Recovery and Maintenance: How Women with Eating Disorders Use Instagram

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**Abstract**
Research tends to consider either the positive or negative impact of technologies on eating disorders but rarely considers how technology can be used to aid in recovery as well as exacerbate users’ conditions. Social media is not overtly harmful or helpful within this context, but rather, Instagram, like other spaces, serves as a double-edged sword that can both help recovery and enable pro-eating disorder behaviors. We conducted semi-structured interviews about ICTs and social networking sites with 16 women with eating disorders. Instagram emerged as the most commonly used ICT. We found Instagram can aid in recovery by helping women: (1) learn about the recovery process, (2) track their own recovery, (3) learn about healthy foods and exercises, and (4) reduce stigma, increase awareness, and create a community for social support. Instagram can also (1) be used to maintain eating disorder symptoms and (2) promote comparisons, which can trigger and exacerbate eating disorders. This research has implications for design, healthcare, and education.

**Keywords:** eating disorders; Instagram; social media; Information Communication Technology (ICT); recovery; qualitative; anorexia nervosa; bulimia nervosa


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1 Introduction

Women with eating disorders utilize various forms of Information Communication Technologies (ICTs) to receive support, advice, and treatment. Conversely, women also utilize these same devices, forums, platforms, and mediums to maintain the symptoms of their disorder, often with the ideology that eating disorders are a lifestyle rather than a mental health condition. Many researchers have examined the effects of eating disorder recovery and treatment programs (Bauer, Percevic, Okon, Meermann, & Kordy, 2003; Bowler, Oh, He, Mattern, & Jeng, 2012; Gulec et al., 2011; Heron & Smyth, 2010; Juarascio, Manasse, Goldstein, Forman, & Butryn, 2015; Ljotsson et al., 2007; Norton, Wonderlich, Myers, Mitchell, & Crosby, 2003; Robinson et al., 2006; Shapiro et al., 2010; Whitlock, Powers, & Eckenrode, 2006) as well as websites and communities that promote eating disorders as a lifestyle (pro-eating disorder communities) (Chang & Bazarova, 2016; Cspike & Horne, 2007; Ransom, La Guardia, Woody, & Boyd, 2010; Rouleau & Von Ranson, 2011). This research predominantly focuses on spaces and devices that are designed specifically and designated for users with eating disorders (e.g., eating disorder forums, recovery apps for mobile devices, etc.) There has been less research on the use and impact of general-purpose ICTs and online spaces (e.g., social media), which are often designed without this specific user group in mind, related to eating disorders.

Researchers have begun to explore eating disorder-related content on social media platforms, such as Instagram and Facebook (Andalibi, Ozturk, & Forte, 2017; Chancellor, Lin, & De Choudhury, 2016; Kim & Chock, 2015; Pater, Haimson, Andalibi, & Mynatt, 2016; Tiggemann & Zaccardo, 2015). While these studies are useful in understanding the use and impact of social media within this specific context, these research streams are often dichotomized. That is, research has considered either the positive or
negative impact of these technologies but rarely considers how technology can be used in ways that aid in recovery as well as exacerbate users’ conditions. Tan et al. (2016) articulate that social media in particular can be both helpful for eating disorder recovery and maintain or even exacerbate eating disorder symptoms (Tan, Kuek, Goh, Lee, & Kwok, 2016). This potential duality of interactions and outcomes provides a space for scholarly exploration, begging the question, how do users with eating disorders use and interact with ICTs, particularly social media, in these two different ways? In order to fill this gap, we conducted a study where we semi-structured interviews with 16 women with a history of eating disorders and asked about their perceptions and use of ICTs and social networking sites (SNS) in relation to their eating disorders.

Our goal is to bridge these dichotomous research streams by exploring the types of technologies women with eating disorders use and how they use them. We first aimed to answer: What types of technologies do women with eating disorders use (RQ1)? This question sought to establish, rather than assume, the participants actively engaged with SNS. Through our conversations with women with eating disorders, Instagram emerged as the most commonly used technology. Then we were interested in understanding how they use Instagram in relation to their eating disorders (RQ2). This study sheds light on how Instagram can exacerbate and improve eating disorder symptoms. This research has implications for not only for our understanding of users, but also for design, healthcare, education.

2 Background

In this section, we describe what eating disorders are and provide background literature describing the existing ICTs and spaces designed for both eating disorder recovery and promotion.

