Tennessee v. Meta
Case No. 23-1364-IV

DX1495

Promoting connection: Designing social media experiences to support people with eating disorders

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Abstract Eating disorders are characterized by extreme emotions, beliefs, and behaviors related to weight and food. They can cause serious psychological and physical problems and have the highest mortality rate of any mental illness. Research has established the strong connection between disordered eating and emotion, namely that the disordered behaviors around eating serve as a coping response to deal with distressing and overwhelming emotion. Instead of focusing on the behaviors or outcomes of an eating disorder, effective support should include addressing the underlying emotional experience of someone with an eating disorder. Social media companies are at a unique advantage to provide support for those who post eating disorder related content by offering more supportive experiences that better match people's needs. This paper explores ways to address the emotional needs of social media users through designing experiences that (a) make people feel seen and heard by focusing on their suffering and emotions rather than their eating behaviors; (b) help people feel they belong by focusing on activities and opportunities that enable connection with themselves and things they value; and (c) help people feel in control by focusing on resources and information to receive support or take steps toward recovery.

Keywords *Social media, Eating disorders, Mental health, Well-being, Emotion regulation*

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Introduction

Prevalence and mortality of eating disorders

According to the National Eating Disorder Association, eating disorders are defined by extreme emotions, beliefs, and behaviors about weight and food (NEDA, 2016). They include anorexia nervosa, which is characterized by severe weight loss and self-starvation; bulimia, characterized by consuming excessive calories followed by self-induced purging to rid oneself of calories consumed; binge eating disorder, which involves repeated episodes of consuming large amounts of food without control; and eating disorder not otherwise specified, which includes partial symptoms of the aforementioned eating disorders (NEDA, 2016). A recent study of a nationally representative sample of adolescents found that 6.1% of the people ages 13 to 18 years old in the United States met diagnostic criteria for an eating disorder (Swanson, et al., 2011), with women diagnosed at ten times the rate as men (American Psychiatry Association, 2013). Prevalence of eating disorders across countries and cultures has steadily increased over the years, often attributed to globalization and urbanization, which brings with it increased media exposure and promotion of the Western thin ideal of beauty (Smink, Hoeken, & Hoek, 2012). Due to the mental toll and physical demands of the disorder, it has the highest mortality rate of any mental illness (Lozano et al., 2012), with lifetime mortality estimated at approximately 5-20% (Sullivan, 1995).

Eating disorders and emotion

There is no clear consensus on the cause of eating disorders, though decades of research have identified many contributing factors that can be psychological (low self-esteem, depression, lack of control), interpersonal (difficult personal relationships, history of abuse), social (cultural pressure to be thin, specific definitions of beauty), or biological (unbalanced chemicals related to appetite and digestion, genetic; NEDA, 2016). Compared to common misconceptions, weight and food are not often considered causes, rather are thought to be tactics to control or avoid extremely distressing and overwhelming feelings and emotions. People with an eating disorder may be using the control of food "as a way to cope with painful emotions and to feel in control of one's life" (NEDA, 2016). Thus, people with eating disorders use the behaviors commonly associated with the disorder – food restriction, binging, purging – to regulate their emotions. Haynos and Fruzzetti (2011) describe this cycle in more detail with people diagnosed with anorexia nervosa. People with anorexia nervosa were often highly sensitive and emotional as children and have a history of experiencing invalidating responses to their emotions. They learn to distrust or be fearful of their emotions, thereby encountering even an ordinary emotional event will cause them great stress

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and to become emotionally disregulated. This takes the form of heightened arousal and anxiety, which feels threatening and overwhelming and is subsequently met with overt efforts to try to reduce, remove, or avoid the emotion through starvation, excessive food consumption, or extreme behaviors to eliminate calories consumed. People close to those with an eating disorder often focus on the behaviors or outcomes ("Why don't you just eat more?" or "You look so skinny!") rather than noticing or attending to the underlying emotion or psychological pain that is causing these symptoms. This experience further invalidates the feelings of those with an eating disorder and heightens the emotional vulnerability they already experience, leading to a vicious cycle of them becoming overwhelmed by their feelings and implementing maladaptive eating strategies to cope with the deeply felt emotions. Similar emotional processes have been put forth for both bulimia and binge eating disorders as well (Chen, Matthews, Allen, Kuo, & Linehan (2008). As such, eating disorders and emotion are intimately tied – eating disorders may arise as a coping mechanism to deal with overwhelming emotions and also produce more negative emotions as a consequence of the demands of the disorder.

