much else left.... The blog is not as big a part of my life as it could have been."

"I guess I'll keep on writing, but it is all about priorities, and life has priority number one, not blogging."

In general, it appears that there is a correlation between the bloggers' position

concerning their EDs and the importance of the blogs in their lives. The more affected they

are by their EDs, the more important the blogs seems to be in their lives, and the more the

blog activities affect them psychologically.

### The development of the blog's content. For most of our participants, the content of

their blog seems to have developed through the course of having one. A few of the

participants have previously kept anonymous blogs, and one of them states that the blog was

a place for her to express her miserable life. She describes that blog as harmful and

destructive, and says that she now has a more positive focus:

"So, when I first started blogging, it was like I had an online diary. A diary where I elaborated out my, at the time, terrible and depressing life; just to have somebody, to have someone reading my thoughts. It wasn't exactly very thought through, to put it mildly."

Several of the participants talk about a change of focus during the course of blogging,

and state that they initially wrote in a more negative and less reflected manner. This is

illustrated by the following quotation:

"I think many of the bloggers go through a process much like the process of growing up. It's like you start out in an experimental way. You make a lot of mistakes, like writing stupid things and disclosing too much of yourself. It's a kind of a youth rebellion. But then you calm down and find the style which you are comfortable with. It's not like I've magically figured this out, I've made my share of blunders."

As described earlier, the negative focus might reflect the blogger's mental state.

Several of the participants describe that when they got better with the help of professionals, it

was reflected on their blogs. In addition, the bloggers have developed a maturity in how they

write about their condition. Some participants relate blogging activity to their ED only, and believe that they will quit blogging when they have recovered.

The participants appear to be aware of the powerful effect writing may have in their own lives, as well as how it may affect others, and that the effect depends on the focus.

### Writing as Therapy

As described in the introduction, a topic of interest in this study has been whether writing on blogs can function as a therapeutic tool for this particular group of patients, and if so, what it is that the participants find therapeutic about blogging. We will now describe the specific ways that blogging can be experienced as therapeutic.

**Changing one's view of the ED through blogging.** By writing their blog, the participants spend time focusing on their thoughts, emotions, and reactions, and hence are likely to become more aware of their own inner worlds. Several of the bloggers claim that they get a chance to clear their minds, sort out thoughts and reflect upon the different topics of focus through the blog. They also feel more committed to personal goals when these have been published online:

"My project when I started it [the blog], was to use it as a part of self-development, so to speak... Give myself homework and things like that. Make jokes about myself.... Yes, and making sub-goals and larger goals. But maybe also.. yes.. looking ahead. Yes, it has meant a lot. Very often, it [blogging] has been the only reason to do things, for example gaining weight and things like that.... Being committed to oneself and family wasn't enough.... I needed to be committed to (laughs) hundreds of people [through the blog] to make it."

Many of the participants appear to change the way they think when addressing their thoughts and emotions on the blog. Several of them point out that when reading their own published blog posts, they often see the content through a new perspective, both because the readers' comments provide new insights, and because the written material has become more distant. The latter is illustrated by the following quotation: "There's a thing about writing something, publishing it, doing something else, going back; reading it as if it weren't you, it can be easier to give yourself some good advice....I think it is easier to give others advice than giving myself some, I think it is very difficult to "see" myself. But if I have written something, and can think [about the content] afterwards, it is much easier to say that this person should do this or that to get better."

Furthermore, some participants report that the blog can serve as a means of self-

encouragement, as they portray themselves as more positive than they really feel. Also,

receiving positive feedback from readers further reinforces this portrayal of a positive self:

"Theoretically, I try to portray myself differently than I am, more motivated than I am, more this and more that. But I show it through my behavior as well. I use it as self-motivation, so to speak, so, not [appear] different than I am, but different than I feel, maybe, or the way I want to feel, I don't know. I was not very happy about gaining weight, for example, but I turned it into something positive along the way of doing it.... And seeing that people react positively on it is contagious. So when people are happy, I am happy (laughs)."

Reducing shame. Writing in order to reduce the shame or to break taboos seems to be

one of the main motivations for blogging among some participants. Some started out

blogging to defy the shame, and some continue blogging for the same reason:

"The motivation when I started, was to get rid of the shame, and that, it is still a motivation, because I feel that it helps, writing feels good."

Many of the bloggers say that by writing about topics they feel ashamed about the

blog functions as a transition stage, between keeping their thoughts and feelings to

themselves and talking openly about their problems face-to-face. This is illustrated by the

following quotations:

"Earlier I didn't dare, as I said, even to talk about the eating disorder. It was on the blog that it started, and now I'm sitting here talking about it. It would have been out of the question earlier."

"I try to break the taboos by writing about it on the blog. Also so that I can feel that I don't need to feel ashamed.. Even if I do, when I write enough about it, maybe it will help after a while."

Some of the participants describe specific blog posts in which the main motivation was to remove the shame they felt related to having an ED. When writing about topics they feel shameful about, they often feel anxious in the moment of publishing. Nevertheless, they describe feeling relieved in the aftermaths of having done so. The following quotation is from a blogger who felt shameful about revealing personal information to her therapist, and thus used the blog as a transition stage:

"Blogger: Earlier this year, I published a list of the things I had been eating during a binge-eating episode.... And I actually did that in order to dare telling my therapist about it. It was safer writing it on the blog first. But I also wanted to show my readers what it is about, when I have been binge-eating and purging.

Interviewer: How was it for you, publishing that post?

Blogger: It was terrifying. It was really scary. What I worried about the most, was those that I know in "real life", whether they would read it.... I don't think I'd dare to tell my friends face-to-face, showing them the list of all the food and.. But I wanted them to know.... So it was this thing about getting rid of the shame."

"Getting it out". Many of the participants say that they "just need to get it out", and

that they feel relieved when publishing their thoughts and feelings. Some say that posting on

the blog calms them and helps them to stop thinking too much. It appears as if the blog can

function as a valve, and that things seem to stabilize when letting some air out. This can be

described as a form of catharsis:

"I calm down [after publishing], I often feel that. It might be something that I walk around thinking about a lot, and then I get to "blog it out", and then the racing mind might calm down."

"Interviewer: What is it that.. makes you feel better [after publishing a post]?

Blogger: That you've achieved something. You can leave it behind. Uhm.. like I spoke of yesterday, feeling that you can close a chapter and move on to the next."

Even though most of the bloggers interviewed state that they feel relieved when

pushing the publish-button, some feel quite ambivalent towards posting. When asked about

the feelings that occur after a publishing, one states the following:

"It is a mix of. Uhm. Nervous and.. happy I guess. So I start.. But then the stress kind of starts all over again. I am sort of always creating a blog post... It does not feel that good publishing, it is kind of like "oh, now I have to write the next one", that kind of feeling."

# The blog as a means to improve, remember and stay focused. Many of the

participants state that the blog can function as a reminder of how they have been doing

earlier, and that by reading previous blog posts, they can compare their current psychological

state with earlier states. In this sense, the blog becomes a measure of improvement. For some,

reading old posts is deliberately used to motivate themselves to achieve what they have

achieved earlier.

"I use, well, use old posts to motivate myself. Read back to, oh, then I did it. And there's no reason I shouldn't make it again, I got out of it then, I can do it now as well."

For others, reading serves as an encouragement, as a reminder of how far they have

come compared to the time of the posting, and one blogger states:

"I can read a post written one year back, and think that, "oh my God, I don't feel like that at all". And that gives me a confirmation that I'm on the right track....If you never stop to think "where was I six months ago?", it is difficult to feel that you've recovered at all. The process is so slow, and you feel that it lasts forever....To constantly see, put into words, reinforce it. I think that is very important."

Some of the participants state that an important motivation for blogging is to keep

themselves on track. By stating goals and publishing homework on their blog, they feel more

obligated to try to obtain them. The blog can also be a reminder to themselves that they are in

fact sick and vulnerable, and therefore need to be careful not to let the ED take hold of them:

"By having that blog, I reminded myself that I was sick, and that sounds a bit negative, but to me it has been important to remind myself that I have weaknesses.... reminding me every day that I have things I need to work on. Basically to function. I need to remind myself to take care, to eat. All those things."

Blogging as a supplement to traditional therapy. When exploring the participants'

experiences with blogging, an important focus for us was whether they feel that blogging has

a complementary, opposite or similar effect compared to traditional therapy. The results are clear; the participants all state that therapy is the main reason for their progress. Most of them also state that blogging has a supplementary effect on the process toward recovery:

"Interviewer: So through blogging, have you changed your view on the eating disorder, or have you not?

Blogger: I don't quite know. It might have helped me see that it's [the ED] not something I will continue having. But I think the therapy is the reason for that. Blogging is kind of additional. At the same time, I wouldn't stop doing it, it is a part of it."

However, some of the bloggers feel that the blogging helps them to continue

reflecting upon topics from therapy sessions. The limited time available in a therapeutic

session is a focus for several of the participants, as the blog is always available, unlike the

therapist. Although blogging cannot replace the therapy, it appears that the blog can function

as a prolonged therapeutic arena for some:

"But the things I have learned.. I have groups and learn every single day.. and the things I have learned get more stuck and become more internalized because I write about them afterwards."

"It is complimentary to therapy... Well, it is not everything you get to talk about [in therapy], you have one session every week, so there's not enough time to tell your therapist everything, a lot of things are going on. So I get to write it down, at least I see what, what I write about is what I'm the most preoccupied with. So it might get clearer to me, what I need to bring up in the session with my psychiatrist."

The participants thus feel that blogging has a therapeutic effect, but that his is

secondary to the therapy. It can also assist therapy, in that writing about the topics addressed

in therapy sessions helps to reflect on and internalize them.

# Blogging in Relation to the Mental Health Care: Skepticism and Acceptance

One of our five main themes in the interview guide was "professional help". We

wanted to explore how the participants experience meeting with the mental health care in the

light of keeping a blog about their mental illness, and also how they would prefer to be met

by the health care.

**Experiences with the mental health care.** Unfortunately, many of the participants report being met with great skepticism and negativity. They also experience receiving unclear and diffuse feedback. Some participants reveal that their therapists have told them that they do not want them to blog. One describes that she spends a lot of energy defending something she feels is helpful in her struggle to recover. Further, several of the bloggers call for a scientifically based explanation for the negative attitude, which they do not receive. They express frustration and irritation, illustrated by the following quotation:

"I have experienced that many clinicians talk about blogging in a negative fashion. They haven't said exactly why they are negative; they just think it's bad. So I.. I get annoyed. How can they say that when they haven't even read my blog. They just; "oh, you blog. That's no good"."

However, some of the participants report having been met in an encouraging way. One of them was told by her therapist that blogging would help her battle her social anxiety and fear of exposure. Others have received feedback from health workers saying that reading their blog helped them understand the patient's perspective better:

"I know there are health workers who read my blog ....I think it's a good thing that they read it. That way, they get a new perspective on treatment. And I write in words that can be understood by people who are not a part of the health care. I receive a lot of feedback from readers thanking me for using other words than the "health care" words."

Blogging while being hospitalized. A few of the participants describe their

experience of writing a blog while being admitted in an inpatient clinic. Several of the participants say that they are glad they have continued blogging while being admitted. They see their writing as rewarding, and explain that it helps them underline and remember the progress they have undergone. Nevertheless, they also highlight the potential danger in writing a blog while being ill. One of the participants describes how her blogging even resulted in a conflict between herself and her fellow patients.

The bloggers prefer not to write about their therapy in a direct fashion, but rather describe how the treatment leads to questions and new insights. One participant explains this in the following quotation:

"It's like; I describe the treatment without saying exactly what happened, because that is not really necessary. But [I wrote] a lot of my own reactions and how the treatment shaped me. And what I personally did to get better."