2.1 Eating Disorders and Eating Disorder Behaviors

It is estimated that 20 million women in the United States (US) have an eating disorder, and many more have unhealthy eating behaviors (Reba-Harrelson et al., 2009; Wade, Keski-Rahkonen, & Hudson, 2011). Even when people do not meet the clinical criteria for a specific eating disorder diagnosis, such as anorexia or bulimia nervosa, their eating behaviors can still be disordered. For instance, research has shown that there is a large portion of people who suffer from all the symptoms of anorexia nervosa but are not underweight (Fielder-jenks, 2013), which is a requirement to be officially diagnosed.

In the US, the Diagnostic and Statistical Manual of Mental Disorders (DSM) provides standard criteria for the classification of mental disorders, including eating disorders (American Psychiatric Association, 2013). According to the DSM-V:

“Eating and feeding disorders are characterized by a persistent disturbance of eating or eating-related behavior that results in the altered consumption or absorption of food and that significantly impairs physical health or psychosocial functioning” (p. 329) (American Psychiatric Association, 2013).

For the purposes of this research, we will focus primarily on anorexia nervosa and bulimia nervosa and disordered eating behaviors related to these disorders because the behaviors associated with these two types of eating disorders are similar (American Psychiatric Association, 2013). Additionally, it is estimated that up to 41% of people who had had anorexia nervosa develop bulimia nervosa (Bulik, Sullivan, Fear, & Pickering, 1997). We refer to behaviors associated with anorexia and bulimia nervosa as eating disorder behaviors, which include excessive calorie or food restriction, intense fear of gaining weight, obsession with weight and consistent behavior to prevent weight gain, self-esteem overly related to body image, bingeing, feeling of being out of control during bingeing, purging, dramatic weight loss, preoccupation with weight, food, calories, fat grams, and dieting, refusal to eat certain foods, comments about feeling “fat”, hunger denial, excessive exercise regimen, and development of food rituals.
2.2 Technology for Eating Disorder Recovery and Support

There are a myriad of studies that consider how ICTs can be leveraged to provide eating disorder treatment. ICTs can increase access to help and support (Olsen & Kraft, 2009). There are numerous types of ICTs for eating disorder recovery; however, the most commonly studied tend to be online communities, internet-based treatment programs, and mobile technology applications and interventions.

Online communities provide a cost-effective and accessible service to people with eating disorders. Eating disorders are often negatively socially stigmatized within the US, and as a result these communities provide a space for users to discuss their issues and concerns often with some level of perceived anonymity. Research has shown that users find it easier to discuss these types of issues online as opposed to face-to-face (Kummervold et al., 2002). Internet-based interventions, including both synchronous and asynchronous communication tools, have been shown to be effective on a number of mental health outcomes (Mohr, Burns, Schueller, Clarke, & Klinkman, 2013) and may provide some advantages over face-to-face therapy (Taylor, Luce, Taylor, & Luce, 2003). Some online treatment programs utilize forums and message boards as part of their services (Gulec et al., 2011; Ljotsson et al., 2007). For example, Gulec et al. (2011) used an internet-based treatment program for Eating Disorder Not Otherwise Specified (EDNOS) (now Other Specified Eating Disorder [OSFED]), which had group chat and peer support boards. The authors found that users were satisfied with the treatment and adherence to the program’s guidelines was high. Similarly, Ljotsson et al. (2007) conducted internet-based cognitive behavioral therapy (CBT) with discussion boards for binge eating disorder and bulimia nervosa and found that users showed significant clinical improvements.

Other studies have considered the use of mobile technology for treatment (Bauer et al., 2003; Heron & Smyth, 2010; Juarascio et al., 2015; Norton et al., 2003; Robinson et al., 2006; Shapiro et al., 2010). However, there have been mixed findings on the development and effectiveness of such technology. Robinson et al. (2006) have found that mobile technology interventions, such as text-messaging, had low acceptance and high attrition rates. On the other hand, some researchers have reported high acceptance of such programs (Bauer et al., 2003; Shapiro et al., 2010). Smartphone applications or apps are promising for delivering effective care. However, the majority of these apps have fallen short of their desired outcomes (Juarascio et al., 2015).