Eating disorders and social media

The media and exposure to unrealistic ideals of beauty is also considered to be a contributing factor to eating disorders (NEDA, 2016), and social media may be an influence as well. Studies indicate that active involvement in social media can be harmful when people use these sites to find and create communities around their disorder. Preliminary research found a correlation between more time spent online and higher levels of disordered eating among females (Mabe, Forney, & Keel, 2014) and receiving negative comments on posts may increase risk for disordered eating (Hummel & Smith, 2014). More carefully controlled studies are needed to fully understand if and how social media sites influence disordered eating, in addition to understanding protective factors that may limit any such effects.

Designing for mental health

Much of the previous work on designing for mental health has focused on environmental design. Urban design suggests access to greenery, open space, mixed land use, and places for community gatherings are key principles to health (Jackson, 2003). Organizations have been formed to create innovative solutions to the physical and structural aspects of mental health units – instead of a focus on security, seclusion, and safety they are using design principles to move toward environments that promote and support healing. This often involves designs that incorporate natural light, color, nature, and art (DiNardo, 2013).

Designs for mental health focused on technology have been a more recent development. Recognizing that more people are receiving health information through technology, Choe, Duarte, and Kientz (2010) suggested that this technology should focus on building trust, being honest, instilling hope, presenting the information simply, and acknowledging the emotional discomfort the patient is experiencing. New apps designed for supporting mental health such as Ginger.io and Headspace have taken a similar approach by focusing on simplicity—of information provided and of design—and communicating and presenting visuals in a warm, minimalistic way. Most prominent social media companies offer information pages about mental health but few specifically focus on eating disorders, with Facebook, Instagram, and tumblr being exceptions. These sites offer dedicated information pages about eating disorders and how to receive or offer support. But research is needed to understand what kinds of support people experiencing an eating disorder most need from technology (e.g., should the eating disorder or eating behaviors be the focus or instead should the focus be on the underlying emotions?). Additionally, most of this information and support comes in the form of a static webpage with lines of text. Further research is needed to explore different design options for more engaging, visually appealing ways to deliver information (e.g., is it best to communicate through blocks of text or are images or other visuals helpful?).

Designs for social media to better support those with eating disorders

Some have suggested limiting social media use for people who may be at risk for or have a history of eating disorders (e.g., Mabe, Forney, & Keel, 2014), but given that social media is a large part of many people's lives and there are also many positive benefits to being socially connected online other ways to address this concern warrant exploration. Accordingly, this paper will discuss the opportunity for social media companies to design tailored experiences to better support people who are struggling with eating disorders. One such avenue is targeting and redesigning the information people see when they have posted something related to eating disorders that has been flagged by another user. We will use Facebook's platform as an example given the pre-existence of support provided when someone flags another's post as promoting or struggling with an eating disorder – if the post is deemed a credible concern Facebook will provide information, which includes a number to a helpline, to the person who posted the eating disorder-related content.

This paper seeks to address two primary questions: (1) what are the most effective methods of supporting people with an eating disorder? and (2) what aspects or guiding principles should be used to most effectively address emotional aspects of eating disorders through design? No user data or posts were analyzed for this project. Facebook will be used to develop a proof of concept model that can then be expanded to other online and social media sites.

Method

Participants

A cross-functional team of product design ($N = 2$), user experience research ($N = 2$), content strategy ($N = 1$), and product management ($N = 1$) formed a working group to better understand eating disorders and how they play out on social media. The team consulted with

researchers and clinical psychologists who specialize in eating disorders ($N = 3$), representatives from the National Eating Disorder Association ($N = 2$), an eating disorder activist ($N = 1$), and people who have had a past history or are currently struggling with an eating disorder ($N = 12$, *Median Age* = 26). All participants were female (we had hoped to also talk to male participants but due to tight recruitment timelines and lower frequency of diagnoses we were not able to schedule them).

