When Privacy is Painful: Designing for Multiple Needs and Trade-offs

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Abstract

My current research examines how people with chronic pain discuss their pain experiences on public social network sites, what this means for how they view privacy, and how they balance their need for privacy with their need for social support and community-building. In this position paper, I provide a summary of my initial findings, including that people with invisible illnesses are often frustrated by the "privateness" of their condition. I discuss how disclosures on these sites are best understood using Altman's conceptualization of privacy as a bidirectional, dynamic process of granting and withholding access to the self to satisfy multiple aims. I also discuss the necessity of researching people's unique privacy trade-offs and needs when designing for such subpopulations.

Author Keywords

Privacy; Online Pain Communities; Chronic Pain; Invisible Illness; Health; Social Media.

ACM Classification Keywords

K.4.1. Public Policy Issues: Privacy; H.5.2: User Interfaces: User-centered design

Introduction

Privacy is not a monolithic concept or an objective, ideal state of being: historically, there have been

multiple definitions of privacy [2, 5]. The unifying theme in these definitions is the concept of control over informational disclosure, which is especially vital when it comes to health information. However, these definitions do not identify whether there is an ideal level of privacy, or what that entails. Petronio [8] states that privacy boundaries vary from person to person based on individually-held privacy rules. The subjective nature of privacy highlights the need for the users of any system to help determine the values in its design. This position paper begins by reviewing some of the privacy considerations in delivering health interventions online, and then discusses how research on online pain communication can shed light on what privacy means to individuals with chronic, invisible pain and the way they balance privacy with the need for social support.

Research on populations with health issues online is often faced with the challenge of balancing privacy with beneficial outcomes. For example, researchers are now able to identify markers of distress on social media sites such as Instagram [7]. These technological breakthroughs have a range of positive applications, including improving our understanding of vulnerable or at-risk populations, and in developing support and interventions for those who need them.

However, technological interventions and support systems that are developed from these new ways of identifying specific groups of users online can run the risk of having unintended negative consequences. For example, The Samaritans, a non-profit organization in the United Kingdom, developed an application called *Radar* that was able to identify distressed or suicidal content in tweets; the app would then alert users if any of their friends posted such content so that they could offer them social support [5]. The app was withdrawn within days after public outcry that it violated people's privacy by analyzing their tweets for sensitive information about their mental health. While the app only parsed publicly posted content on Twitter, this example highlights that people often have an expectation of some form of basic privacy even in their public disclosures. In this case, the expectation may be that, while tweets are often public and easily accessible by anyone who wants to read them, they will not be systematically collected, analyzed, and then acted upon without the user's consent.

Current Study: Online Pain Communities

Broadly, my research focuses on how people manage their privacy in online spaces, and how technologies can be designed to support users in this process. Particularly pertinent to the 2017 CSCW Networked Privacy workshop is my ongoing research studying online and offline chronic pain communities to understand how people balance their need for privacy with their need for social support and community-building. I am using a mixed methods approach comprising interviews and content analysis to explore these questions.

Online forums are a popular venue for people to discuss many health issues from eating disorders to anxiety. Profiles on these sites are often pseudonymous or anonymous, rather than immediately tied to a user's personal information and offline identity. However, people also communicate about their health issues and conditions on non-specialized social network sites such as Twitter and Facebook. On these sites, people often use their real names and pictures, and their social network may be broader than just the pain community.

"My pain has been unbearable"
"Well you look fine"

"I have a rare disease...I feel like my pain condition isn't validated."

Image 1. Excerpts from public chronic pain tweets about the frustrations of dealing with an invisible illness that is "too private"

The fact that several health-related hashtags (e.g. #chronicpain, #spoonies[1], #invisibleillness) are very frequently used on such social media sites suggests that individuals make a trade-off between their privacy and the ability to connect with people on these sites.