Therapists as readers. The bloggers all state that their therapist knows/knew about

their blog. However, not all of them think that their therapist actually reads it on a regular

basis. Some of the participants describe that they use the blog as an approach to bring up

specific topics in therapy, and that it helps them to express what they feel: They send extracts

from the blog to their therapist, or bring extracts to therapy sessions.

Some participants, however, say that they do not want their therapist to read the blog.

Even though the blog is public and open for everyone to read, some bloggers perceive it as

highly personal. One blogger describes her experiences with this in the following quotation:

"Well, it was actually addressed the first time I was admitted. And to be honest; I think no therapist would ever allow a blog like that. But, when they first said they had read my blog, I got really angry. Even though they defended themselves with the fact that the blog was public, I did not perceive it as that. It was my blog, my words, and they had no right to sneak in and read it. Well.. they actually did have the right to do so."

One participant explains that she does not want her therapist to read her blog because of its diversity in themes. She explains that she writes about her daily life and not solely about her ED. The private sphere would therefore be violated if a therapist were to read the blog in a professional purpose:

"It's like two separate things. You don't want to bring your therapist home with you, or into your everyday life. But if one were to write only about the ED, I guess it would be alright.."

Blogging behind others' backs. Some of the participants report a problem

concerning gossiping in the blogosphere. The term "back blogging" refers to bloggers

backbiting about the mental health cares on their blog. The "back blogging" can address dissatisfaction with a treatment institution or a specific therapist, or it can even be about fellow patients. The participants express concern with the phenomenon, and point to several drawbacks. For example, people struggling with EDs can hesitate before seeking much needed treatment, when reading negative things about the mental health care. Another drawback is that the treatment institution or therapist in question will most likely never hear about the things their patients are dissatisfied with – and will therefore not be able to improve. The following quotation illustrates one of the participant's reactions when she discovered "back blogging" by a fellow blogger:

"And I told her loud and clear; 'you are ruining both yourself and others by doing that. You may slowly kill yourself, but you are not allowed to spread those words of poison.' Because that's the way I see it. I think of it as bad as selling drugs. I'm disgusted with people who write that kind of blogs."

Advice for the mental health care. We asked our participants how they would like to be met by the mental health care, in light of having a blog about EDs. All of the participants report that they want to be met by the mental health care in an open and exploratory way. They want their therapist to be curious of what blogging is like, and suggest that the therapist and patient can explore how blogging affects recovery together.

As discussed in "The effects of keeping an optimistic versus a pessimistic focus", the bloggers speak of positive versus negative blogs. While they see their own blogging as constructive, they are critical of the negative blogs, as they consider them more likely to influence the readers in a negative fashion, and also prevent the blogger from recovering. The participants agree that these blogs need to be addressed in some way by the mental health care. Some say that the therapist should discuss the style and focus with the individual blogger in order to try to shift their focus, while others say that these bloggers should maybe not be allowed to blog. This may illustrate the ambivalence the participants feel concerning

### **BLOGGING AND EATING DISORDERS**

the blog sphere. The following quotations illustrate some of the bloggers' views of this matter:

".... To be met with respect and understanding on why they blog, but at the same time they [therapists] should explain why it's inappropriate and rather encourage them to write positive blog posts.. in order to experience that it's so much better. That it helps your sense of achievement and. ..To get positive feedback, and to hear from others that what you are doing is good. That is so encouraging, and it strengthens your sense of self. I don't think that they [negative bloggers] write negatively on purpose, so meet them on that [ground]."

"I don't think it's a good idea to deny patients the right to blog.... I think it will create a lot of negative consequences, because they will write anyway; secretly or on anonymous blogs. And then the focus of the blog will probably shift towards a more negative and triggering one."

We have now presented seven categories of meaning related to the experience of

blogging about EDs. Whether or not this activity is positive and health promoting seems to be depending on various factors. Some of these will be further addressed in the discussion.

## Discussion

The aim of this study was to explore the experience of having an ED and blogging about the illness. We wanted to examine the experienced effect of blogging about the condition, and whether the participants think of the blogging as therapeutic writing, as described in Pennebaker's paradigm. The interviews have provided us with much information about this relatively new research field. During the analysis we were surprised by the number of positive elements related to blogging about EDs. One might think that the bloggers' dealing with EDs are in line with the pro-ana trend, with a style of blogging that may amplify and strengthen the illness. In fact, the women interviewed claim the opposite: They wish to use the blog as a therapeutic tool during recovery. The community and sense of belonging seem to provide vital support for the women during times when they feel misunderstood and isolated from the rest of society. There are several issues worth elaborating further in the discussion. First, we will take a look at the primary motivations to blog among our participants. We will then comment on our assessment of using blogs and other Internet arenas (hereafter called social interaction online) when one is suffering from an ED. Specifically, we will present elements that we regard as possible advantages and disadvantages when trying to recover. Our findings will be related to some of the research described in the introduction. Furthermore, we evaluate the therapeutic effect of blogging per se. Finally, there are some methodological issues worth elaborating.

## **Motivations to Blog**

It is evident that the participants have several motivations to blog, whereas the most important seem to be: Being able to express personal emotions and thoughts to an audience; receiving feedback and support from this audience; feeling part of a community online consisting of likeminded others; writing in a way that assists recovery; reducing shame and stigmatization of EDs; and being a valuable contributor to society, both by providing information about EDs and by helping others who suffer. These motivational factors seem to be similar to the research described in the introduction (Nardi et al., 2004). None of our participants reported trying to provide or receive tips and tricks on getting thinner, glorify EDs or in other ways try to amplify the condition. The pro-ana trend described in the introduction seems to be the opposite of what the participants wish to achieve. Nevertheless, the motivations to *blog* among pro-ana bloggers (Mantella, 2007) do not seem too different from those of our participants, although the specific content on the blogs seems to be influenced by the outlook on EDs and the readiness to recover. Thus, the reasons for blogging seem to be quite similar among different sub-groups, but the presented material on blogs differs according to psychological state and readiness to change.

### **Advantages Concerning the Social Interaction Online**

There are certain characteristics of the social interaction online that we consider benign or even potentially beneficial to our participants. Our findings will be viewed in light of earlier research.

**Friendship formation**. There are different opinions about the Internet as a possible arena for establishing meaningful relationships (Cummings et al., 2002; McKenna et al., 2002). Our participants have developed friendships on the Internet that they value and sometimes feel dependent upon. Some of them have ongoing relationships with people that they have never met in person, but still consider close friends. Still others have met occasionally, even though the contact primarily is situated on the Internet. The bloggers state that they feel empathy towards each other, participate in each other's joys and sorrows, and encourage each other to overcome obstacles and daily hassles. However, some of them highlight the difference between friendships formed online and those that they have in real life. It seems that the participants' opinions are in line with findings by both Cummings et al. (2002) and McKenna et al. (2002): Stable and profound friendships do form on the Internet, but they lack certain features that are present in other relationships. It seems that to compare the two types of relationships is less meaningful, as they are based on different grounds, and the relationships formed online have different purposes and qualities.

**Self-representation; real me = "the blogged me"?** As the results show, blogging provides the participants with the opportunity to choose how to present themselves. The participants differ somewhat in their responses regarding authenticity. Some of them say that they try to be completely honest and portray themselves as they really are. Nevertheless, they may hold back certain information in order to protect their privacy. Other bloggers say that they deliberately put on a mask or play a role when blogging, either to protect themselves, or because doing so helps them see things differently. Some of them use the blog and feedback on the posts as a means to convince themselves to go through with difficult tasks in recovery,

such as gaining weight. They thus seem to play the role in order to change their thoughts and feelings toward recovery. Also, the bloggers wish to protect the audience from the most destructive content. The bloggers seem to be more or less conscious of the persona (Goffman, 1959) they portray. Even though it may seem less authentic, it appears to have a therapeutic effect for these bloggers.

However, it is possible that the concept of a "real self" is too simplistic. Several of the participants highlight the need for editing, but not deceiving, when writing to an audience, much like Suler (2004) has described. The bloggers choose which parts of themselves that they wish to amplify, and further withhold information that they consider unhelpful or too private. This means that the self presented is not complete - still, what is published is not less real.

**Coming out to friends and family.** Previously, there have been different findings concerning the likelihood of "coming out" to friends and family about a stigmatized identity if this identity has first been revealed online (Gavin et al., 2008; McKenna & Bargh, 1998). Most of our participants state that it is easier to talk openly about their ED face-to-face if they have blogged about it first. One may see the blog as a transition stage, where the blogger rehearses the disclosure and tests it on the readers (i.e. their reaction) before implementing disclosure in face-to-face interactions. It is possible that blogging can even promote motivation to seek treatment for those who are initially reluctant to talk about their situation. One participant exemplifies how she uses the blog to rehearse before daring to open up in therapy. By writing shameful and distressing material on the blog and receiving positive feedback, she feels more confident when meeting her therapist face-to-face. Other participants explain that they use the blog as a means to convey certain things to friends and family, or to the community in which they live. However, this practice may have possible pitfalls: One participant says that she feels that the communication with her friends has

become one-directional, as they know a lot about her through her blog, while she knows little about them. It seems that she misses the normal interaction and mutual self-disclosure that usually define friendships (Derlega et al., 1993). Another pitfall may be that the bloggers who have already come out to their close ones refrain from talking face-to-face, as they can convey the messages online. Some participants say that their families want them to talk faceto-face about certain things and not just write it on the blog, and that this can be difficult to carry out. It is possible that the blog is keeping the participants from exposing themselves to face-to-face interactions, as this feels too threatening and difficult.

Feeling competent. Some of the participants have dropped out of school or higher education programs and spent several years of their lives admitted in hospitals. Although they appear to be articulate and intelligent young women, they have not been able to fulfill their potential because of their EDs and other diagnoses. The blog represents an arena where the participants can use their analytic, creative and courageous abilities. They submit comprehensive and inspiring stories to an audience who appreciates it. Further, the women are skilled in managing a form of communication which is unfamiliar to most people. They have experienced trial and error in developing the blog, and have become more mature in the way they represent themselves. One can say that these women possess high competency in information exchange and self-representation. They are conscious of how they portray themselves, know how to be creative and how to keep the readers interested, as well as how to write well. Another important quality displayed, is the ability to consider where to write what - on the blog or in the forum. Due to empathic concerns, they try to avoid publishing triggering postings on their blogs. Also, they make use of several different genres, such as writing poems, song lyrics, letters and essays. The competency that follows blogging experience seems to be important to them, and could also be useful to mental health professionals when trying to understand the phenomenon of blogging.

### Possible Disadvantages Concerning the Social Interaction Online

In addition to the potential advantages regarding social interaction online, there are also aspects that we consider to be potentially harmful to our participants.

**Negative focus.** Cochran (2009) examined recovery blogs and warned about potential negative effects of blogging about EDs. She argues that the blogging activity may promote the disease, due to the constant focus on food, exercising etc. However, there are differences between the blogs examined by Cochran and those of our participants. Cochran (2009) describes how the bloggers take pictures of food and post detailed information about how much they eat, even though they keep so called "recovery blogs". This type of posting is not accepted among our participants. Thus, one cannot conclude that blogging has the same effect in our sample.

Another aspect of negative focus is related to the feedback from the audience. Gavin et al. (2008) describe how writing in a self-derogatory way can lead to a specific kind of feedback, which is not necessarily beneficial. Our participants describe a different outlook on this. Some say that they portray things, such as gaining weight, in a positive fashion even though they feel the opposite. This is because the positive feedback from the audience helps them change the negative feeling into a positive one. Others say that when they are quite ill, and write accordingly, they receive supporting and encouraging feedback which helps them stay motivated. The self-derogatory writing does not seem to be prominent in our sample of bloggers, and the feedback from the readers is thus less inappropriate. It appears that our specific group of participants strives to keep a more constructive focus than participants in other studies (Cochran, 2009; Gavin et al., 2008) and that some of our participants succeed in using the audience as a tool in the recovery process. This may be due to them being in a stage of readiness to change where this is more achievable (Gavin et al., 2008).