Procedure

The main goals of the study were to (1) understand the most effective ways to support people with an eating disorder and (2) to identify topics that could be turned into design principles to guide creating new support flows for online spaces. In order to address these aims, we hosted discussions and conducted interviews with a diverse group of people knowledgeable about eating disorders.

Our team first met with the researchers, psychologists, activist, and nonprofit all together as a group. We asked the researchers and clinicians about how emotions play into eating disorders and what support people most need and resonate with. We asked the group for ideas of ways social media companies could be more proactive in creating healthy online spaces and providing better support to people who are struggling with disordered eating.

Our team then met individually with people with a past or current eating disorder. Each person was asked to briefly describe their experience with disordered eating and the main challenges they faced. They were also asked how they would best like to be supported. Given the sensitive nature of the topic, these research interviews were moderated by trained clinical psychologists who specialize in eating disorders. At the end of the interview, the psychologist would check in with each participant to assess how she was feeling and would debrief with each person as necessary.

Results

Themes of support and needs from participants

Based on the discussions with experts and people with eating disorders, we identified themes across all discussions and interviews. The first theme that emerged was feeling seen and heard – the disorder is about emotion, not about the eating behaviors. People feel most supported when others ask how they are feeling or what they are going through, instead of commenting on their weight or eating behavior. The second theme was the importance of people feeling like they belong. An eating disorder can be very isolating and attention is often narrowed to focus on behaviors around eating and exercising at the expense of friends and hobbies. Helping people build and strengthen connection to friends, family, and their community can be very helpful. The third theme was that people want to feel in control. For the people we talked with, their eating disorder often arose out of feeling a lack of control in their lives (not being able to influence complex family dynamics or not being able to control grades or test scores, for example) so they end up strictly controlling their food intake since it is the one thing they feel they could directly influence. People do well when control is offered in other aspects of their lives – knowing there are options and resources available to help cope would allow people to take charge of their environment and possibly seek out help.

Formulating design principles

Next, we took these themes and turned them into design principles based on participant's needs. To help people feel seen and heard we wanted to be sure to validate feelings – the design should focus on the emotional experience and suffering, not the eating disorder itself or weight/eating concerns associated with the disorder. To help people feel like they belong we wanted to expose them to content unrelated to their disorders – the design should focus on activities, people, and opportunities that could allow people to reconnect with themselves and their community and provide something other than their eating disorder to build their life around. To help people feel in control we wanted to offer resources and plant a seed – the design should be useful, offering information and resources that could help people think about things in a new way or provide first steps toward recovery.

Building Prototypes

Taking the knowledge gained from the interviews, our team designed a new experience for how eating disorders could be handled online. Since our interviews focused on people who have experienced an eating disorder (as opposed to the perspective of people viewing content and wanting to provide support) we focused on redesigning the information screens that a company sends to the person who may have an eating disorder. As highlighted through the interviews, the following pages were designed to support people who may be struggling with an eating disorder by focusing on the underlying emotion and suffering and providing a sense of belonging, control, and information about resources or ideas people could use to help themselves.

Intro screen

The introduction screen (Figure 1) is the first page people (who have posted eating disorder-related content that has been reported by a concerned friend) see when going on Facebook. The main components of this page include a description of why the person is seeing this screen followed by different support options. People can chose between having a moment of peace, connecting with someone, contacting a helpline, or can skip this at any point and return back to Facebook.

The "moment of peace" option was included to validate and speak directly to the underlying emotions behind the post. Rather than trying to tell them what is right or wrong, we offer suggestions on how to alleviate emotional pain and reduce anxiety in small, actionable ways.

