Privacy and Weight Loss Apps: A First Look at How Women with Eating Disorders Use Social Features

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ABSTRACT

Women with eating disorders benefit from using social and community features of apps because they can get social support and information about their disorder. Although seeking help online may be easier than getting face-to-face treatment, there still may be a number of privacy concerns to sharing information, especially on apps not specifically intended for those with eating disorders, such as weight loss apps. Women with eating disorders are using weight loss apps, but are they using features that could help them get support for their disorder? This research begins to answer this question by presenting preliminary results from a qualitative study on how women with eating disorders use community and social features of weight loss apps. Early findings suggest women with eating disorders rarely use the community and social features of weight loss apps. This work highlights the tradeoffs between sharing information and privacy and has implications for app design.

CCS Concepts

• **Human-centered computing → Ubiquitous and mobile computing → Ubiquitous and mobile computing systems and tools**

Keywords

Eating disorders; weight loss apps; mobile technology; privacy; social computing; stigma

1. INTRODUCTION

It is estimated that 20 million women in the United States have an eating disorder [16, 21]. Women with eating disorders benefit from participating in online communities [9]. Prior studies have found technologies that facilitate social support are helpful to users with eating disorders [2, 24], and a number of studies have found technology can be a useful tool for eating disorder recovery [2, 8, 24]. However, do users with eating disorders want to use the community and social features of mobile health applications (apps), especially if those apps are not specifically intended for users with eating disorders?

Because of the stigma often associated with eating disorders and other mental health conditions, women with eating disorders may be reluctant to participate in online communities and utilize social

features of health apps like weight loss apps. Few studies have examined how women with eating disorders use weight loss app social features, such as adding friends, interacting with friends, and participating in forums. In order to fill this gap, I am conducting think-aloud exercises and interviews with women with eating disorders who use weight loss apps. My research is guided by the following research question:

RQ: How do women with eating disorders use community and social features within a weight loss app?

In this paper, I discuss preliminary results from a qualitative study that examines the use of social and community features of weight loss apps by women with eating disorders. Thus far, my findings indicate that while women with eating disorders use weight loss apps, they rarely use the community and social features. This work sheds light on the importance of considering user privacy concerns and promoting sharing and interacting with other users. Additionally, this research has implications for the design of apps to balance this tradeoff and to best meet the needs of women with eating disorders.

2. RELATED WORK

2.1.1 Eating Disorders

Eating 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) [1]. Eating disorder behaviors 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. These behaviors are commonly associated with anorexia nervosa, bulimia nervosa, and eating disorder not otherwise specified/ other specified feeding or eating disorder.

2.1.2 Support for Users with Eating Disorders

Research has shown that users find it easier to discuss their issues online as opposed to face-to-face [10], which may explain why women with eating disorders are turning to online spaces. Online communities allow easy access to help and support, offer users a space to express their thoughts about different types of problems, including eating disorders, and provide a cost-effective and accessible service [15].

Research on online communities for eating disorder recovery and support is vast [4, 6, 7, 9, 10, 12, 13, 17–19, 22–24]. Online communities have the potential to be therapeutic for those with eating disorders [9]. Researchers have studied online forums and

social media for providing support for eating disorder recovery and found that these communities provide essential social support for isolated individuals with eating disorders [2, 24] where the majority of users tend to be younger women [10]. There is often a stigma with eating disorders, so these communities provide a space for users to discuss their issues and concerns often with some level of anonymity. Since there is a high chance of relapse with eating disorders, some form of social support is necessary to recovery especially after individuals leave treatment centers [13]. Eating disorder discussion groups are particularly helpful during early stages of recovery [9]. Eating disorder forum participation is useful for both informational needs and social contact and support [10]. These communities may provide new information about health conditions, concerns, and treatments and give people the ability to help others with the same condition or issue [14].

3. METHODS
3.1 Recruitment
Because anorexia and bulimia nervosa tend to affect young women (often college-aged) [3] and weight loss apps users tend to be younger [5, 20], I am focusing on women between the ages of 18 and 25 with a history of anorexia and/or bulimia nervosa who use or have used weight loss apps. In order to recruit users with a history of eating disorders, I am posting flyers at the local university and town. Each participant is compensated $25.

3.2 Data Collection and Analysis
With users, I am using two primary data collection methods: 1) think-aloud exercises and 2) formal semi-structured interviews, which occur during the same data collection session. For each data collection, we begin with the think-aloud exercise, where participants show me how they set goals, view progress visualizations, and use social and community features. Next, during the interview, I ask additional questions about eating disorders, weight loss apps, and other types of technology. The think-aloud exercises are video recorded, and the entire data collection session is audio recorded.

To date, I have conducted think-aloud exercises and interviews with 14 participants. Each data collection session is approximately 1 hour. Currently, I am transcribing and analyzing data collection sessions using thematic analysis while recruiting participants and conducting more sessions.

4. PRELIMINARY FINDINGS
Through an initial analysis of a portion of the think-aloud exercises and interviews, I found women with eating disorders may be reluctant to use community and social features of weight loss apps.

Many participants believe their eating disorder and weight-related journeys are private, as illustrated by these quotations:

"I never interact with people because I feel like my diet is like my, it's only my thing. Do you know what I mean? It's like individual stuff." (U01)

"Yeah, I haven't done that [friended anyone on the app/participated in the forums] just because again, it's like something I've kept secret for so long that I don't really share it with anybody." (U02)

Participants often say they would be embarrassed if other people knew they had an eating disorder or knew more detail about their behaviors:

"I don't like to share with my friends. It's a little bit awkward, yeah. I just keep it private, I think. Because I really like, it's kind of… makes me uncomfortable because if you, like I don't know, like I use this pal because I think it's kind of give some privacy. I don't know. I just don't like to share." (U01)

"I mean, I mean if I was sharing it with people and they saw I was eating so few calories, then that'd be embarrassing." (U04)

"I just didn't want other people to be involved. I guess that's just me personally, but I feel like a community where other people could have helped me probably would be better, but I was just like so embarrassed because I've been on this thing my whole life where I'm like, k, I'm strong, I'm mentally strong, I don't have anything to face, like I'm fine, but I was not fine at all in all reality, so I was like more embarrassed an didn't want friends and family to know and stuff, so I didn't even want to do the social part of it, so." (U05)

These quotations show that participants rarely use the community and social features of weight loss apps and would feel uncomfortable if others knew about their eating and exercise behaviors.

5. DISCUSSION AND CONCLUSION
Although women with eating disorders use weight loss apps, they are reluctant to use the community and social features of these apps. Even though online communities have been shown to be beneficial to women with eating disorders, they still express privacy concerns with participating in online communities and sharing information. Perhaps this is due to the stigma associated with eating disorders [11] or fears related to consequences of revealing such information, especially on an app intended for weight loss not eating disorders.

This raises questions regarding the trade offs between privacy and not only the need for information, but also social support. Would users feel better about sharing and using these features if they could share anonymously? If so, what design changes could we employ to encourage users to share? Do users in other types of online communities have the same reluctance to share information? What about in face-to-face treatment programs and groups? Depending on where they are in terms of their eating disorder (i.e., recovery or not), do users feel differently about sharing information and using these social and community features? Future research will begin to answer these questions, and further analyses will focus on answering why these users rarely utilize these features. This research has implications for design and for our understanding of how to balance maintaining user privacy and promoting use.

6. ACKNOWLEDGMENTS

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