**Disinhibition.** The participants' responses seem to be in line with findings by Suler (2004), in that anonymity can cause a disinhibition effect: When no one is watching, the individual is free to disclose more and reflect less on the audience. In general, the participants are skeptical toward anonymity when blogging, and explain that it is much easier to write triggering material and take fewer precautions when no one knows who you are. Some of the bloggers used to have anonymous blogs, but learned that it was destructive, both to themselves and to their audience. However, the disinhibition effect may operate on open blogs as well. The participants explain that it is much easier to self-disclose on the blog than face-to-face. This might be due to an avoidant style and tendency to withdraw from other people, like patients with EDs have been described (Schmidt & Treasure, 2006). However, it may also be a natural effect of socializing on the Internet, as asserted by Suler (2004), and the lack of gating-features (Chandler, 1998; McKenna & Bargh, 1999; Valcheva, 2009). The act of publishing requires nothing but a computer command, whereas talking face-to-face can be strenuous and sometimes even painful. However, it seems that some of the participants have difficulties acknowledging or recognizing just how many readers have access to their most private thoughts and feelings on the blog. The faceless audience is less daunting than their personal friends and family, which is in line with Derlega and Chaikin's findings (1977). It is possible that the bloggers reveal more about themselves than what is ideal, and that they will regret this later on. Health professionals should be aware of the disinhibition effect and keep an open dialogue with their blogging patients about possible consequences of revealing higly personal information online.

**Ingroup and extreme community.** The group of bloggers seems to constitute an ingroup for the participants. Further, the bloggers seem to help each other construct identity by commenting on each other's posts, much like Larson's description (2007). The bloggers have developed norms that are commonly accepted within the community. They seem to

identify with the group, and they speak of being understood to a greater extent than in the rest of society. They have also created a forum where only members of the blogring can attend. It is uncertain how many of the bloggers interviewed are actually members of one or both forums. Four of the participants stated openly that they attended, while others might be members, without having mentioned it. The participants describe the community in different ways; some see it as unproblematic, supporting and as a great help in their lives. Others have some concerns, such as alienating oneself from the norms of society, making it difficult to relate to the world outside of EDs. In addition, some say that the heavy focus on EDs can contribute to being held back and prevent recovery.

The bloggers do not always manage to obey to the recovery-oriented norms that have developed within the community. In times when they feel worse and the ED is stronger, they write in a less constructive way, which may affect both themselves and others negatively. In addition, the norms seem to have developed spontaneously, and they appear somewhat volatile and varying. The same norm can have a different meaning to different members of the blogring, causing different levels of triggering.

When looking into the forums, it is tempting to draw the line to Bell's findings (2007) on extreme communities. In his work, pro-ana Internet forums and sites are mentioned as examples of this kind of community. Some of the theoretical background for our study related to sense of belonging and understanding among stigmatized groups, are studies conducted on the pro-ana movement. Even though the participants distance themselves from this movement, their behavior on the forum shows similarities to the pro-ana thinking. On the forum, participants are more likely to write in a unilateral manner, reflect less and trigger more. The bloggers mention posting pictures of their bodies as more accepted on the forum as compared to on the blog. The "binge-and-purge" meetings described earlier further amplifies this impression, although they were arranged by the other, more triggering forum. It is

possible that only a few of our participants were members of this forum. It is difficult to analyze how blogging about EDs affects recovery without taking the tendency on the forum into account. The blogging in itself is not necessarily detrimental to health, and may even be an aid in recovery. However, participating on the forum blurs the picture, and it seems to complicate the blogger's thoughts and feelings towards the ED and how to portray it. The fact that the forum allows a greater degree of triggering, makes it similar to the anonymous blogs that the participants dislike. A difference is that the triggering only affects the participants themselves, and not a vulnerable audience.

Immersing oneself in the world of EDs. One can question whether spending large amounts of time on blogs and on the forum is fruitful when trying to recover, regardless of focus of the content. The bloggers read and write about EDs, both their own ED and their fellow bloggers'. Some of the participants spend several hours on this activity every day. Even though this does not necessarily mean being triggered instantly, it may cause the bloggers to spend a lot of time immersed in the very topics that might be detrimental to recovery, as pointed out by Cochran (2009). Topics such as food consumption, weight and working out may become more central and immersive when spending much time on websites with such foci. In addition, one does not receive the same amount of correcting input online as one would in the "real world", which may lead to a polarization of the ED thinking. This may function as a hindrance in the bloggers' recovery process. It is also possible that the group identity and the identity as eating disordered become internalized, so that it is difficult to disentangle from it.

A demonstration of this long-term triggering effect was how we were personally affected by working on the project. By interviewing, transcribing and analyzing the interviews, as well as reading blogs, we entered the unique life world of the participants and other bloggers. Although we had some preconceptions about what we would encounter both

### **BLOGGING AND EATING DISORDERS**

regarding the interviews and blog content, we had not reflected on how this would affect us personally. We were not aware that immersing ourselves in this field would have a direct impact on our own lives, also outside of working on the thesis. However, we experienced that our own focus on eating, working out and other related topics increased. We had ongoing conversations regarding this topic, and found that we all had similar reactions to immersing in the field. To use the words of the bloggers, we experienced being triggered. This caused us to take regular breaks from the material, and to be careful not to seek other sources of information about dieting. We also discussed the matter with our supervisor.

Through this experience, we may have become more able to understand how engaging in ED communities can increase an individual's focus on e.g. dieting and working out, and it has contributed to questioning the effect of spending much time on this field. However, we do not know whether the participants would be preoccupied with these topics regardless of their Internet activities. Still, as one participant expresses (quoted in "The mutual relationship between blog activity and psychic state"), she fears that blogging activity might prevent her from recovering.

### The Blog Activity as Therapeutic

The participants proclaim that there are various therapeutic effects of blogging, as long as the bloggers adhere to the guidelines they have described.

Writing as therapy. According to Pennebaker and Chung (2010) writing as therapy is effective regardless of whether one is writing for an audience or just to oneself. However, our participants consider the audience an important part of their blogging. It seems that they need the feedback and supportive commenting in order to feel motivated to blog. By receiving these comments, they feel valuable, understood, accepted and validated as a person. As described in the introduction, Larsen (2007) argues that people are assisted in constructing identity by others commenting on their online activities. When the blogger presents herself as on her way to recovery, the audience applauds and encourages her to keep on going. And the roles the bloggers have assigned to themselves get validated and strengthened by the audience who expects them to play this role, even though this may feel strenuous sometimes.

Pennebaker's findings, indicating that the more reflection is conducted about a topic, the more therapeutic the writing is (Pennebaker, 1997), seems to hold true for our participants as well. They explain that this is one of the reasons why they prefer writing over talking about the ED; they have the time to sort out thoughts and feelings, and to evaluate the content of the post before publishing it. This is also underlined by Speedy (2000). The mere act of reflecting on and evaluating a post seems to lead to a cognitive restructuring. Difficult tasks in recovery may turn into positive achievements when presenting it accordingly on the blog, followed by receiving supportive comments. This is in line with findings indicating that writing about actual events and feelings can cause a change in the emotion and cognition surrounding these (Ko & Pu, 2011).

The bloggers underline that therapy is what has been most helpful in the process of recovery, and they do not equate blogging to traditional therapy. Rather, they see it as a useful addition. When blogging in what they see as the "right way"; i.e. keeping a positive blog as opposed to a negative one, they view it as therapeutic and meaningful. In contrast, blogging in the "wrong way" may have the opposite effect: Worsening the condition and holding the blogger back in the ED. Further, it seems that the social support provided by the fellow bloggers and other readers is different from the support provided in therapy, as the bloggers and readers often have experienced similar problems. This reduces the feeling of isolation and being unique in one's ED. Also, advice may be more effective coming from someone who has actually implemented the advice in their own life.

**Alexithymia.** Patients with EDs are often described as alexithymic: They display more difficulties recognizing and labeling emotional states than most people (Buhl, 2002;

Páez et al., 1999). As the results demonstrate, these women describe difficulties opening up and to be aware of their thoughts and feelings when talking directly to another person. However, writing might aid them in accessing their bodily signals, memories, thoughts and feelings. It can provide the opportunity to direct their focus inwards, in their own pace and in the privacy of their own home. One participant says that she often receives compliments on her ability to be articulate on the blog, while she is struck by an inadequacy to speak her mind in the presence of another person. Our participants thus seem to be far from alexithymic when they are allowed to blog about their experiences. It is possible that the term "alexithymic" needs to be considered in light of the context in which the naming and speaking of emotions takes place. Several of the participants highlight the difference between talking face-to-face and writing alone, where no one can see them. This is possibly due to the over-concern with body and shape – when no one is watching, the person with an ED can be free from others' glance and judgment concerning weight. Shame is considered a central emotion in patients with EDs (Skårderud, 2003) and is probably closely related to this over-concern with body weight and shape (Skårderud, 2007a). The advantage of writing for patients described as alexithymic has already been pointed out by Schmidt et al. (2002).

However, we question whether the term "alexithymia" in itself may be misleading, as it is used to describe enduring traits that a person possesses. It is possible that the problems with recognizing and describing emotional states are merely a result of social pressure situated in the context.

## **Blogging and the Mental Health Care**

We wanted to investigate the participants' experiences of meeting the mental health care. The participants describe different experiences. Some say that their blog activity is not a focus in therapy. Others report that their therapist has objections to their blog activities, while some have been encouraged to blog by mental health care professionals. The bloggers are

### **BLOGGING AND EATING DISORDERS**

quite unanimous regarding how they would like to be met by the mental health care: They all say that they wish for an open and curious therapist, with whom they can discuss the blogging and its effects. Several of them say that they understand the skepticism, as many blogs do have a detrimental effect on recovery. However, they feel pre-judged when the mental health care automatically places them in this category. It would be appropriate for mental health workers to adopt an open and exploratory take on this issue when meeting with bloggers in therapy.

There should be an agreement between therapist and patient on whether or not the therapist is to read the blog. As one participant explains, the blog is a private sphere that she does now want to mix with treatment.

Recently, there has been an increased focus on the importance of client feedback, or user participation, in the therapeutic context. The principle of user participation states that the user's knowledge and experiences must be taken into account, in order to provide the best help possible (Valla, 2010). Our participants state that it is common to blog about experiences with the mental health care. Thus, the blogs can provide valuable insights for professionals in this field.

It is important that health care professionals become aware of blog activities. Most young patients with EDs today know what a blog is, and possibly also read blogs about EDs on a regular basis. Therapy could be improved by the patient and therapist examining the effect blogging may have on recovery. In doing so, it is possible to establish strategies for blogging in a health-promoting fashion.

### **Methodological Issues**

We want to point out some methodological issues that are of relevance to the data generation and interpretations of the findings. First, the study has been limited in time and resources available. We only *interviewed* bloggers, although the blog itself could potentially

provide us with valuable information. Due to the fact that the blogs were not subject of analysis, we do not have any knowledge of potential differences between the women's portrayal of their blog in the interview and their actual blog.

Second, during the interviews it became clear that most of the women know of each other and participate in the same blogring. Some of the women mentioned other participants by name, and some have met in person. This fact has without a doubt affected the interviews. The women have a figure of speech which is very homogenous, and they seem to have discussed several of the topics in the interview with each other (such as triggering and norms for avoiding this). Therefore, this study is a dive into the worlds of a certain type of bloggers, and a certain community, and the generalizability to other samples is unknown. An additional aspect worth noting is the fact that the bloggers were the ones to contact us after having received information about the study. It is possible that our respondents differ from the bloggers who refrained from contacting us. This might also be the case for bloggers who write anonymously and who are not in treatment, thus not being included in our recruitment. It is worth examining further the meaning and effect of blogging for this group of people.