The "connect with someone" option was included to address the design principle of exposing people to

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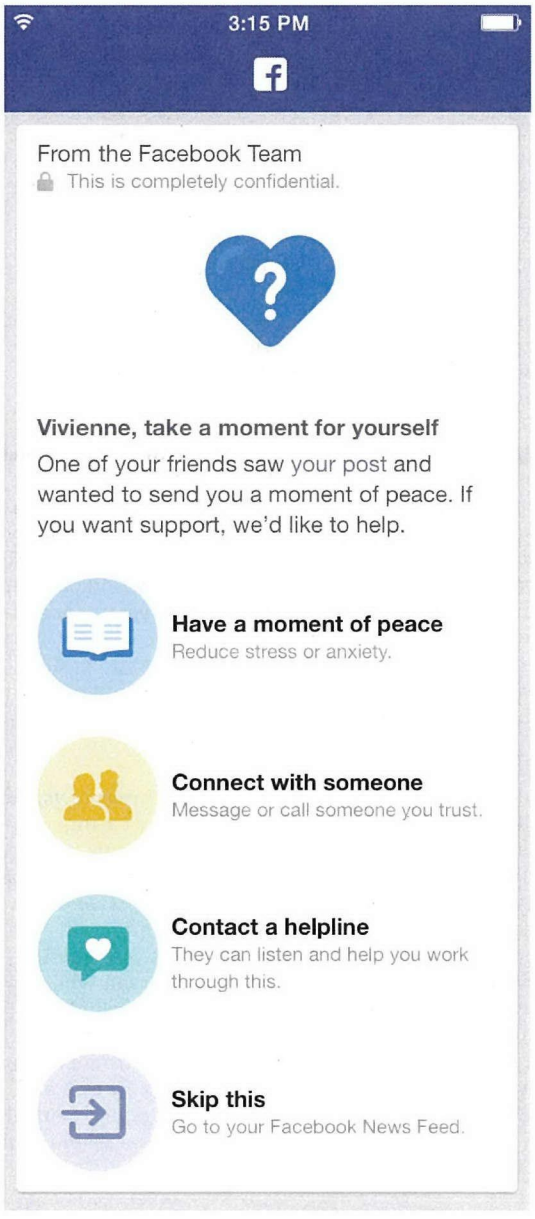


Figure 1. Introduction screen.

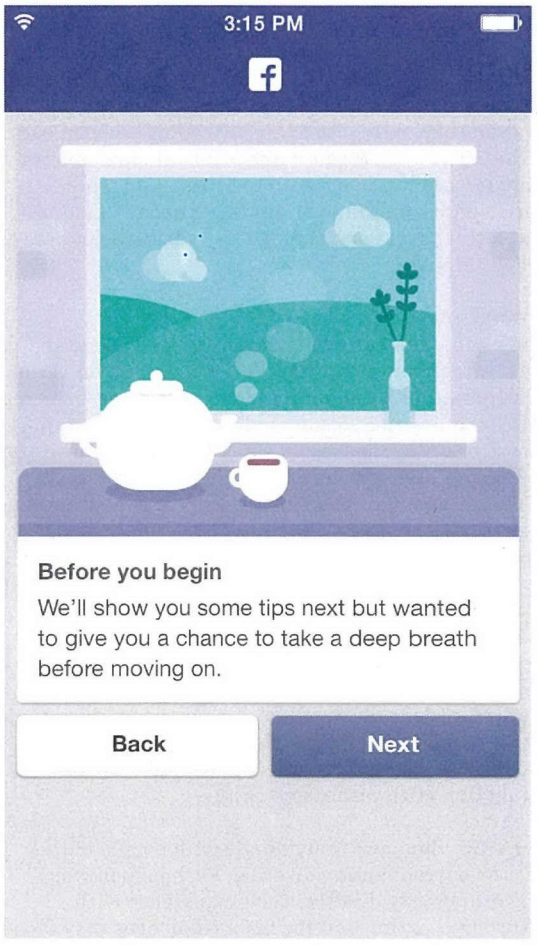


Figure 2. Moment of peace – animation.

content unrelated to their disorder. Because having an eating disorder can be very isolating, we hoped to encourage the person to reach out to someone, as texting can often be easier than calling or asking for help in person. Here, we help people choose from their friend list and provide a template for crafting a message to ask for support.

The "contact a helpline" option was included to address the design principle of planting a seed, or removing obstacles to make it as easy as possible for people take first steps towards recovery. We wanted to be sure to offer resources so people know who they can reach out to if they don't want to talk at the moment. We also wanted to be sure to offer a variety of ways to connect with other people, for those who feel more comfortable talking with a helpline rather than with someone in their social circle

The "skip this" option was included to make this experience optional. Given people may be at different stages of the eating disorder experience, it is important that this step be optional as it may be too difficult for someone deeply in the throws of an eating disorder or unnecessary to someone who is comfortably on the road to recovery.