2.3 Technology that Exacerbates Eating Disorders or Is Used to Maintain Symptoms

A great deal of research has considered the use of pro-eating disorder sites and communities, in which users view and understand eating disorders often as a lifestyle choice rather than a serious disorder requiring treatment (Sharpe, Musiat, Knaptin, & Schmidt, 2011). On pro-eating disorder sites and forums, users share information on how to lose weight and essentially maintain the symptomology of eating disorders (Sharpe et al., 2011).

Many researchers have found that pro-eating disorder communities have negative effects on their users (Cspkie & Horne, 2007; Ransom et al., 2010; Rouleau & Von Ranson, 2011). For instance, Cspkie and Horne (Cspkie & Horne, 2007) found pro-eating disorder communities worsened eating disorder symptoms of users who are “silent browsers” (i.e. users who do not actively interact within the community). Pro-eating disorder communities have been associated with higher levels of body dissatisfaction, higher levels of eating disturbance, greater negative affect, lower social self-esteem, lower appearance self-efficacy, decreased perceived attractiveness, perceptions of being overweight, higher drive for thinness, perfectionism, increase in harmful activities (such as diet pill abuse and self-injury), lower quality of life, and increased hospitalization rates (Bardone-Cone & Cass, 2006, 2007; Custers & Van den Bulck, 2009; Grimes & Harper, 2008; Harper, Sperry, & Thompson, 2008; Jett, La Porte, & Wanchins, 2010; Peebles et al., 2012).

Recently, researchers have begun to examine general-purpose technology, such as social media, in relation to eating disorders. This research tends to focus on pro-eating disorder-related content. For example, Pater et al. (2016) analyzed hashtags on Tumblr, Instagram, and Twitter and found pro-eating
disorder-related hashtags, images, and text despite these platforms’ attempts to remove this type of content. Tiggeman and Zaccardo (2015) discussed how certain hashtags (such as #fitspiration, which aims to inspire fellow users to be physically “fit”) are used promote or even mask eating disorder behaviors. They found “fitspiration” can have unintended negative effects on college-aged women. Even when social media does not necessarily promote eating disorder behaviors, it can have negative effects on users (Andsager, 2014; Fardouly, Diedrichs, Vartanian, & Halliwell, 2015; Mabe, Forney, & Keel, 2014; Meier & Gray, 2014; Stronge et al., 2015). For example, Kim and Chock (Kim & Chock, 2015) conducted an online survey to examine Facebook’s impact on users’ desire and drive for thinness. They found engaging in social media behaviors such as checking friends’ profiles, leaving messages, and commenting on profiles is correlated with a drive for thinness in both females and males (Kim & Chock, 2015).

While more researchers are exploring the use and impact of social media on users with eating disorders, the vast majority of this literature views social media as a negative influence on those with eating disorders. Research on the positive effects of technology tends to be about internet-based programs specifically for eating disorder recovery. Our study differs in that we examine how women with eating disorders who interact with social media platforms, specifically Instagram, can use these interactions to aid in recovery as well as exacerbate symptoms.

3 Methodology

Participants included in the study reported currently or previously having an eating disorder (or symptoms related to anorexia and/or bulimia nervosa) and were 18-25 year old women. Because some people do not meet the full criteria for a specific diagnosis and because many people never seek treatment for their eating disorder, we recruited both participants who were formally diagnosed and those who were not. We posted flyers at the university and at public locations. Each participant was compensated $25.

The first author conducted all semi-structured interviews. Through the interviews, we sought to understand how women with eating disorders use social media and other types of ICTs. Each interview was audio-recorded and took approximately one hour. The audio files from the interviews were transcribed into electronic format. This was appropriate because the goal was “to analyze the content of communication” to understand the participant’s experience (p. 2937) (Wang & Lien, 2013). We used thematic analysis to identify emergent themes across the data set (Braun & Clarke, 2006). We conducted a total of 16 sessions until we saw repetitive themes in participants’ responses (i.e., data saturation) (Marshall, 1996).

4 Findings

In this section, we provide information about our participants, and then we present our findings on types of technologies women with eating disorders use. The most commonly reported ICT used was Instagram, and therefore, we discuss the how Instagram can both aid recovery and exacerbate eating disorders.