Third, during the study our focus of attention is biased, as we are not objective. Our preconceptions have affected the study in every step of the process; when designing the interview guide, during the interviews, in the analyzing of the data and the presentation of it. The focus during the interviews was very much depending on the focus in the interview guide, which will influence what the results will look like. It is possible that the participants would have emphasized other aspects than those we have chosen to highlight if the interviews were less structured. Hence, the results of the study must be regarded as a combination of the researchers' preconceptions and focus of attention, and the participants' responses to these, as well as additional information they have provided.

77

Fourth, nonverbal signs from the participants were taken into account during the course of the interviews, in order to lead the conversations in constructive directions. Two of the interviews were conducted through the use of the software application Skype. The interviewer experienced this as being a challenge for natural interaction. This was mainly due to the difficulties of taking in the subtle signs of the participant, and also the technical problems representing obstacles for optimal communication. It is also possible that the participants have been affected by the researchers, as some of their demographic characteristics are quite similar to ours. We are three women of approximately the same age as the participants, in the verge of finishing our education in becoming psychologists. The similarity in age and gender, but difference in life situations, may have caused the participants to become self-conscious, or affected the interaction during the interviews. In addition, this unspoken fact may have affected which questions were asked, and which were left out. Our potential impact on the results in this way is difficult to analyze, but worth noting. In an attempt to maintain the primary focus on the participants, we continuously asked ourselves; does the information stem from the participants, or is it an interpretation made by us?

Finally, during the process of writing the thesis, the quotations have been translated from Norwegian to English. It is possible that some of the meaning of the original quotations has been altered or lost.

## **Future Research**

As the participants' blogs not were explored, we know little about the relationship between the impression the bloggers give in the interviews and how they actually appear on their blogs. For example, it would be of interest to explore whether the bloggers comply with the norms concerning triggering. Further, to obtain more insight on the topic of blogging and EDs, one needs to explore the life worlds of other bloggers with EDs, such as those who write the "negative" blogs that our participants speak of. However, recruiting these bloggers may prove to be a challenge, as many of them are anonymous, and it will likely require more time and recourses than what has been available in this study.

Originally, we were interested in exploring the experience of *blogging* about EDs. During the course of the study, it has been increasingly difficult to disentangle this activity from other kinds of online participation, such as memberships on forums. Most of our participants appear to be a part of a tightly knit community. It would be beneficial to recruit bloggers who are not members of forums, in order to address the effect of blogging per se. The effect of forum participation should also be examined.

It is possible that the people who choose to blog, especially bloggers who write about mental health, as opposed to writing a personal journal, have some different traits. Also, bloggers who write about EDs may differ from bloggers who write about other topics (such as other diseases, hobbies, sports or politics). It is possible that this group of people appreciates the possibility of hiding behind a screen to a greater extent than other types of bloggers. This aspect might be of interest in future research.

## Conclusion

The aim of this study was to explore the experience of having an eating disorder and blogging about the illness. Blogging about one's mental health seems to be of help for those who do not have the possibility to receive sufficient support and understanding elsewhere. In addition, feeling valuable to others seems to be of importance. The feedback that the bloggers receive provides them with a feeling of mastery and sense of worth, and it is likely that this might be an aid and a motivation in the process of recovery. However, the tendency to create ingroups that operate with different norms than in the rest of society may be problematic when trying to reintegrate oneself in it. Also, spending large amounts of time on blogs and forums discussing EDs might hold one back in the condition and prevent complete recovery.

It seems important to acknowledge the bloggers' wish to have an open dialogue with the mental health care about how blogging affects the progress in treatment. In conclusion, it appears that blogging can have a positive effect on the bloggers' EDs. Still, one should be aware that blogging in a negative manner and spending time on ED forums may represent hindrances when trying to recover.

### References

- Allen, J. G., Fonagy, P., & Bateman, A. W. (2010). *Mentalisering i klinisk praksis* (A. Bonnevie, Trans.). Copenhagen, Denmark: Hans Reitzels forlag.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders IV-TR* (4th ed.). Washington, DC: Author.
- Ashworth, P. (2003). The origins of qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology. A practical guide to reseach methods* (pp. 4-25). London, England: Sage Publications Ltd.
- Baker, J. S., & Moore, S. M. (2008). Distress, coping, and blogging: Comparing new
  Myspace users by their intention to blog. *Cyber Psychology & Behavior*, *11*(1), 8185. doi: 10.1089/cpb.2007.9930
- Bargh, J., McKenna, K., & Fitzsimons, G. (2002). Can you see the real me? Activation and expression of the 'true self' on the Internet. *Journal of Social Issues*, 58(1), 33-48. doi: 10.1111/1540-4560.00247
- Bell, V. (2007). Online information, extreme communities and Internet therapy: is the Internet good for our mental health? *Journal of Mental Health*, 16(4), 445-457. doi: 10.1080/09638230701482378
- Birkeland, M. S., Rimehaug, T., Arefjord, K., & Jøraas, T. (2009). Klienters erfaringer med
  e-terapi som tillegg til vanlig psykoterapi. *Tidsskrift for Norsk Psykologforening,*46(4), 348-354. Retrieved from

http://www.psykologtidsskriftet.no/index.php?seks\_id=77458&a=2

. BlogPulse. (2011, November 11), from <a href="http://www.blogpulse.com/">http://www.blogpulse.com/</a>

boyd, d. (2006). *Identity production in a networked culture: Why youth heart Myspace*. American Association for the Advancement of Science. Talk held at a conference. St. Louis, MO. Retrieved from

http://www.danah.org/papers/talks/AAAS2006.html

- Brown, R. (2000). *Group processes: Dynamics within and between groups*. Oxford, England: Blackwell.
- Buhl, C. (2002). Eating disorders as manifestations of developmental disorders:
  Language and capacity for abstract thinking in psychotherapy for eating disorders. *European Eating Disorders Review*, *10*(2), 138-145. doi: 10.1002/erv.440
- Chandler, D. (1998). *Personal home pages and the construction of identities on the web.* Linking Theory and Practice: Issues in the Politics of Identity. Paper for a conference. Aberystwyth University. Retrieved from

http://www.aber.ac.uk/media/Documents/short/webident.html

Cochran, A. (2009). *Blogging the recovery from anorexia: A new platform for the voice of ED*. Young scholars in writing. Department of English. University of Houston-Clear Lake. Retrieved from

http://cas.umkc.edu/english/publications/youngscholarsinwriting/volumeseve n.html

- Cooley, C. H. (1964). *Human nature and the social order* (rev ed.). New York City, NY: Schocken.
- Cummings, J., Butler, B., & Kraut, R. (2002). The quality of online social relationships. *Communications of the ACM, 45*(7), 103-108. doi: 10.1145/514236.514242
- Derlega, V. L., & Chaikin, A. L. (1977). Privacy and self-disclosure in social relationships. *Journal of Social Issues, 33*(3), 102-115. doi: 10.1111/j.1540-4560.1977.tb01885.x

- Derlega, V. L., Metts, S., Petronio, S., & Margulis, S. T. (1993). *Self-disclosure*. London, England: Sage Publications
- Dias, K. (2003). The ana sanctuary: Women's pro-anorexia narratives in cyberspace. *Journal of International Women's Studies, 4*(2), 31-45. Retrieved from http://www.bridgew.edu/soas/jiws/April03/index.htm
- Ellison, N., Heino, R., & Gibbs, J. (2006). Managing impressions online: Self-presentation processes in the online dating environment. *Journal of Computer-Mediated Communication*, *11*(2), 415-441. doi: 10.1111/j.1083-6101.2006.00020.x
- Erickson, T. (1996). The world wide web as social hypertext. *Communications of the ACM 39*(1). doi: 10.1145/234173.234174
- Farrell, H., & Drezner, D. (2008). The power and politics of blogs. *Public Choice, 134*(1), 15-30. doi: 10.1007/s11127-007-9198-1
- Finlay, L. (2003). Through the looking glass: Intersubjectivity and hermeneutic reflection. In L. Finlay & B. Gough (Eds.), *Reflexivity. A practical guide for reaserchers in health and social sciences* (pp. 105-119). Oxford, England: Blackwell Science.
- Frable, D. E. S. (1993). Being and feeling unique: Statistical deviance and psychological marginality. *Journal of Personality and Social Psychology*, 61(1), 85-110. doi: 10.1111/j.1467-6494.1993.tb00280.x
- Gavin, J., Rodham, K., & Poyer, H. (2008). The presentation of "pro-anorexia" in online group interactions. *Qualitative Health Research*, 18(3), 325-333. doi: 10.1177/1049732307311640
- Gergen, K., Gergen, M., & Barton, W. H. (1973). Deviance in the dark. *Psychology Today, 11*, 129-130. Retrieved from <u>http://www.swarthmore.edu/x20607.xml</u>

Gilbert, P. (2002). Body shame: A biopsychosocial conceptualisation and overview with treatment implications. In P. Gilbert & J. Miles (Eds.), *Body shame: Conceptualisation, research and treatment* (pp. 3-54). New York, NY: Brunner-Routledge.

Giles, D. (2006). Constructing identities in cyberspace: The case of eating disorders. *British Journal of Social Psychology*, 45(3), 463-477. doi:
10.1348/014466605X53596

Giorgi, A., & Giorgi, B. (2003). Phenomenology. In J. A. Smith (Ed.), *Qualitative psychology. A practical guide to reseach methods* (pp. 25-50). London, England: Sage.

Goffman, E. (1959). *The presentation of self in everyday life*. Garden City, NY: Double Day.Goffman, E. (1963). *Stigma*. London, England: Penguin Group.

- Goss, K., & Gilbert, P. (2002). Eating disorders, shame and pride: A cognitive-behavioral functional analysis. In P. Gilbert & J. Miles (Eds.), *Body shame: Conceptualisation, research and treatment* (pp. 219-255). New York, NY: Brunner-Routledge.
- Graybeal, A., Sexton, J. D., & Pennebaker, J. W. (2002). The role of story-making in disclosure writing: The psychometrics of narrative. *Psychology and health*, *17*(5), 571-581. doi: 10.1080/08870440290025786
- Guardiola-Wanden-Berghe, R., Sanz-Valero, J., & Wanden-Berghe, C. (2010). Eating disorders blogs: Testing the quality of information on the Internet. *Eating Disorders, 18*(2), 148-152. doi: 10.1080/10640260903585565
- Haas, S. M., Irr, M. E., Jennings, N. A., & Wagner, L. M. (2010). Communicating thin: A grounded model of online negative enabling support groups in the pro-anorexia movement. *New Media & Society, 13*(1), 40-57. doi: 10.1177/1461444810363910

- Helse- og omsorgsdepartementet. (2008). Lov om medisinsk og helsefaglig forskning. Retrieved from <u>http://www.lovdata.no/all/hl-20080620-044.html</u>
- Herring, S. C., Scheidt, L. A., Bonus, S., & Wright, E. (2004). Bridging the gap: A genre analysis of weblogs. *Proceedings of the 37th Annual Hawaii International Conference on System Science, 4*, 40101b. doi: 10.1109/HICSS.2004.1265271
- Kjelsås, E., Bjørnstrøm, C., & Götestam, K. G. (2004). Prevalence of eating disorders in female and male adolescents (14–15 years). *Eating Behaviors*, 5(1), 13-25. doi: 10.1016/s1471-0153(03)00057-6
- Klump, K. L., Bulik, C. M., Kaye, W. H., Treasure, J., & Tyson, E. (2009). Academy for eating disorders position paper: Eating disorders are serious mental illnesses. *International Journal of Eating Disorders*, 42(2), 97-103. doi: 10.1002/eat.20589
- Ko, H.-C., & Pu, H.-J. (2011). Understanding the impact of bloggers' self-disclosure on resilience. Paper presented at the 5th International Conference on Ubiquitous Information Management and Communication, Seoul, Korea.
- Krämer, N., & Winter, S. (2008). Impression management 2.0: The relationship of selfesteem, extraversion, self-efficacy, and self-presentation within social networking sites. *Journal of Media Psychology: Theories, Methods, and Applications, 20*(3). doi: 10.1027/1864-1105.20.3.106
- Kvale, S. (2004). *InterViews: An introduction to qualitative research interviewing* (2nd ed.). Copenhagen, Denmark: Hans Reitzels Forlag.
- Larsen, M. C. (2007). *Understanding social networking: On young people's construction and co-construction of identity online*. Paper presented at the The Society for Social Studies of Science 4S Annual Vancouver, British Columbia.
- Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of*