Moment of peace

The "moment of peace" section (Figures 2-4) provides a few suggestions for how to alleviate distress in order to get to the heart of the matter by speaking to the emotion behind the post about disordered eating. In the first screen, we set expectations and give the person an opportunity to pause and watch a peaceful animation of clouds floating by and tea steaming by a windowsill (Figure 2). We hoped to create a calm environment and shift the mood through artwork and animation. On the next screen, we provide suggestions on things they can do on their own to create a moment of peace (Figure 3). We use photographs from real people to depict the suggestions, as we learned from our research sessions that images that felt authentic



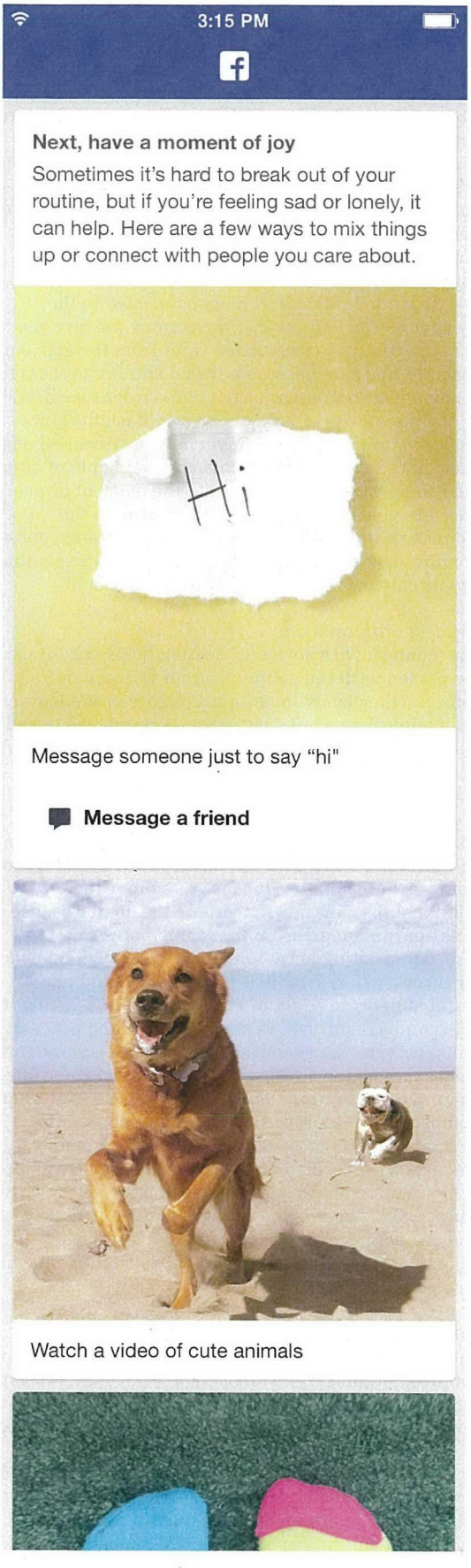


Figure 3. Moment of peace - ideas (left).
Figure 4. Moment of peace – more ideas (right).

helped give people an idea of what the activity might actually feel like and encourage them to take that step. We carefully designed the suggestions so that the easiest activities to do were shown first, based on what we learned about the types of activities that are potentially triggering or especially daunting. In this way we hoped to plant a seed, helping people to take a first step that leads to a greater second step. In the final step in this section, we offer people the option to see suggestions to create a moment of joy (Figure 4). Building on the principle of planting a seed, we suggest more ambitious activities for someone to do that might help them feel more connected to the broader world. For a few of the actions, we give you the opportunity to get started right from the app. For example, you can message a friend and invite them to watch a movie. In many of the photographs we drew on the popularity of animals on social media, since images of animals had a universally positive response from our research participants and were able to alter their mood significantly. Overall, the moment of peace section's goal is to help relieve suffering in the moment that drives disordered eating patterns, and to provide examples of positive coping mechanisms that people can use immediately or remember later.