What factors influence these trade-offs? One possible explanation is that people who post information about their symptoms on Twitter using chronic pain hashtags may value the potential to reach a broad audience of like-minded individuals more than the privacy cost of such disclosures. The way people navigate these trade-offs is particularly interesting given context collapse on social media: there are multiple real and imagined audiences online, which complicates self-presentation for any one intended audience [2]. In several cases in these public pain communities, individuals seem to choose to make sensitive disclosures about their health status instead of tailoring their communication to be appropriate to all audiences. This decision may stem from multiple, unexpected motivations, including the desire to be public about a health condition that is so often rendered private in the public sphere. Similarly, a recent CHI paper found that people take a nuanced approach to managing their privacy when using mobile health devices, and that there can be both positive and negative outcomes from revealing these devices rather than concealing them [1]. The communication practices of these online health communities support Altman's [5] conceptualization of privacy as a bidirectional, dynamic process wherein we restrict access to some people while granting access to others. In the context of invisible illnesses, this act of granting access to personal information may intentionally encompass one's entire social network. This conceptualization of privacy highlights the need to understand individuals' privacy trade-offs in everyday life: their privacy concerns, when they choose to reveal versus conceal, and the implications of these decisions.

When Privacy is Painful
A particularly striking finding from my initial analyses is that, on these social media sites, an often-voiced source of frustration involves the inherently invisible, or *private*, nature of many chronic illnesses (See Image 1). Pain conditions, such as fibromyalgia, chronic migraines, and Crohn's disorder, often do not exhibit a concrete public manifestation of pain. As a result, online chronic pain communities (such as #chronicpain or #spoonies on Twitter) can use these communal online venues to vent and bond over difficulties of having an invisible illness that others are not aware of or do not understand.

The sense of isolation and privacy around these health conditions exacerbates their perceived painfulness, as explained by Dr. David Biro in *Listening to Pain* [1]. Thus, it's not hard to understand why people may want to attach their identity to their communication, despite its potentially sensitive nature, if they struggle with public non-recognition of their condition.

Debilitating pain can also encumber people from meeting others in offline spaces, and thus, necessitates online interactions. As part of this research, I aim to explore the differences between online and offline pain disclosures and to compare the factors that drive the decision to disclose or conceal health information in

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[1] An active subcommunity (on multiple social media platforms) of individuals with chronic pain call themselves *Spoonies*, which is meant to be a reference to their limited stores of energy throughout the day

online and offline contexts. For example, do people reserve particularly sensitive information for online pain communities where they can interact with others with similar experiences, or do they only share these with their closest confidantes that they know offline? Understanding the factors that influence these decisions around privacy and disclosure can help illuminate how to design technologies to address people's specific needs for support.

Individuals with chronic pain may also have a nuanced perspective on what privacy means in offline spaces, as indicated by interviews with seniors with chronic pain, such as arthritis and lower back pain. When asked about his privacy concerns when using mobile health devices in public spaces, a participant said that he was not concerned about keeping activities such as pain tracking private from others, since he used a walking cane, and thus, his pain was already public for others to see. However, he still advocated for mobile health devices to be discreet in form: this design preference was motivated out of the desire to "not make a big deal" of pain, rather than to maintain privacy per se. This highlights that *privacy* can often be conflated with other concepts, such as the need for *discreetness*, and these differences often need to be teased apart.

Design Implications

The use of public social network sites as venues for communicating about sensitive health issues has implications for privacy research, design, and policy. Understanding subpopulations' particular privacy trade-offs can allow researchers to piece together the many benefits and costs of privacy that people must navigate in their daily lives, instead of conceptualizing privacy as a monolithic, universal end goal. Rather than designing

a one-fits-all privacy nudge or default into technologies and online environments, designers need to take into account the unique needs of their users in terms of what information should be disclosed versus concealed. Moreover, empowering people by giving them agency to decide what type of privacy they want would help alter the power dynamics that have historically shaped the design of privacy defaults and interventions. Finally, care must be taken in studying, designing, and reporting on online spaces where health information is discussed, particularly in light of the fact that people may attach their offline identities to these sensitive disclosures. For subpopulations such as these, the issue of designing for privacy may additionally involve empowering these users in making their sensitive disclosures (rather than nudging them towards a privacy-protective behavior) while ensuring that these disclosures cannot be taken advantage of by inappropriate data collection and usage.

Acknowledgements

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