*Qualitative Methods, 2*(3). Retrieved from

http://ejournals.library.ualberta.ca/index.php/IJQM/article/view/4510

- Lenhart, A. (2005). Unstable texts: An ethnographic look at how bloggers and their audience negotiate self-presentation, authenticiy, and norm formation. Master's Thesis. Graduate School of Arts and Sciences. Georgetown University. Retrieved from http://lenhart.flashesofpanic.com/Lenhart\_thesis.pdf
- Lenhart, A., & Fox, S. (2006). Bloggers: A portrait of the Internet's new storytellers. *Technical report, Pew Internet & American Life Project*. Retrieved from <u>http://www.pewinternet.org/Reports/2006/Bloggers.aspx</u>
- Liao, H., Liu, S., & Pi, S. (2011). Modeling motivations for blogging: An expectancy theory analysis. *Social Behavior and Personality: An International Journal, 39*(2), 251-264. doi: 10.2224/sbp.2011.39.2.251
- Mantella, D. G. (2007). "Pro-Ana" web-log uses and gratifications towards understanding the pro-anorexia paradox. Communication Theses. Department of Communication. Georgia State University. Retrieved from

http://digitalarchive.gsu.edu/communication\_theses/24

- Maso, I. (2003). Necessary subjectivity: Exploiting researchers' motives, passions and rejudices in pursuit of answering "true" questions. In L. Finlay & B. Gough (Eds.), *Reflexivity. A practical guide for researchers in health and social sciences* (pp. 39-51). Oxford, England: Blackwell Science Ltd.
- McKenna, K. Y. A., & Bargh, J. A. (1998). Coming out in the age of the Internet: Identity "demarginalization" through virtual group participation. *Journal of Personality and Social Psychology*, *75*(3), 681-694. doi: 10.1037/0022-3514.75.3.681

- McKenna, K. Y. A., & Bargh, J. A. (1999). Causes and consequences of social interaction on the Internet: A conceptual framework. *Media Psychology*, 1(3), 249-269. doi: 10.1207/s1532785xmep0103\_4
- McKenna, K. Y. A., Green, A. S., & Gleason, M. E. J. (2002). Relationship formation on the Internet: What's the big attraction? *Journal of Social Issues*, 58(1), 9-31. doi: 10.1111/1540-4560.00246
- McNeill, L. (2003). Teaching an old genre new tricks: The diary on the Internet. *Biography An Interdisciplinary Quarterly, 26*(1), 24-47. doi:
  10.1353/bio.2003.0028
- Miura, A., & Yamashita, K. (2007). Psychological and social influence on blog writing: An online survey of blog authors in Japan. *Journal of Computer-Mediated Communication*, 12(4), 1452-1471. doi: 10.1111/j.1083-6101.2007.00381.x
- Mond, J. M., Robertson-Smith, G., & Vetere, A. (2006). Stigma and eating disorders: Is there evidence of negative attitudes towards anorexia nervosa among women in the community? *Journal of Mental Health*, *15*(5), 519-532. doi:

10.1080/09638230600902559

Morgan, A. (2000). *What is narrative therapy? An easy-to-read introduction*. Adelaide, South Australia: Dulwich Centre.

Mulveen, R., & Hepworth, J. (2006). An interpretative phenomenological analysis of participation in a pro-anorexia Internet site and its relationship with disordered eating. *Journal of Health Psychology*, *11*(2), 283-296. doi: 10.1177/1359105306061187

Nardi, B. A., Schiano, D. J., Gumbrecht, M., & Swartz, L. (2004). Why we blog. *Communication of the ACM, 47*(12). doi: 10.1145/1035134.1035163

- Newton, M. S., & Ciliska, D. (2006). Internet-based innovations of the prevention of eating disorders: A systematic review. *The journal of treatment and prevention*, *17*(1), 365-384. doi: 10.1080/10640260600952522
- Nordbø, R., Espeset, E. M. S., Gulliksen, K. S., Skårderud, F., & Holte, A. (2006). The meaning of self-starvation: Qualitative study of patients' perception of anorexia nervosa. *International Journal of Eating Disorders, 39*(7), 556-564. doi: 10.1002/eat.20276
- Núñez-Navarro, A., Agüera, Z., Krug, I., Jiménez-Murcia, S., Sánchez, I., Araguz, N., . . .
  Fernández-Aranda, F. (2011). Do men with eating disorders differ from women in clinics, psychopathology and personality? *European Eating Disorders Review*, n/a-n/a. doi: 10.1002/erv.1146
- Páez, D., Velasco, C., & González, J. L. (1999). Expressive writing and the role of alexythimia as a dispositional deficit in self-disclosure and psychological health. *Journal of Personality and Social Psychology, 77*(3), 630-641. doi: 10.1192/apt.11.5.338
- Pennebaker, J. W. (1990). *Opening up: The healing power of confiding in others*. New York, NY: Oxford University Press.
- Pennebaker, J. W. (1997). Writing about emotional experiences as a therapeutic process. *Psychological science*, *8*(3), 162-166. doi: 10.1111/j.1467-9280.1997.tb00403.x
- Pennebaker, J. W., & Chung, C. K. (2010). Expressive writing and its links to mental and physical health. In H. S. Friedman (Ed.), *Oxford handbook of health psychology* (pp. 417-437). New York, NY: Oxford University Press.
- Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992). In search of how people change. Applications to addictive behaviors. *American Psychologist*, 47(9), 1102-1114. Retrieved from

http://www.uri.edu/research/cprc/Publications/PDFs/ByTitle/In%20Search% 20of%20How%20People%20Change%20Applications%20to%20Additive%20B ehaviors.pdf

QSR. (2011). NVivo (Version 9).

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The psychologist,* 18(1), 20-23. Retrieved from <u>http://www.thepsychologist.org.uk/archive/archive home.cfm?volumeID=18&e</u> <u>ditionID=114&ArticleID=798</u>

Rich, E. (2006). Anorexic dis(connection): Managing anorexia as an illness and an identity. *Sociology of Health & Illness, 28*(3), 284-305. doi: 10.1111/j.1467-9566.2006.00493.x

Richards, J. M., Beal, W. E., Seagal, J. D., & Pennebaker, J. W. (2000). Effects of disclosure of traumatic events on illness behavior among psychiatric prison inmates. *Journal of Abnormal Psychology*, *109*(1), 156-160. doi: 10.1037/0021-843X.109.1.156

Robinson, L. (2007). The cyberself: The self-ing goes online, symbolic interaction in the digital age. *New Media and Society*, 9(1), 93-110. doi:
10.1177/1461444807072216

- Rosenvinge, J. H., & Götestam, K. G. (2002). Spiseforstyrrelser hvordan bør
   behandlingen organiseres? *Tidsskrift for Den Norsk Lægeforening*, (3), 122-285.
   Retrieved from <a href="http://tidsskriftet.no/article/481427">http://tidsskriftet.no/article/481427</a>
- Schmidt, U., Bone, G., Hems, S., Lessem, J., & Treasure, J. (2002). Structured therapeutic writing tasks as an adjunct to treatment in eating disorders. *European Eating Disorders Review*, 10(5), 299-315. doi: 10.1002/erv.465

 Schmidt, U., & Treasure, J. (2006). Anorexia nervosa: valued and visible. A cognitiveinterpersonal maintenance model and its implications for research and practice.
 *British Journal of Clinical Psychology*, 45(3), 343-366. doi: 10.1348/014466505x53902

Seierstad, A., Langengen, I., Nylund, H. K., Reinar, L., & Jamtvedt, G. (2004). Forebygging og behandling av spiseforstyrrelser. Oppsummering av systematiske oversikter. *Rapport nr. 13*. Retrieved from

http://www.kunnskapssenteret.no/Publikasjoner/Forebygging+og+behandling +av+spiseforstyrrelser.1519.cms

- Skårderud, F. (2003). Sh@me in cyberspace. Relationships without faces: The e-media and eating disorders. *European Eating Disorders Review*, 11(3), 155-169. doi: 10.1002/erv.523
- Skårderud, F. (2007a). Psychiatry in the flesh. Embodiment of troubled lives. Studies of anorexia nervosa and eating disorders. Doctoral dissertation, University of Oslo, Oslo: Norway. (563)
- Skårderud, F. (2007b). Shame and pride in anorexia nervosa. A qualitative descriptive study. *European Eating Disorders Review, 15*(2), 81-97. doi: 10.1002/erv.774
- Smith, J. A. (2003). Validity and qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology. A pratical guide to research methods.* (pp. 232-235). London, England: Sage Publications Ltd.
- Smith, J. A., Flowers, P., & Larkin, M. (2010). *Interpretative phenomenological analysis. Theory, method and research.* London, England: SAGE Publications Ltd.
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative Psychology. A practical guide to research methodes.* (2nd ed., pp. 53-81): SAGE Publications Ltd.

- Smyth, J. M. (1998). Written emotional expression. Effect sizes, outcome types, and moderating variables. *Journal of Consulting and Clinical Psychology*, 66(1), 174-184. doi: 10.1037//0022-006X.66.1.174
- Snider, M. (2003). The intimacy of blogs: Web-based writers reveal all in their digital diaries. Retrieved from

http://www.macleans.ca/science/technology/article.jsp?content=20030915\_65 375\_65375

- Speedy, J. (2000). The storied helper: An introduction to narrative ideas in counseling and psychotherapy. *The European Journal of Psychotherapy Counseling and Health*, *3*(3), 361-375. doi: 10.1080/13642530010012011
- Statens helsetilsyn. (2000). *Alvorlige spiseforstyrrelser. Retningslinjer for behandling i spesialisthelsetjenesten*. Oslo, Norway.
- Suler, J. (2004). The online disinhibition effect. *CyberPsychology and Behavior*, 7(3), 321-326. doi: 10.1089/1094931041291295

Swanson, S. A., Crow, S. J., Le Grange, D., Swendsen, J., & Merikangas, K. R. (2011). Prevalence and correlates of eating disorders in adolescents results from the national comorbidity survey replication adolescent supplement. *Archives of General Psychiatry*, 68(7), 714-723. doi: 10.1001/archgenpsychiatry.2011.22

- Tajfel, H., & Turner, J. C. (1986). The social identity theory of inter-group behavior. In S.Worchel & L. W. Austin (Eds.), *Psychology of Intergroup Relations* (pp. 7-24).Chigago, IL: Nelson-Hall.
- Turkle, S. (1995). *Life on the screen. Identity in the age of the Internet.* New York, NY: Touchstone.
- Valcheva, M. (2009). *In the pursuit of understanding the cyberself*. Mediatized stories: Self-representations in digital storytelling. Universitetet i Oslo.