Connect with someone

The "connect with someone" section helps encourage the person with the eating disorder to reach out to someone they know for support (Figure 5). We learned from clinical psychologists and the people we talked to that having an eating disorder can create a sort of tunnel vision, where everything narrows in on the eating disorder until there is no room left for previously cherished relationships and hobbies. People will often avoid social situations where there will be food or they will use all free time available to exercise, for example. This lack of supporting relationships can then exacerbate the anxiety, sense of isolation, and depression that contributes to disordered eating behaviors. It is extremely important for recovery to reestablish relationships and have social support in times of struggle. Because asking for help can be daunting, we designed a guided process that leverages the person's social media network and makes messaging a friend as frictionless as possible. We provide an option to message or call, if their phone number is available, so the person can choose the method they feel most comfortable with. A main obstacle we identified was that people often struggled to figure out what to say when asking for help. To address this, we provide a template for the message so that the person can choose to just hit send, make adjustments, or start from scratch, depending on what they need.

Contact a helpline

The "contact a helpline option" provides a short list of nonprofit organizations the person can contact to get support (Figure 6). For many people, they may not have someone they trust enough to ask for help, or they feel more comfortable talking to someone who does not know them personally for fear of burdening friends or being judged. We designed this section with the principles of planting a seed and addressing the underlying emotion in mind. Even if someone does not

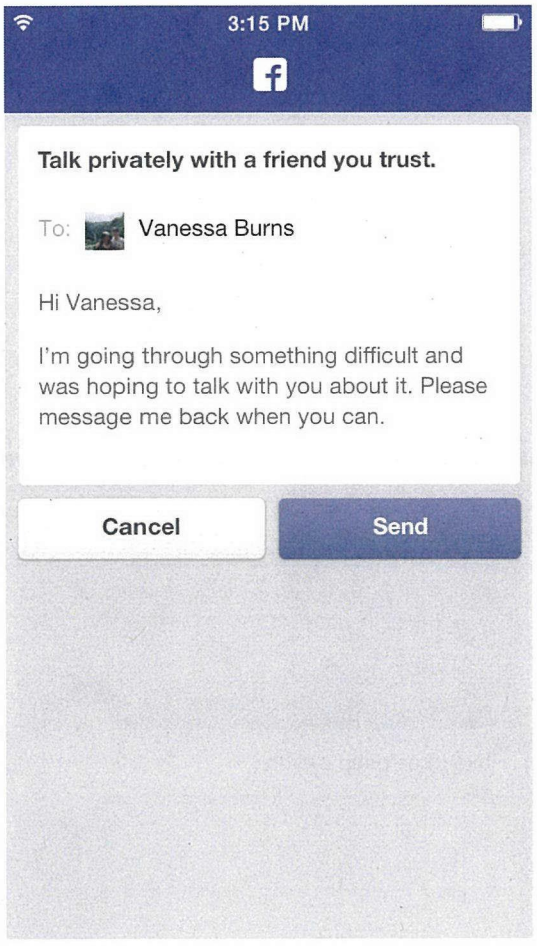


Figure 5. Connect with someone.

contact a helpline in the moment they see this experience, they are reminded that it is an option, and they now have curated recommendations. We also ordered the list so that the easiest option is first – the ability to text rather than talk. We hoped to make these options as approachable as possible so people would feel more encouraged to take a first step. From our research participants, we learned that a simple directory of contact information felt unapproachable and cold. We revised the screen to include each organization's logo so it is easier to get a sense of who they are and make the options as inviting as possible. It is also important to note that this is one of the only screens that mentions eating disorders. Because of our principle of focusing on the underlying emotions rather than on the disorder, we do not assume or label the person's experience. Instead, we frame all of the options around self-care and social support. This way, the options feel more universal, nonjudgmental, and empathetic, increasing the likelihood that this intervention will have an impact.

