

Consent, Privacy, and Needs: Thinking about Ethical Challenges in My Research

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INTRODUCTION

Certainly in my own research, I have thought about the ethics surrounding consent, privacy, and determining user needs. My current work focuses on women with eating disorders. Because of the sensitivity around eating disorders, it is important to consider the ethics around conducting research with this population [9]. In this workshop paper, I will describe ethical questions and/or challenges I have faced in my own research.

Consent and Privacy

Consent and privacy are two major ethical topics, which have come up in my own research. My colleagues and I conducted a study exploring how women discuss eating disorders within an online weight loss community. The company that owns and operates the community gave us permission to conduct the research and provided de-identified data, including forum posts and portions of users' profile data. Anyone can create an account for free and read posts on the forums. Because the data was anonymized before we received it, we were unable to obtain consent from individual participants.

We did our best to maintain user privacy. First, the name of the community was changed to protect users' privacy. Also, we changed the wording of the quotations to ensure users could remain anonymous while still maintaining the tone and theme of the quotations. Examining users' posts helped us understand users' perceptions of how the technology they use and community they participate in impact their eating disorders.

- How do ensure our research is ethical if we cannot obtain consent from participants?
- What about in cases where the researcher's presence could interfere with the data?
- How do we think about users' privacy when conducting research (especially when we are dealing with vulnerable populations and sensitive topics)?

Determining "Needs"

When we think about studying and designing technology and permitting certain types of content, we need to think about what happens when what a user wants is not necessarily in his/her best interest at least from the researcher's (or someone's perspective) and who gets to decide what is "best". Because I study eating disorders,

there are times when I encounter users who wish to maintain their eating disorder.

- When thinking about what is "ethical", do we design technology for what users want or what is "best" for the user?
- Who decides what is "best" for the user?

This is not a new challenge. A prime example of this is pro-eating disorder communities. Many researchers have found that pro-eating disorder communities have negative effects on their users. Some researchers believe that these sites are a façade of "support" but actually are anti-help-seeking and anti-recovery [6]. While users report an increase in perceived support, these communities actually exacerbate their symptoms [2, 6] and perpetuate unhealthy habits [5].

Since pro-eating disorder content is controversial, some have called for censorship of these sites and their content in order to do what is in the "best" for the users. However, some have cautioned that censorship may actually be harmful [1, 3, 8]. For one, banning pro-eating disorder sites and content will make it more difficult for clinicians, researchers, families, and charities to reach out to pro-eating disorder communities [1] and limit people from creating their own online communities [7]. Additionally, some argue that pro-eating disorder communities may actually have positive effects on their users also. Some researchers have found that pro-eating disorder communities and sites offer support, a sense of community, and a coping mechanism for users with a stigmatizing condition [2, 4, 8].

My view has always been to advocate for the user. Especially when it comes to health and behavioral changes, we cannot force someone to do seek help, change their diet, etc., but we can provide them with resources. However, the best way to deal with these challenges is not really known.

I hope to discuss privacy, consent, needs, and other ethical issues further during the workshop.

BIOGRAPHICAL SKETCH

I am a PhD candidate in the College of Information Sciences and Technology at The Pennsylvania State University. My research broadly focuses on technology for health and wellness, including mental health. I am

particularly interested in how people use technology to support various health needs and how the design of these systems impacts users in intended and unintended ways. In my research, I take a sociotechnical approach, which allows me to explore users as humans and technology situated in a context and the interplay between the user, the technology, and various other social and environmental factors. My work has implications for technology design as well as healthcare practices.

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REFERENCES

1. A.A. Casilli, F. Pailer, P. Tubaro 2013. Online networks of eating-disorder websites: Why censoring pro-ana might be a bad idea. *Perspectives in Public Health*. 133, 2 (2013), 94–95.
2. Emese Csipke and Outi Horne. 2007. Pro-eating disorder websites: Users' opinions. *European Eating Disorders Review*. 15, (2007), 196–206.
3. Debra Ferreday. 2003. Unspeakable bodies: Erasure, embodiment and the pro-ana community. *International Journal of Cultural Studies*. 6, 3 (2003), 277–295.
4. Ruaidhri Mulveen and Julie Hepworth. 2006. An interpretative phenomenological analysis of participation in a pro-anorexia internet site and its relationship with disordered eating. *Journal of Health Psychology*. 11, (2006), 283–296.
- [5] Danielle C. Ransom, Jennifer G. La Guardia, Erik Z. Woody, Jennifer L. Boyd. 2010. Interpersonal interactions on online forums addressing eating concerns. *International Journal of Eating Disorders*. 43, 2 (2010), 161–170.
- [6] Codie R. Rouleau and Kristin M. von Ranson. 2011. Potential risks of pro-eating disorder websites. *Clinical Psychology Review*. 31, 4 (2011), 525–531.
- [7] Leslie Regan Shade. 2003. Weborexics: The Ethical Issues Surrounding Pro-Ana Websites. *ACM SIGCAS Computers and Society*. 33, 7 (2003), 2.
- [8] Helen Sharpe, Peter Musiat, Olivia Knapton, and Ulrike Schmidt. 2011. Review Pro-eating disorder websites: facts, fictions and fixes. *Health (San Francisco)*. 10, 1 (2011), 34–44.
- [9] Wyke Stommel. 2009. *Entering an Online Support Group on Eating Disorders: A Discourse Analysis*. Rodopi.