Forskningsassistentrapport ved Institutt for medier og kommunikasjon. Retrieved from

http://www.uv.uio.no/intermedia/english/research/projects/mediatizedstories/publications/

- Valentine, G., & Holloway, S. L. (2002). Cyberkids? Exploring childrens identities and social networks in on-line and off-line worlds. *Annals of the Association of American Geographers*, 92(2), 302. doi: 10.1111/1467-8306.00292
- Valla, B. (2010). Brukers medvirkning i psykoterapi behov for kompetanseutvikling. *Tidsskrift for Norsk Psykologforening*, 47(4), 308-314. Retrieved from <u>http://www.psykologtidsskriftet.no/index.php?seks\_id=109720&a=2</u>
- Vestergaard, P., Sørensen, T., Kjølby, M., & Videbech, P. (2008). *Psykiatri. En lærebog om voksnes psykiske sygdomme*. Copenhagen, Denmark: Fadl's forlag.
- Warin, M. (2004). Primitivising anorexia: The irresistible spectacle of not eating. *The Australian Journal of Anthropology*, *15*(1), 95-104. doi: 10.1111/j.1835-9310.2004.tb00368.x
- White, M. (2011). *Narrative practice: Continuing the conversations*. New York, NY: W.W. Norton & Company.
- Willig, C. (2008). Phenomenological methods *Introducing qualitative research in psychology. Adventures in theory and method* (2 ed., pp. 52-72). London, England:
   McGraw-Hill.
- Wolff, P. (2003). The blogcount estimate: 2,4-2-9 millions weblogs. Retrieved from <a href="http://dijest.com/bc/2003-06-01-bc.html">http://dijest.com/bc/2003-06-01-bc.html</a>
- World Health Organization. (2000). The ICD-10. Classification of mental and behavioural disorders, clinical descriptions and diagnostic guidelines. Geneva: Author.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health 15*(2),

215-228. doi: 10.1080/08870440008400302

Appendix A

### Invitational letter



## UNIVERSITETET I BERGEN

Institutt for samfunnspsykologi

Bergen .....

## Forespørsel om deltakelse i forskningsprosjektet

### " Spiseforstyrrelser, terapi og blogging"

#### Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie for å delta i forskningsprosjektet "Spiseforstyrrelser, terapi og blogging".

Vi er tre psykologistudenter på femte året ved Det psykologiske fakultet ved Universitet i Bergen, og er i dette prosjektet under veiledning av professor Norman Anderssen og psykiater Finn Skårderud. Studien blir gjort i forbindelse med hovedoppgaven på profesjonsstudiet i psykologi. Den fokuserer på hvordan personer med spiseforstyrrelser som skriver blogger erfarer dette. Det er av interesse å utforske hvordan blogging oppleves sammenlignet med terapi.

#### Hva innebærer studien?

Studien vil omfatte omlag 6 personer som har spiseforstyrrelser, går i terapi og blogger. Det vil innebære et intervju der en av oss intervjuer deg om erfaringer med blogging og terapi. Intervjuet vil ta omlag en time, og vil bli tatt opp på lydfil.

#### Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg, skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. All informasjon vi får fra deltakere vil dermed bli anonymisert. Ved nedskriving fra lydfil til tekst vil all personidentifiserbar informasjon bli omskrevet, og lydfilen vil bli slettet. Utskriften fra intervjuene vil oppbevares i fullstendig anonymisert form etter prosjektslutt. Det vil ikke være mulig å identifisere informantene i teksten ved publisering av hovedoppgaven eller i andre faglige tekster. Den som gir deg denne invitasjonen, vil ikke bli informert om hvem som ønsker å delta i prosjektet.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg.

#### Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier

Gateadresse:	Postadresse:	Telefon:	Telefax:
Christiesgate 12	5015 Bergen	55 58 31 90	55 58 98 79

ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling.

Dersom du ønsker å delta i studien, kan vi bli enige om tidspunkt for intervjuet. Dette vil gjennomføres i ditt nærmiljø, slik at det ikke medfører lang reisetid. Dersom du vil være med eller har spørsmål til studien, kan du kontakte Solveig Askim på mobil <u>47 86 06 28</u> eller epost: <u>solveig.askim@student.uib.no,</u> eller Hilde Wanvik på mobil <u>922 22 835</u>, e-post: hilde.wanvik@student.uib.no

Med vennlig hilsen

Solveig Askim Stud. Psychol.

Hilde Hove Pettersen Stud. Psychol. Hilde Wanvik Stud. Psychol.

<u>Veileder</u>: Norman Anderssen Christies Gate 12 5015 Bergen Tlf: 55 58 20 55

# Appendix B

Interview guide.

# Erfaringer med blogging og terapi hos pasienter med spiseforstyrrelser

## **Intervjuguide**

## Guidens tekniske utforming

Rød tekst er enten instrukser til intervjueren eller stikkord som hjelp til å minne om hva som skal være i fokus.

Blå tekst er forslag til direkte spørsmål.

## Introduksjon av studien, formålet og hvordan intervjuet skal foregå.

## Takk

Du er viktig: Takk for at du stiller opp og bidrar! Bidraget ditt er viktig for økt kunnskap og forståelse slik at andre i en lignende situasjon kan i større grad bli møtt med en forståelse og dermed få et bedre hjelpetilbud.

## Målsettingen med prosjektet

Først og fremst øke kunnskap om hvordan bloggpraksis påvirker brukere som er diagnostisert og er under behandling for anoreksi. Studien vil belyse hvordan spiseforstyrrelsen påvirker og påvirkes av aktiv blogging omkring temaer som for eksempel mat, kroppsbildet og selvfølelse.

Denne kunnskapen vil videre kunne benyttes innenfor behandlingsapparatet. Et mål med studien er å bidra til et utvidet perspektiv på behandling av spisefortyrrelser.

## Tid og temaer for intervjuet

Intervjuet kommer til å halvannen time, og følgende temaer vil bli gjennomgått:

- Bloggpraksis
- Spiseproblemer, dine egne tanker om din historie
- Skriving som terapi
- Stigmatisering
- Profesjonell hjelp

Noen av spørsmålene behøver ikke å være relevant for deg. Og noen av spørsmålene vil bli gjentatt.

## Understrek anonymiteten

Det du sier blir tatt opp på bånd, skrevet ut og anonymisert. Lydfilen blir deretter slettet. De involverte prosjektmedarbeiderene, dvs de tre studentene som skriver oppgaven samt veiledere ved UIB, har taushetsplikt ovenfor det som kommer frem i intervjuet.

## Informert samtykke

Presentere skjema, og sørge for at dette blir underskrevet.

Dette skjema ønsker vi at du skriver under på. Skjemaet er en bekreftelse på at du forstår og godtar de rammene rundt prosjektet som jeg nettopp har beskrevet.

Har du noen spørsmål? Er det noe du har lurt på i forkant av intervjuet?

## Intervjuspørsmål

Temaoverskriftene er kun en hjelp til å strukturere og skape overblikk for den som foretar intervjuet og skal ikke eksplisitt brukes som spørsmål eller del av spørsmål.

## **TEMA 1: BLOGGPRAKSIS**

Målet her er å få frem forskjellige opplevelsesformer og "bruksmåter" av blogging

Jeg skal stille noen spørsmål om ditt forhold til blogging. Vi er spesielt oppfatt av forskjellige grunner for å drive med blogging, og hvordan du selv opplever det

- Hvor lenge har du blogget?
- Hvor mange timer om dagen/uken driver du bloggrelaterte aktiviteter?

Forsøk å være ganske presis i forhold til en uke du oppfatter som gjennomsnittlig. Eksempelvis tiden som går med til forberedelse, skriving, lesing av andres blogger

- Kan du fortelle litt om bloggingen din?
- Kan du si litt om ditt forhold til blogging, hva det betyr for deg?

# Viktig med utdyping. Forsøk å få frem konkrete eksempler.

Hva er det du i hovedsak skriver om?

- Når blogget du sist? hva fikk deg til å blogge da?
  - Husker du hva du tenkte mens du blogge?
  - Hvordan følte du deg etterpå?

Utdypende spørsmål:

- Hva er dine **fremste motivasjoner** for å blogge?

Noen mulige områder:

- Kreativitet og skaping
- Skrive om det som er vanskelig dagbokfunksjon
- Sosiale aspekter sosial støtte, et publikum
- Utagere indre uro/spenning
  - Straffe seg selv

- Eksempler?

### Føler du deg stolt over den du er på bloggen? Og har fått til?

- -
- Endrer dette seg over tid og med situasjon?
- Kan du fortelle kort om hvor du henter inspirasjon til bloggen din? hverdagslivet, proana-internettsider, terapitimene, andre blogger,

### Generelt om blogging og spiseforstyrrelsen

Forsøke å få frem utsagn som peker mot *deres tanker om kausalitet* i forhold til utviklingen av egen spiseforstyrrelse/problemer omkring mat og kropp.

- Hvilke tanker gjør du deg *mer generelt* om sammenhengene mellom å utvikle og ha spiseforstyrrelser og det å lese/produsere blogger rundt temaet kropp og mat?
- Kan du i den sammenheng si noe om betydningen av forholdet til
  - Å lese andres blogger
  - Fellesskapet
  - Publikum/lesere
  - Familie
  - Mediaomtale
  - Andre/annet

### Kontroll -

Bloggere har muligheten til å kontrollere (sensurere) all informasjon om seg selv som legges ut på bloggen. Blogging kan på så måte foregå helt anonymt – hvilke konsekvenser tror du det kan ha?

### Er du anonym?

### Hvordan fremstiller du deg på bloggen?

Er det viktig for deg å framstå på bloggen akkurat slik du er i virkeligheten? Eller ønsker du å fremstille deg anderledes?

Identitet og rollespill i de sosiale rommene

Hvor mange lesere som er inne på bloggen din daglig?

Tenker du over hvem som leser bloggen din?

## Hvilken betydning har leserne for deg som blogger?

- Hvilken betydning har tilbakemeldinger fra lesere for din blogging?
  - Kom gjerne med eksempler på positive og negative tilbakemeldinger.
    - Hva tenkte/følte du da?
- -
- Hva tenker du om at flere ukjente mennesker har tilgang til "privatlivet" ditt?
  - -
    - Tilpasser du innholdet i blogginnleggene med tanke på hvem du tror leser bloggen, og/eller hvilket inntrykk vil du at leserne skal få av deg?
    - Føler du at leserne dine har forventninger til deg?

## Noen kan føle det som om de går inn i en rolle, eller tar på seg en maske når de blogger. Har du noen gang følt det sånn?

Hva tenker du om det?

Leser du andres blogger?

- Hvilke type blogger leser du?
- Gjennomsnittlig, hvor mye tid bruker du på å lese andres blogger?
- Skriver du tilbakemeldinger på andres blogger?
  - Er dette viktig for deg?
  - -

Har du fått venner gjennom bloggen din?

Utdyp med spørsmål rundt kvaliteten på vennskapet/-ne. Oppfølging av inn-/utgruppe forhold senere.

- Holder dere kontakten gjennom internett, eller har dere møtt hverandre ansikt til ansikt? Mailer, telefonerer
- Er disse vennskapene annderlededs enn venner etablert gjennom skole/jobb/nærmiljø?

Hvis du hadde møtt noen av de vennene du har fått gjennom bloggen, tror du de ville synes du var lik eller veldig annerledes fra den du er på bloggen? Spiseproblemer blir ofte definert som "overopptatthet av mat, vekt og kropp", det vil si mange og plagsomme tanker om temaene. Opplever du at dette stemmer for deg?

Ved positivt svar:

- Hvordan påvirker slike fenomener deg og hva du skriver på bloggen din?

Blogging omkring mat, kropp og slanking får gjerne negativ oppmerksomhet fra media. Omtalene går ut på blant annet at bloggene er med på å fremme et usunt kroppsideal og at de "rekrutterer" nye inn i spiseforstyrrelsen. Hva tenker du om dette?

Har du noen gang fått eller gitt kostholdsveiledning/råd fra/til andre bloggere? Hva er dine tanker omkring dette? Oppfølgingsspørsmål hvis positivt svar.

Det finnes såkalte "pro-ana"-internettsider- har du noen gang vært inne på disse?