Discussion

This study sought to identify the ways people with an eating disorder could best be supported and turn these learnings into guiding principles for supportive

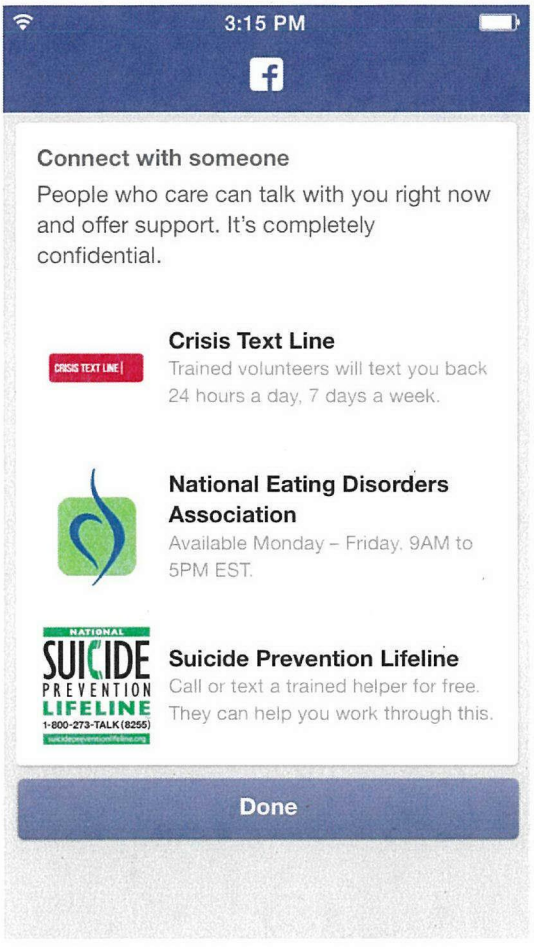


Figure 6. Contact a helpline.

designs. The discussions and interviews with experts and people with lived experience highlighted that people wanted to feel seen and heard, that they belong, and that they want to feel in control. These themes were turned into the design principles of validating feelings by focusing on the emotional experience and not the eating disorder itself, making people feel like they belong by highlighting activities that allow people to reconnect to themselves and their community, and providing useful information and resources that people could take action on themselves. Designs were created to put these principles into action. We took notes from previous research by incorporating photos from nature and activities, in line with past research that incorporating elements of nature could be helpful (DiNardo, 2013). Also in line with previous research, we made sure to keep the content clear, concise, and caring yet unassuming in tone to acknowledge the underlying emotional experience of the person (Choe, Duarte, Kientz, 2010). This study seeks to fill the gaps in previous literature by providing information about the experience of eating disorders from experts and people with past or current histories of disordered eating, and turn these themes into ways companies can design supportive experiences that best meet people's needs and resonate with them, instead of isolating them.

One limitation of the current study is that it does not focus on the experience of the person reporting the content. This person is very important given the process of people receiving support hinges on the person who sees the content and flags it to Facebook or the social media companies. Though important, this perspective was out of the scope of the current investigation. There are many reasons a person would flag concerning content – people could be reporting eating disorder content because they are concerned about the person, or they could be reporting to get that person in trouble, or they could not have an interest either way in that person specifically but are more so serving as community moderators focused on keeping online spaces safe for others. Future research is needed to understand the different motivations of reporters and which designs would best support or detract from these agendas. Another limitation of the study is that only female participants with a past or current history of an eating disorder were recruited. Though females are ten times more likely to have an eating disorder than males, having the male perspective would still be very valuable. Future user research is also needed to evaluate the designs created and ensure they are clear, usable, and supportive. Other avenues of research could investigate how these designs should change based on the social media company in order to best match each company's tone and target user base.

Conclusion

Eating disorders pose serious mental and physical health risks. Without proper support and treatment they can lead to permanent physical damage and even death. One way to support people struggling with an eating disorder is to address the underlying emotional needs that may contribute to or be an outcome of the disorder. Social media companies have the opportunity to interact with and support people in need when they post concerning eating disorder-related content on their sites. Effective support should go beyond providing a helpline number and instead provide richer information and resources that connect with the deeper needs and emotions of the person struggling – to feel connected, seen, and in control of their experience. The proposed Facebook designs aim to address these needs by providing suggestions of ways people can reconnect to themselves and their lives and find information and resources. The designs should not be taken as a replacement for professional help or treatment; rather they can provide steps and information to aid people in seeking help. They can also serve to plant a seed in someone who is contemplating recovery – the idea behind the designs is not cure people, but rather to provide ideas, inspiration, or motivation that may allow people to take the first step toward help seeking and recovery.

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