4.1 Participants

Participants were ages 18-23 with the mean being 20.88 years. The majority of participants identified as White (non-Hispanic) (n=12) with one from Israel. Two identified as Asian, Asian American, or Pacific Islander, 1 identified as multi-racial, and 1 identified as Native American or American Indian. As shown in Table 1, most participants had not been professionally diagnosed with an eating disorder, and most reported being in recovery. Participants estimated they had an eating disorder anywhere from 2 months to 7 years, and their eating disorder behaviors included extreme restriction, obsession with “healthy” foods, bingeing, excessive and compensatory exercise, purging, and extreme anxiety and concern related to food and weight.
<table>
<thead>
<tr>
<th>ID</th>
<th>Professionally Diagnosed?</th>
<th>ED / ED Behaviors</th>
<th>Do you think you currently have an ED?</th>
<th>ED Length</th>
</tr>
</thead>
<tbody>
<tr>
<td>U01</td>
<td>Yes</td>
<td>Anorectic behaviors, binge eating</td>
<td>No</td>
<td>2 months</td>
</tr>
<tr>
<td>U02</td>
<td>Yes</td>
<td>Anorectic behaviors, orthorexia</td>
<td>Yes</td>
<td>1 year</td>
</tr>
<tr>
<td>U03</td>
<td>No</td>
<td>Anorexia nervosa, exercise anorexia</td>
<td>No</td>
<td>6 years</td>
</tr>
<tr>
<td>U04</td>
<td>No</td>
<td>Anorectic behaviors, EDNOS/OSFED, excessive exercise, strict diet</td>
<td>No</td>
<td>1 year</td>
</tr>
<tr>
<td>U05</td>
<td>No</td>
<td>Anorectic behaviors, back and forth between eating and not eating</td>
<td>No</td>
<td>2 years</td>
</tr>
<tr>
<td>U06</td>
<td>No</td>
<td>Anorexia nervosa, orthorexia, binge eating disorder</td>
<td>No</td>
<td>3 years</td>
</tr>
<tr>
<td>U07</td>
<td>No</td>
<td>Anorectic behaviors, restriction, purging</td>
<td>No</td>
<td>1 year</td>
</tr>
<tr>
<td>U08</td>
<td>No</td>
<td>Anorectic behaviors, barely ate, some bingeing, EDNOS/OSFED</td>
<td>No</td>
<td>1 year</td>
</tr>
<tr>
<td>U09</td>
<td>No</td>
<td>Anorexia nervosa</td>
<td>No</td>
<td>2 years</td>
</tr>
<tr>
<td>U10</td>
<td>No</td>
<td>Bulimia nervosa</td>
<td>No</td>
<td>6-7 years</td>
</tr>
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<td>U11</td>
<td>No</td>
<td>EDNOS/OSFED, binge eating and compensatory exercise, diet-binge eating cycles, great anxiety related to eating/dieting</td>
<td>No</td>
<td>Over 4 years</td>
</tr>
<tr>
<td>U12</td>
<td>Yes</td>
<td>Bulimia nervosa</td>
<td>No</td>
<td>6 months</td>
</tr>
<tr>
<td>U13</td>
<td>Yes</td>
<td>Anorexia nervosa</td>
<td>Yes</td>
<td>3 years</td>
</tr>
<tr>
<td>U14</td>
<td>No</td>
<td>EDNOS/OSFED, always thinking about food, need to track everything eaten, concern when not hitting macronutrients, restriction, bingeing</td>
<td>Yes</td>
<td>7 years</td>
</tr>
<tr>
<td>U15</td>
<td>No</td>
<td>Anorexia nervosa</td>
<td>No</td>
<td>1 year</td>
</tr>
<tr>
<td>U16</td>
<td>No</td>
<td>EDNOS/OSFED, anxiety about food, afraid to eat &quot;unhealthy&quot; in pubic, bingeing in private, compensatory exercise, diet-bingeing cycles</td>
<td>No</td>
<td>4 years</td>
</tr>
</tbody>
</table>

Table 1. Participant Information (Information about participants’ eating disorders)

4.2 Types of ICTs Used (RQ1)

We present findings on the types of ICTs women with eating disorders use to get information about diet, exercise, and eating disorders (Table 2). The most frequently talked about technology was Instagram followed by Facebook, Twitter, YouTube, Google, Pinterest, Tumblr, pro-eating disorder sites and communities, notes on a smartphone, and Microsoft Word. It was important to ask participants about the types of ICTs they engaged with. While recent research suggests social media is largely used by users with eating disorders, this inquiry helped us establish that this was also the case for these participants.