Hvis positivt svar:

- Hvor ofte?
- hva er motivasjonen din får å besøke slike sider?

Eksempelvis thinspiration, sosial søtte, informasjon og råd

Kan du huske en spesielt god opplevelse i forhold til bloggingen?

Kan du huske en spesielt negativ/dårlig opplevelse med bloggingen?

## **TEMA 2: SPISEFORSTYRRELSEN**

Nå skal jeg stille spørsmål om den rollen spiseproblemene har i ditt liv. Du må si ifra om du har problemer med å skjønne hva jeg spør om:

Kan du si noe om hvordan du i dag har, eventuelt ikke har, et anstrengt forhold til kropp og mat.

- Betrakter du selv dette som en spiseforstyrrelse?
  - Hva kaller du dine egne problemer? Ved klart svar bruk dette i intervjuet, eks. "bulimien min/bulimien din".

Nå ønsker vi å få belyst din historie, spesielt i forhold til spiseproblemer:

- Hvor gammel er du nå?

### BLOGGING AND EATING DISORDERS

- Hvor lenge vil du si at du har hatt problemer omkring mat og kropp?
- Nå ønsker vi at du sier noe om utviklingen av slike problemer, om hvordan det startet. Viktige begivenheter eller vendepunkter, både positive og negative. Vi er interessert i alle tanker du har om dette.

Kan du fortelle litt om hvordan det å ha et anstrengt forhold til mat og kropp påvirker deg på

en negativ måte?

Eksempelvis: helseskader, sosial tilbaketrekning, reduserte fungering m.m.

Finnes det "positive sider" ved din atferd i forhold til mat og kropp?

Eksempelvis: opplevelse av kontroll, lykkes med noe, slippe unna ubehagelige tanker og følelser, få ut spenninger m.m.

Hvordan tror du ditt liv ville se ut uten dine problemer med mat og kropp?

- Hva ville være de viktigste forskjellene?
  - Bedre?
  - Verre?

Det er viktig å følge opp disse problemstillingene: Forsøke å få gode beskrivelser av symptomers og problemers funksjon.

- Hvordan påvirker disse problemene forholdet til andre mennesker?

Eksempelvis: forhold til familie og andre nære relasjoner

- Er det lettere å kommunisere med noen over nettet om disse problemene?

### **TEMA 3: SKRIVING SOM TERAPI**

# Hvilke tanker gjør du deg om sammenhengen mellom *dine* spiseproblemer og det at du blogger?

Hvor mange av innleggene har fokuset ...

- Mat
- Kropp
- Hvordan du har det (depresjon, selvbildet)
- Terapiforløp
- andre

# Husker du sist gang du skrev et innlegg knyttet til spiseforstyrrelsen din? Kan du fortelle meg om det?

- Hva var det som fikk deg til å skrive det?

- Endret følelsene seg underveis /etter du skrev innlegget?

## Tror du at din rolle som aktiv blogger

- forverrer
- reduserer/hjelper
- eller er av ingen eller liten betydning

for dine problemer omkring mat og kropp/spiseforstyrrelse? Hvilke aspekter tror du er mest potent? Kan du si litt mer om det?

## Hva ville skje hvis du ikke lengre fikk lov til å blogge om din spiseforstyrrelse?

Arbeider du mye med innleggene dine – eller skriver du på impuls?

Leser du gamle innlegg du har skrevet?

## **Uttrykker du sykdommen din på andre måter enn gjennom blogging?** Eksempelvis skriving av dikt, maling, sang

## Skriver du dagbok?

Oppfølingsspørsmål:

- Hva tror du er forskjellen på å skrive dagbok og det å skrive en blogg?
- Hva er det som gjør at du blogger i stedet for å skrive dagbok?

-

Skriver du annerledes om sykdommen din – enn på måten du snakker om den?

Hender at skrivingen av et blogginnlegg får deg til å føle deg bra i etterkant? Har det hendt at du har følt deg verre?

Skriving som terapi, eksponering og utlevering, tilbakemeldingene versus mangel på,

Leser noen av dine nærmeste venner bloggen din?

## Ville noen av dine nærmeste – som kjenner til dine problemer – ha en annen forståelse av deg enn den du er på bloggen? Roller i det sosiale rom

Kan du gi et eller flere eksempler på konkrete situasjoner hvor dine problemer er særdeles lite fremtredende, hvor de "glemmes". Alternativt: Når tenker du minst på problemer omkring om mat og kropp? i sammenheng med eller uten blogging?

Kan du gi et eller flere eksempler på konkrete situasjoner hvor dine problemer er særdeles mye fremtredende. Alternativt: Når tenker du mest på problemer omkring om mat og kropp?

Blir du påminnet spiseforstyrrelsen din når du skriver selv eller leser andres blogger?

## **TEMA 4: STIGMATISERING**

## I forhold til blogging

Som tidligere nevnt, kan blogging foregå helt anonymt. Leseren forholder seg kun til tekst – eventuelt bilder – som du velger å legge ut. De kan hverken se eller høre deg, eller snakke direkte til deg. Gjør dette det enklere for deg å blogge?

Eksempelvis i forhold til ansvarsforhold, unngåelse, uavhengighet ift tid,

flerdimensjonalitet borte.

Roller i sosiale medier, fellesskap, venner ovs

Vi har allerede gått litt inn på ulike roller på nettet. Tror du andre bloggere er åpne i forhold til hva de skriver/hvem de er på nett?

Vil du beskrive dere som blogger som et fellesskap?

....

Føler du deg friere til å ta opp aspekter ved spiseforstyrrelsen på bloggen din versus å snakke direkte?

## Beskyttet

Vet du om dine nærmeste venner eller familien din leser det du skriver på bloggen din?

- Har det hendt at du skriver innlegg på bloggen som du skulle ønsker dine nærmeste leste?
- Kan bloggen din fungere som et talerør ut til dine nærmeste eller blogg-vennene dine?

## Er det noen du ville ha vært flau for å vise bloggen din til?

**Har det hendt at du angrer på noe du har skrevet og publisert ute på bloggen?** Prøv å gjenkalle den episoden;

- Hva handlet innlegget om?
- Hva fikk deg til å skrive det/motivasjonen?
- Hva tenker du nå?

- Skammet du deg?
- Har du noen gang slettet et publisert innlegg?

Blogger om mat, kropp og slanking får, som tidligere nevnt, en del negativ

oppmerksomhet fra media. Føler du deg forhåndsdømt av media?

Hvis venner eller familie leser bloggen; føler du deg noen ganger dømt av dine nærmeste?

Tilhørlighet til en stigmatisert gruppe..

Føler du deg akseptert av de andre bloggerene?

Hvis venner gjennom blogging:

Er begrepet skam noe du har et forhold til? På hviken måte?

- Hva legger du i ordet "skam"?

## **TEMA 5: PROFESJONELL HJELP**

- Kan du beskrive den hjelpen du har fått/får for dine problemer omkring mat og kropp?

## Utdypende:

- Fra helsevesen
- Fra andre
- Kan du si noe om hva du har opplevd som god hjelp? På hvilken måte?
- Kan du si noe om hva du har opplevd som dårlig hjelp? På hvilken måte?
- Kan du si litt om *din motivasjon* for å komme ut av problemene omkring mat og kropp:
  - Din motivasjon nå og tidligere
  - Er det noe som særlig bidrar/har bidratt til å fremme en slik motivasjon?
  - Er det noen som særlig bidrar/har bidratt til å fremme en slik motivasjon?
  - Er det *noe* som særlig hemmer/har hemmet en slik motivasjon?
  - Er det noen som særlig hemmer/har hemmet en slik motivasjon?
  - Har du tanker om det er *noe/noen* som kunne ha hjulpet deg til å mer motivert?

## I forhold til blogging

Hender det at du blogger om temaer du og din terapeut har snakket om i terapitimene? Eksemplifiser!

- Hvordan er det for deg å skrive/blogge om spiseforstyrrelsen sammenlignet med å snakke om den?
  - Skriver du annerledes om sykdommen din på bloggen enn måten du snakker om den på i terapi?
  - Har bloggingen gjort at du tenker annerledes om sykdommen din?

# Synes du at bloggingen har en kompletterende, motsatt eller lik virkning som tradisjonell terapi?

- på hvilken måte?
- Finnes det tema som du velger å ta opp på bloggen som du ikke vil ta opp i terapitimene? og motsatt?
- -

Vedrørende utlevering og tilbakemeldinger;

Føler du at tilbakemeldingene du får gjennom bloggen kan dekker behovet for sosial støtte?

Tror du din terapeut/miljøkontakt/eller andre i behandlingsapparatet leser bloggen din?

Nå ønsker vi å bruke deg som en ressursperson for å forbedre tilbud til dem som er i lignende situasjoner som deg.

- Bør hjelpeapparatet vie mer oppmerksomhet på bruken av sosiale medier som blogging i møte med mennesker som sliter med spiseforstyrrelser? Begrunn dette nærmere.
- Om du bruker deg selv som eksempel: hvordan ønsker du å bli møtt av behandlingsapparatet ift at du er en aktiv blogger?

### **TEMA 6: ANDRE TEMA**

- Er det andre ting du har lyst til å ta opp eller si mer om?
- Hvis du etterpå kommer på at det var noe viktig som du ikke fikk sagt, kan du bare ringe meg. Gi telefonnummer.

### Tusen takk - for at du tok deg tid til å hjelpe oss i vårt arbeid!

## Appendix C

## Overview of nodes Nodes

Name	- ^ &	Sources	References
Bloggens betydning for bloggeren		0	0
Bloggens betydning for bloggeren		0	0
bloggens rolle i livet		8	30
Motivasjon		9	19
		8	30
O Motivasjon		9	19
Positive effekter ved blogging		5	16
Bloggeren i møte med behandlingsapparatet		0	0
		2	2
		9	17
		9	23
Skriving om behandling		4	4
) Fellesskap		0	0
- O Forum		4	10
🗿 Generelt om fellesskap		7	9
Inngruppe utgruppe		4	13
Normer og regler for innhold		5	12
Positivitet		5	12
Polarisering		1	2
🔘 Inspirasjon til bedring		6	8
🔘 Negativt fellesskap		6	11
O Positive fellesskap		8	35
Potensielle skadelige effekter ved blogging		0	0
Forverring		7	14
O Selektivt fokus og effekt		8	30
Trigging		8	28
		8	18
		8	24
Variasjon i blogging og -innhold knyttet til psyken		5	11
Publikum		0	0
Det ansiktsløse publikum		7	17
Uønskede lesere		2	2
- O Forhåndsdømmelse		3	4
Forventninger fra lesere + press		7	16
O Negativt		8	22
Positivt		2	3
O Ikke bli misforstått		5	10
Komme andre i forkjøpet		3	4

## BLOGGING AND EATING DISORDERS

Publikums betydning	9	50
🔾 Anerkjennelse og validering	6	12
O Containment	5	7
Sårbarhet ifht eksponering og respons	6	29
🖃 🔘 Være betydningsfull - inspirere andre	9	36
	5	7
Dele erfaringer	4	5
Selvrepresentasjon	0	0
Autentisitet og selvrepresentasjon	9	28
Anonymitet	7	13
Bloggen som stillbilde i en flytende verden	4	6
O Blottlegging	2	4
🧿 Forlengelse av sin identitet	3	3
🧿 Fravær av lystighet	2	2
Opprettholde egne grenser	6	14
Gjemme seg bak det generelle	1	1
🔾 Ikke la andre komme for nær	5	14
Rolle	5	11
Skriving som terapi	7	22
Bedring	7	13
Bloggen som mål på bedring	7	12
Blogging vs tradisjonell behandling	8	17
- Få utløp	8	22
Kognitiv restrukturering	6	11
- Narrativer	1	1
Redusere skam	4	12
Skriving, sentrale aspekter	0	0
O Egne forventninger til kvalitet	2	4
Skriveprosessen	8	13
Skriving vs. snakking	9	33
Hinder for toveiskommunikasjon	3	3
Talerør	6	7
O Ulike skrivearenaer	7	11
Utvikling av bloggens innhold	7	21