<table>
<thead>
<tr>
<th>Type of ICT Used</th>
<th># of Users</th>
<th>User(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instagram</td>
<td>10</td>
<td>U01, U02, U03, U04, U05, U06, U07, U10, U13, U14</td>
</tr>
<tr>
<td>Facebook</td>
<td>5</td>
<td>U02, U05, U12, U13, U16</td>
</tr>
<tr>
<td>Twitter</td>
<td>4</td>
<td>U04, U06, U07, U14</td>
</tr>
<tr>
<td>YouTube</td>
<td>4</td>
<td>U01, U09, U12, U14</td>
</tr>
<tr>
<td>Google</td>
<td>4</td>
<td>U01, U02, U04, U15</td>
</tr>
<tr>
<td>Pinterest</td>
<td>1</td>
<td>U08</td>
</tr>
</tbody>
</table>

1 ED stands for eating disorder
4.3 How Women with Eating Disorders Use Instagram (RQ2)

For participants, Instagram can be both helpful for recovery and can intensify or trigger eating disorder symptoms. Instagram can aid in recovery by helping women (1) learn about the recovery process, (2) track their own recovery, (3) learn about healthy foods and exercises, and (4) reduce stigma, increase awareness, and create a community for social support. On the other hand, Instagram can also (1) be used to maintain eating disorder symptoms and (2) promote comparisons, which can trigger and exacerbate eating disorder behaviors.

**Learn about the recovery process**

Participants discussed how they learned about the recovery process from their eating disorder through profiles and images of other people who had eating disorders. One participant talked about how some Instagram users showcase their progress in a way that highlights positive body image and praises weight gain instead of weight loss, which can help take the focus away from thinness to health:

“There was a lot of accounts that it was like before and after pictures of someone, actually there was a lot I came across where the people were already anorexic and then became body builders. Those are the really cool ones ‘cause it’s just like, wow, just like their body looks so much healthier, you know.” [U07]

Other participants discussed how they came across other users’ Instagram accounts that are dedicated to the eating disorder recovery process and how having a window into that process made recovery seem like less of an obstacle:

“I haven’t talked [to others directly on Instagram], but I have seen where people are trying to gain back weight, and they really celebrate that. And it’s encouraging to see that people are going through it and they want to share for other people, it’s not just like themselves too. It’s helping other people realize that they can overcome it, so I think they’re helpful.” [U02]

Similarly, another participant talked more specifically about the process of recovery and how Instagram alleviated some of the concerns she had with her weight changing:

“Like I would follow, it was like #eatingdisorderotherwisensotspecified and the initials EDNOS, like #ana, #bulimia, #EDrecovery, like that... Like when I would go look at like the hashtags, I would try to find transformation pictures where after your weight redistributes because that’s like the biggest trouble that I had. I’m like, my weight’s not redistributing, what do I do, what do I do?! And like I see all these people like oh, their weight’s redistributing, why isn’t mine? And then I realized like yeah, it finally is.” [U03]

Instagram can provide users with a unique look into eating disorder recovery. The way in which Instagram is designed allows users to see other users’ progress over time. Looking at other users who also have had eating disorders, participants can get information about unknown and often anxiety-inducing aspects of eating disorder recovery, which makes the process seem less daunting and the outcomes (often weight gain) less terrifying.

**Track recovery progress**

In addition to looking at other users’ recovery process, participants also discussed how they used Instagram to track their own recovery, including health meals, exercises, and photos of themselves that highlight their
progress. One participant talked about how she used Instagram to track her meals as well as post photos of how she has changed since before she began recovery:

“I would either post my meals, that’s a popular thing, or like my progress and transformations and stuff.” [U03]

Similarly, another participant discussed how she liked to post photos of foods that were healthy and also visually appealing:

“Meals, like if I make something really pretty and it's healthy. I made this nice yogurt parfait the one day.” [U10]

The focus on tracking things that were indicative of healthy behaviors seemed to help women with eating disorders. In addition to tracking meals, some participants also post photos after completing an activity or exercise, which can be especially important for women who have experience physical health implications from their eating disorders, such as low heart rate and muscle loss. These types of posts are celebrated as a strength and health achievement not as way to lose weight:

“Like I post occasionally if I go on a long run or something, I’ll post that, like just to celebrate it.” [U02]

Much like seeing others’ progress, participants felt that using Instagram to track their own recovery process was useful. They liked seeing how they changed over time as well as celebrating smaller milestones, such as eating healthy meals and being able to exercise.

**Learn about healthy foods and exercises**

Instagram can also be used a source to get information about healthy foods and exercises. One participant discussed how one woman’s account provided her with different types of foods and recipes to eat for various meals:

“I used to follow a food one, and it provided me so much information about how to eat more healthy... She’s like a person that posts, like she’s a European, because you know Europeans, they eat kind of healthy, right? She posts the picture of breakfast, and what do you eat for breakfast, something like that with the hashtag.” [U01]

Similarly, two participants talked about how they found new products on Instagram that helped them ease into recovery by finding foods that were not high in calories

“My main thing was Instagram because I’m very visual so that even helped me find new products to eat that are like low in calorie but they’re healthy and they taste good, so it would kind of like be a safe food but also helping me too.” [U03]

“I also found out about Quest bars through Instagram ’cause maybe I was looking at some sort of fit food page, and I saw the Quest bar... and at first I was scared to try them ’cause I was like, “wow, they’re probably for like muscle. I don’t want to gain too much muscle!” So then I started eating those, and then those actually really helped me like not be so, like have sugar cravings a lot because they were kind of sweet already. So actually social media was a really huge outlet for me to find other food brands.” [U07]

In addition to finding foods on Instagram, some participants also looked for new exercises on Instagram as a way to improve both their mental and physical health. One participant talked about how she used Instagram to find yoga videos:

“I’ve been trying yoga and relaxing videos and seeing if that will help my image more... Her name’s yoga fitness girl on Instagram. She’s got a lot of good videos and inspirational quotes and stuff, so
I've been trying to like relax, feel the energy or whatever, you know? [laughs]. Yeah, [I think it's helped].” [U05]

Instagram can be used to find new foods and recipes as well as exercises. Incorporating new foods helped them alter their typically strict diet but reduced their anxiety about food by still allowing them to find lower calorie options, which helped ease them into recovery. Participants also sought out new exercises without focusing on how many calories they would burn by performing the exercise, which helped improve their mental health.

Reduce stigma, increase awareness, and create a community for social support

Participants also talked about using Instagram as a platform to boost awareness about eating disorders and reduce the stigma associated with them. This allowed them to create a community where they could both get support and provide support to others. One participant explained how when she withdrew from college to seek in-patient treatment for her eating disorder, it would have been easier to have another illness, one with less stigma associated with it. Because she did not want people to think she just quit college, she began posting about her eating disorder and recovery process. She received a lot of support and felt the need to give back, so she began posting to Instagram to boost awareness about eating disorders, raise money for eating disorder recovery groups, and create a space where others could come to her for help:

“I post stuff now about trying to recover... So, I would post a bunch of stuff about trying to raise money and awareness... In a good way [posting to Instagram has impacted my recovery] because I just hate how the stigma... If I withdraw from college from mono or something, it’s just so much more comfortable to talk about, and the fact that like, 'Oh, I had to make up reasons why I withdrew,' it was just so annoying, and eventually I was like, 'I'm so tired of this, I don't care. I'm not embarrassed; like it's a disease.'... I was like, 'I just want people to know why I'm home and not that I just dropped out, like 'messed up, don't care about college' person...” And then when I came out with everything, when I would post pictures of my walk or being two-year recovery, people would post and be like, "So proud of you," all the time... I just felt like all these people were very supportive and that helped... I'm like, 'If anyone needs help please speak up. You shouldn't have to go through this alone,' because really I just want people that are struggling to talk to me because I’m in a sorority, and I feel like just if I post on Instagram, they’ll all see it.” [U13]

One participant talked about how she both received support and provided others with support:

'I'm really into yoga, so I post poses and stuff like that, so people really like them, so the affirmation from that... I'll like them [people’s posts] or if I have a friend who lost a lot of weight, I'll always comment on it, like say like, “you're whatever, you're on a good path, you've done this in a healthy way”, because I don't want somebody else to go through what I'm going through like, so I try to encourage them in a healthy way, not just say, “oh, you’ve lost weight, you look great.”' [U02]

Another participant discussed how having a recovery account and following other recovery accounts gave her a sense of community:

“I made a separate account for my recovery and my progress, and I think that helped because I saw a lot of people, like some I still follow on my personal account, and I remember when I followed them, like first started following them like 3 years ago, and it's nice to see how far everybody's come.” [U03]

Instagram can be used to create awareness around eating disorders and thus reducing stigma. By creating this type of community, users have a space where they can not only give support to others, but also receive support.
**Maintain eating disorders**

Participants also use Instagram in ways that allow them to maintain their eating disorders. One participant described how scrolling through food photos allowed her to “visually” consume foods she wanted without actually eating them, which enabled her to continue to restrict:

“I would use Instagram to look up food that I couldn’t eat, so I could visually just see it. I remember late at night sometimes, I couldn’t sleep ’cause I was hungry, so I’d literally just go through Instagram like look at all this food, and then thinking about eating the food, I would fall asleep. And sometimes I would have dreams about eating the food, and I’d wake up and be like, “thank god I didn’t eat that!” But I was actually dreaming about food [laughs]. Like what? I was dreaming about food! So I would use Instagram to kind of look at the cravings, so I was kind of visually eating them without eating them” [U07]

Another participant talked about how following thinspiration accounts gave her the reassurance to continue to restrict:

“I think I followed like Fitspo, not Fitspo ’cause I wasn’t fit, like thin, Thinspiration on Instagram. I think they have... ’Cause constantly seeing thin people on my feed helps. I was like, “Okay, I kind of look like that so I’m okay”... So make me not eat more...” [U13]

This participant would also get affirmation for her eating disorder by posting photos of herself:

“When I had my eating disorder, I was posting pictures of me in a bathing suit all the time, ’cause I was like, ‘Yay.’ When I posted a picture of me in a bathing suit, people would comment, "Oh my God, you look so good. Teach me your ways."... It fueled it [my eating disorder] more obviously. I was like, "Oh my gosh, I’m great." [laughs] I just felt like... I don’t know. I just felt like I could just eat less than a normal person, so I was just better. I don’t know, it just gave me this weird sense of accomplishment, and I could tell other people were jealous of me kind of, that I was good at something.” [U13]

Instagram can be used to maintain and even intensify eating disorder behaviors by providing users with ways to restrict their calories and affirmation to continue their eating disorder. The visual aspect of Instagram provided some users with a way to experience food without actually eating anything. Users also received affirmation for their behaviors both indirectly, by comparing themselves to other users’ photos, and directly, through comments made on their own photos.

**Promoted comparisons**

Participants often discussed how Instagram gave them many opportunities to compare themselves with other people regardless of whether or not they follow those specific accounts. One user talked about how she sought out inspiration by following fitness accounts but that it also made her upset and feel inadequate in comparison. She also followed a number of fashion models, who she aspired to look like:

“I follow many weight loss accounts in Instagram because I use Instagram most of the time. I think they are kind of providing some inspiration for me... But sometimes it makes me upset because why they are doing exercise every time!? They are so energetic all the time! It makes me feel like I’m not that good!... I began following one thing and it makes suggestions about the weight loss, there are so many. Sometimes I will hashtag, like self-control, diet, weight loss transformation, weight loss, detox, skinny, lean waist, and abs... I follow many models [for inspiration], fashion models, like Gigi Hadid, and some like from Europe... I follow them because I just love them. And I follow some male models too because I think they are so cute! Because if you want to find a boyfriend like him, then I need to become more skinny.” [U01]
Another participant, who competed in fitness shows, followed fitness competitors, and she would compare her weight and body to other competitors:

“When I was competing, I would follow a lot of competitors and feel like maybe guilty if I couldn’t maintain a low weight after my show and stuff like that... It [technology] makes it [comparing] so easy... Especially with Instagram! Instagram’s so horrible! It’s so bad [laughs].” [U06]

Not only do participants compare their weight and bodies to others, but they also compare what they eat. One participant explained how she compared her meals to others and often felt pressure to eat less:

“I’d say it [Instagram] plays a big part into it [my eating disorder]. I try to taper away from it just because like looking at some people’s like portion sizes, I compare myself to that, like I’m eating very healthy foods in larger quantities, I think. But then they, like you know, more fatty, good fats and stuff like that, which I’m not getting, and so they have smaller portions because of that or they’re on a weight loss goal, so I don’t even consider some of those factors. I just see oh they’re eating less than me, and they’re exercising more than me. So it’s I kind of feel like I need to measure up to that.” [U02]

Because there are always different photos to look at, users have many ways in which they can compare themselves to other people, including others’ weight, body, and even food consumption. Users often follow fitness accounts, models, and search for weight loss-related profiles and photos through specific hashtags. These photos often make users feel badly about themselves and inadequate by comparison, which can exacerbate their eating disorders.