### Appendix D

### Excerpts of analysis

### Transkript

1 Intervjuer: Hender det at du leser gamle 2 innlegg som du har lagt ut for lenge siden? 3 4 Informant: ja, det hender. Ehm, jeg synes 5 det er veldig.. det er greit. For det er så 6 lenge siden. Det er ikke nå. Samtidig hvis 7 jeg leser gjennom veldig åpne innlegg før 8 jeg legger dem ut, så kommer jeg ikke til å 9 legge dem ut. Fordi da føler jeg meg veldig 10 åpen og sårbar, og så tenker jeg at nei. 11 (småler) Når jeg leser gamle innlegg, så... 12 ser jeg at, det er veldig anndeledes enn der 13 jeg er i dag. Hvis jeg ser to år tilbake. Og 14 det er veldig, all right å se at, at jeg 15 forandrer meg. 16 17 Intervjuer: Ja. Hva er din fremste 18 motivasjon din for å blogge? 19 20 Informant: (pause) Jeg vet ikke. Det 21 begynte med at jeg tenkte; jeg vil være 22 åpen om... min spiseforstyrrelse og 23 hvordan jeg har det. Eh, i forhold til 24 lokalsamfunnet og... jeg følte det ble veldig 25 mye... hvisking bak min rygg som jeg fikk 26 høre litt om, men jeg visste ikke hva... 27 visste ikke hva noen visste eller ikke 28 visste, og hva de tenkte for seg selv. jeg 29 tenkte at jeg ville være åpen om det. Da 30 var det lett å starte en blogg og så skrive... 31 32 Intervjuer: ja, så det ble som et talerør for 33 deg da? 34 35 Informant: Ja. Så etterhvert så er det blitt 36 mer, ehm, (pause), både støtte fra andre 37 og... kunne sette ord på det andre føler. 38 39 Intervjuer: sette ord på? 40 41 Informant: eller det jeg føler. Fordi jeg fant 42 en trygghet i det å lese andres blogger som

Nodekategorisering

Linjer 1-10: "Sårbarhet i forhold til eksponering og respons" under hovednoden "Publikum".

Linjer 1-10: "Opprettholde egne grenser" under hovednoden "Selvrepresentasjon".

Linjer 10-15:" "Blogg som mål på bedring" under daværende hovednode "Blogg som positivt". (Flyttet til "Skriving som terapi" da "Blogg som positivt" som overnode ble slettet).

Linjer 17-30: "Motivasjon" under "Bloggens betydning for bloggeren" (Motivasjonsnoden ble senere oppløst og innholdet plassert andre steder).

Linjer 32-37: "Publikums betydning" under hovednoden "Publikum".

Linjer 32-47: "Være betydningsfull" under hovednoden "Publikum".

Linjer 39-47: "Positive fellesskap" under hovednoden "Fellesskap".

- 43 hadde det på samme måte, når de satte ord
- 44 på det jeg følte. Når jeg da følte meg ikke
- 45 helt ensom eller veldig sær som hadde det
- 46 på den måte, tenker jeg at da ville jeg
- 47 kunne gjøre det samme for andre.
- 48
- 49 Intervjuer: Så du leste blogger før du
- 50 startet din egen? Om spiseforstyrrelser?
- 51
- 52 Informant: Ja, noen.
- 53
- 54 Intervjuer: er det noen andre ting som
- 55 driver deg nå, til å blogge?
- 56
- 57 Informant: det er vel tilbakemeldinger fra
- 58 andre også. Det blir fort en gruppe som
- 59 følger og leser hverandres blogger og
- 60 kommenterer, og stort sett som sliter med
- 61 mye av det samme. Så det blir støtte fra
- 62 dem. Et nettsamfunn.

Linjer 54-62: "Positive fellesskap" under hovednoden "Fellesskap".

Linjer 54-62: "Anerkjennelse og validering" under undernoden "Publikums betydning" under hovednoden "Publikum"

### Appendix E

### Translation of a quotation

### Eksempel 1:

Det å være anonym, det.. er jeg veldig skeptisk til hvor sunt er i en sånn sammenheng. Da forsvinner veldig mye av filteret du har, for hva du legger ut og hva du fokuserer på. Men hvis jeg skulle ha skrevet ut fra anoreksien min sine synspunkt, så hadde det jo vært et helvete det jeg hadde lagt ut. Og hvis jeg hadde vært anonym, så kan det godt hende at jeg ikke hadde brydd meg på samme måten. Eh, når jeg skal skrive ut fra den jeg er og er nødt til å face folk for resten av livet for hva jeg har skrevet, så tenker du deg en gang eller to om.. før du skriver ting. Being anonymous.. I am very skeptical considering how healthy that is in such a context. A lot of your filter is removed, regarding what you publish and where your focus lies. If I ought to write from the anorexia's point of view, I would have published a living hell. And if I was anonymous, I might not care that much. Uhm, when I write based on who I am, and have to face people with it for the rest of my life, for what I've written, I think twice before I write.

Eksempel 2:

Det er noe med det at hvis du skriver noe, publiserer det, gjør noe annet, går tilbake, leser det som om deg ikke var deg, så kan det være lettere å gi seg selv gode råd. Hvis du skjønner hva jeg mener. Jeg syns det er lettere å gi råd til andre ennå gi råd til meg selv, jeg syns det er veldig vanskelig å se meg selv. Men hvis jeg for eksempel har skrevet noe, og så kan jeg tenke. Det er mye lettere å si at denne personen burde gjøre sånn eller sånn for å bli bedre. There's a thing about writing something, publishing it, doing something else, going back; reading it as if it weren't you, it can be easier to give yourself some good advice....I think it is easier to give others advice than giving myself some, I think it is very difficult to "see" myself. But if I have written something, and can think [about the content] afterwards, it is much easier to say that this person should do this or that to get better.

### Appendix F

### Approval from REK



### UNIVERSITETET I BERGEN

Regional komité for medisinsk og helsefaglig forskningsetikk, Vest-Norge (REK Vest)

Norman Anderssen norman.anderssen@psysp.uib.no Institutt for samfunnspsykologi Universitetet i Bergen

Deres ref	Vår ref	Dato
	2010/2625-2	03.11.10

### Ad. Prosjekt: Spiseforstyrrelser, blogging og terapi.

Det vises til prosjektsøknad, datert 30.09.2010.

Komiteen behandlet søknaden i møte 21.10.2010.

### Forskningsansvarlig

REK Vest anser Universitetet i Bergen som forskningsansvarlig for prosjektet. REK Vest forutset at dette vedtaket blir forelagt den forskningsansvarlige til orientering. Se helseforskningsloven § ( jfr. § 4 bokstav e.

### Komiteens oppfattning av prosjektet

Formålet med denne studien er å se på betydningen å blogge for personer med spiseforstyrrelser som også går i terapi. Hvilken erfaring gir bloggingen og hva motiverer til å blogge? Det vil bli gjennomført dybdeintervju av seks jenter med spiseforstyrrelse og som blogger.

### Komiteens vurdering

Komiteen mener problemstillingen er interessant og at prosjektet er godt gjennomarbeidet. En hat ingen innvendinger til forelagt protokoll.

Rekrutteringsprosed yrene synes å ivareta deltakeren på en god måte. Potensielle deltakere er i behandling og det legges opp til et klart skille mellom behandler og den som rekrutterer slik at de ikke oppstår utilbørlig press.

Informasjonsskivet må forbedres og følge malen som finnes på REK sine hjemmesider: www http://helseforskning.etikkom.no. Følgende punkter må inkluderes se eget vedlegg. Gul lapp frivil trekke seg prosjektslutt hvilke nivå i studien studenten er.

I henhold til søknad skal forskningsdata oppbevares på minnepinne. Bruk av minnepinner til oppbevaring av personidentifiserbare data er ikke tilrådelig og komiteen ber om at forskningsdataene oppbevares etter gjeldende retningslinjer ved Universitet i Bergen.

Postadresse:	E-post: rek-vest@uib.no	Region al komité for medisinsk	Besok sadress e:
REK Vest	Hj emm esi de:	og helsefaglig forskningsetikk,	2. etasje, sentralblokken,
Postboks 7804	http://hel sefors kning, etikkom.no/m et/public	Vest-Norge	Haukeland universitetssykeh
5020 Bergen	Org no. 874 789 542	Telefon 55 97 84 97 / 98 / 99	

Prosjektslutt er satt til 31.12.2011. Personidentifiserbare forskningsdata skal anonymiseres eller slettes straks det ikke lenger er behov for dem og senest fem år etter prosjektslutt.

Prosjektet har karater av et "paraplyprosjekt" som er relativt bredt anlagt og som flere studenter kan inngå som medarbeider ifbm. Sin vitenskaplige studentoppgave. Dette er en god måte å organisere prosjektet på ved at man unngår en serie godkjenningsprosesser for hver enkelt student, og som REK tidligere har anbefalt.

Vedtak: Prosjektet godkjennes på betingelse av at ovennevnte vilkår tas til følge.

Vennlig hilsen

Jon Lekven leder

> Anne Berit Kolmannskog sekretariatsleder

(Brevet er godkjent for elektronisk utsending uten signatur)

Kopi:

Forskningsansvarlig: postmottak@uib.no

Komiteenes vedtak etter forskningsetikklovens § 4 kan påklages (jfr. forvaltningsloven § 28) til Den nasjonale forskningsetiske komité for medisin og helsefag, Klagen skal sendes REK Vest (jfr. fM § 32). Klagefristen er tre uker fra den dagen du mottar dette brevet (jfr. fM § 29).

De regionale komiteene for medisinsk og helsefaglig forskningsetikk foretar sin forskningsetiske vurdering med hjemmel i helseforskningsloven § 10, jfr. forskningsetikkloven § 4.

REK Vest forutsetter at dette vedtaket blir forelagt den forskningsansvarlige til orientering. Se helseforskningsloven § 6, jfr. § 4 bokstav e.

Postadresse:	E-post: rek-vest@uib.no	Regional komité for medisinsk	Besok sadress e:
REK Vest	Hj emm esi de:	og helsefaglig forskningsetikk,	2. etasje, sentralblokken,
Postboks 7804	http://helseforskning.etikkom.no/met/public	Vest-Norge	Haukeland universitetssykehus
5020 Bergen	Org no. 874 789 542	Telefon 55 97 84 97 / 98 / 99	

### Table 1:

An Overview of the Categories and Subcategories

Sense of community
Online community providing support and a sense of belonging
Friendship formation
Belonging to a group and compliance to norms
Forum as a closed community
The power of the audience
Recognition, support and containment
Vulnerability to feedback from the audience
Not knowing who the audience is
Being valuable and sharing one's knowledge
Avoiding misunderstandings and forestalling the audience
Expectations from readers causing pressure
Self-representation online; is this the real me?
Authencity and self-representation
Exposing versus protecting oneself
On anonymity
The blog posts as snapshots
Central aspects of writing
The writing process
Different venues for writing
Writing versusface-to-face interaction
The mutual relationship between blog activity and psychological state
Triggering
Their own negative experiences of being triggered
The effects of keeping an optimistic versus a pessimistic focus
Variation in writing due to psychic state
The importance of the blog related to the strength of the ED
The development of the blog's content
Writing as therapy
Changing one's view of the ED through blogging
Reducing shame
"Getting it out"
The blog as a means to improve, remember and stay focused
Blogging as a supplement to traditional therapy
Blogging in relation to the mental health care – skepticism and acceptance
Experiences with the mental health care
Blogging while admitted
Therapists as readers
Blogging behind others' backs