5 Discussion

The themes that emerged across these 16 interviews offer several implications in terms of ICT and social media design, provider–patient interaction within healthcare spaces, and how various topics are addressed in educational settings. The results suggest that there are various ways in which users, particularly those with eating disorders, use and interact with social media platforms. These different types of unintended uses may be worth considering when designing platforms with user-generated content. Similarly, participant insights may inform the ways in which both educators and healthcare providers talk about the relationships between eating disorder behaviors, body image, and social media.

5.1 Social Media and ICTs

These participants show us that social media (along with ICTs in general) is not overtly harmful or helpful within this context, but rather, Instagram, like other spaces, serves as a double-edged sword that can both help recovery and enable pro-eating disorder behaviors. Because use can widely differ not only between user groups but also from person-to-person, we have to consider the various users that could use social media and other ICTs at each stage of the design process. In this way, we can better anticipate both positive and negative unintended consequences and make better design choices.

It is important to note that several participants talked about the “Explorer” page on Instagram in which they scrolled through pictures, pages, and posts that were algorithmically provided for them (these are not pages they actively sought). This may be problematic at best and triggering and dangerous at worst for users suffering from eating disorders (who, for instance, frequent thinspiration and fitspiration posts). While Instagram and Pinterest ban and/or have warnings on these posts, subsequent hashtags are often developed to circumvent these efforts (Chancellor et al., 2016).

5.2 Healthcare

Psychologists, nutritionists, therapists, counselors, recovery rehabs, etc. should be incorporating social media into their discussions with patients. If users are turning to Instagram to learn about recovery, new
foods, and types of exercise, then it may be beneficial for healthcare professionals to interact with their patients about these processes so that they can work together towards long and short-term recovery goals. In-patient facilities may consider running sessions that talk about information quality, patients’ experiences with technology, or incorporating these conversations into group therapy sessions if they do not already do so. Because participants talked about the benefits of using social media to track their eating disorders, working with patients in ways that include the visual and community elements may be beneficial. It is also important to also consider the shift from thinness to health. Some participants mentioned how fitness pages masked eating disorder behaviors or were triggering. We need to consider how health and fitness is portrayed online when providing treatment for people with eating disorders.

5.3 Education

In the same ways healthcare professionals should be incorporating social media into their discussions with patients, teachers should consider incorporating discussions about body image and social media into their health classes (relevant for K-12 educators) if they do not already do so. Stigmatization of their eating disorders was a recurring theme that participants discussed, particularly when talking about the ways in which social media is beneficial. Educators can work with young people to destigmatize eating disorders (as well as other mental health conditions), which may increase (1) a willingness for those experiencing eating disorder symptoms to get help and (2) people who do not experience eating disorder symptoms to understand, rather than cast judgment on those who do.

Body image is a big deal for young people, and they use social media more than almost any other group. In fact, 90% of 18 to 29 year olds use social media (Perrin, 2015), 71% of teens use more than one social networking site (Lenhart, 2015). It is important to talk about the element of comparisons social media offers, but it is also critical to talk about the positive elements of social media. This is often left out of K-12 education, and we cannot afford to leave this out. Young people spend a lot of time on social media, so it is important not to demonize it in educational settings or it may lead to a breakdown in communication between educators and young people. With the changing nature of problematic content, we also must be careful in how we talk about fitness in health and physical education classes.

6 Conclusions

Research tends to consider either the positive or negative impacts of technology in relation to eating disorders but rarely considers how technology can be both positive and negative. However, as our study shows, social media and other ICTs are not inherently good or bad. Rather, ICTs, specifically Instagram, can help aid eating disorder recovery as well as exacerbate eating disorder symptoms. Women with eating disorders use Instagram in different ways depending on their motivations, needs, and stages of recovery. Thus, it is important to consider different types of users, including those with eating disorders and other health conditions, when designing ICTs. Because use can vary so widely, it is also crucial to incorporate discussions of social media and other ICTs both in the healthcare and education domains in order to make a meaningful impact.

7 References


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