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# #thinspiration: Exploring the Ethics of Research Focused on Teens, Self-harm and Social Computing

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## **Abstract**

Teens use social computing platforms in a myriad of ways. These activities range in nature from exploring the physical world around them to exploring the opportunities of their social network to exploring future opportunities. But what happens when these explorations focus on finding support for alternative lifestyle approaches that the general population and the healthcare system would deem dangerous and unhealthy? This paper explores the ethical challenges and dilemmas facing HCI researchers as we gain a deeper understanding of how self-harm presents itself within the teen population and within the domain of social computing.

## **Author Keywords**

Social computing, self-harm, ethics, teens.

## **ACM Classification Keywords**

K.4. Computers and Society

J.4. Social and Behavioral Sciences

## **Introduction**

Youth culture online is not new to the world of HCI, we have studied it through a variety of lenses and methods in an effort to better understand how youth use social

technologies to create, share, and communicate [4,20]. Understanding these positive attributes of youth life online is a necessary and a useful research pursuit that has been undertaken by many within the CSCW field. A less researched area within our field is that of the negative behaviors and activities associated with youth life online and the potential impacts this has on the individual and the community in which they interact.

Self-harm is a domain that the social computing literature has tended to not focus on, especially in comparison to the amount of scholarship surrounding other health and social computing research domains like diabetes, depression, cancer, and cyberbullying to name a few. While certain types of self-harm, in particular eating disorders, have been present within social computing platforms for years, the additional lens of youth further complicates the research rendering it near non-existent.

Why is this deficit of scholarship so pronounced? From an ethical perspective, working with youth, the affliction of a behavioral disease that is still not fully understood, and the presentation of these behaviors hidden within an online social presentation that parents and physicians might not be aware of make this a challenging, near impossible population to research.

In this paper, we will define self-harm, explore the severity of this health concern for the teen and youth demographic, quickly review technology use patterns within the demographic, and finally posit potential ethical challenges and dilemmas for researchers interested in research activities within this domain.

## **Defining Self-harm**

Self-harm is a clinical behavioral disorder that is often defined in terms of direct and indirect physical injury. Self-harm is often used interchangeably with terms like self-injury [10], self-mutilation [5], and self-wounding [19]. In the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), non-suicidal self-injury (NSSI) is now recognized as a distinct condition<sup>1</sup>. Self-harm behaviors often represent a way for the inflicted person to ground oneself or a way to feel and regain control or a way to inflict self-punishment [14].

Direct self-harm behaviors include cutting, burning, scratching, skin bleaching, hair-pulling, the ingestion of hazardous chemicals, and hitting oneself [12]. Indirect self-harm activities include eating disorders (bulimia, anorexia, bingeing, purging), involvement in abusive relationships, prolonged substance abuse and risky or reckless behaviors [17].

## **Self-harm and Youth**

Self-harm behaviors usually manifest during adolescence [1,13]. A 2014 World Health Organization study found that in England, 20% of 15 year-olds surveyed reported having self-harmed within the last 12 months [2]. This is an increase from 2002, where 6.9% of surveyed teens reported engaging in self-harm activities within the past year [9]. With respect to mortality rates of eating disorders within the teen population, Anorexia is 12 times higher than any other causes of death for females 12-25 years old [18].

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<sup>1</sup> <http://dsm.psychiatryonline.org>

The use of social technologies by individuals how self-harm has been established through previous research, as sparse as that literature might be. Research in this space focuses on the social computing community support and community activities [3,8], information and sharing practices [7], and ethical issues [16].

### **Teen Technology Use**

CSCW research gives a rich understanding of teen and youth social computing applications and motivation. This research spans understanding national trends [11], psychological impacts [20], and exemplars of community-situated use [15]. The use of social media is pervasive throughout most of youth and teen demographics. They use these technologies for a broad range of topics: from education to socialization to entertainment [11,15]. The blending of life online with life offline has become more fluid and balance that individuals as young as 8 and 9 years old have begun adept at managing [4,15]. Social media is a persuasive social computing tool, and this holds true for teens.

Teens report both being persuaded by others as well as actively trying to persuade others in their social networks to act in a certain manner, befriend/de-friend individuals, and in general likes and dislikes [15]. Within the scope of self-harm, we are interested in understanding how the influences impact others in their evolution of self-harm activities.

### **Ethical Challenges**

Several types of ethical challenges arise in the context of the behaviors and the population that have been discussed in this paper. These challenges range in scope from policy to implementation to research design. These challenges have serious implications on

the scope of the research, the methodological approach, and the responsibilities placed upon the researchers.

#### *Imminent Harm*

As researchers, when we come across a participant that we believe is in imminent danger from themselves or others, we are bound by our ethical duty and by community norms formalized within the IRB to take action. Often in research that could potentially yield this type of event, we provide additional safeguards to be put into place that demonstrate the research team's ability to handle the situation and provide specific plans for dealing with potential types of events. What happens when we find this type of data when we use APIs to scrape public data from the web? Do these same norms hold? We have obtained data from the individual, yet the individual is not technically a research participant. What are our obligations as researchers at this point?

#### *Authentication of Public Data*

Continuing this thread of public data, social computing research has maintained the ethical dilemma of ensuring that our data does not represent a vulnerable population of minors without an IRB firmly in place. The current common practice of age verification for social computing platforms is having the individual input their birthday to ensure that they meet certain age requirements. We have scholarship that points to the fact that students as young as 8 and 9 years old have accounts on social platforms that state they are at least 13 years old [15], based on the stipulations of the platform expressed through the terms of service. These types of participants are excluded easy enough in most qualitative research, but what about purely quantitative

research in this domain? Are our current community norms and standards enough to protect these vulnerable populations?

#### *Understanding What Public Data Means as a Teen*

Teens, like most adults, report not reading terms of services when setting up their social media accounts. Fiesler and others have shown that understanding of legal components like copyright and fair use, let alone terms of service[6]. The probability that teens understand that their data is not only being used by the platforms, but is also being used by researchers is probably quite low. I would posit that this is potentially true of the general population, not just teens. Is it ethical to collect public data on individuals that do not realize their data is being collected and used for research purposes? If it is, does that hold for individuals who are technically old enough to be in a platform, but are not old enough to be classified as a consenting adult?

#### *Censuring and Censoring of Communities*

Often communities focused on pro self-harm, and more popularly, pro-eating disorder communities, often find themselves fighting against ISPs and social computing platforms from removing their content as lewd and against community norms [16]. The argument of these communities is that they are not actively promoting behavior change or recruiting members, and therefore their Freedom of Free Speech is being violated. Other communities that are alternative to the mainstream often deal with similar problems. Self-harm communities are not deviant in nature, but are not typically deemed socially acceptable. Many companies and ISPs exploit this as being in violation of community standards and therefore subject to censorship. This is

easy enough for forums and sites that are solely dedicated to pro self-harm activities. Does this hold for less traditional communities, like those decentralized communities that form around hashtags embedded in more general social platforms like Twitter, Instagram, Pinterest and Tumblr?

#### *The Well-being of the Researcher*

Research within these communities can have a significant impact on the research team. The types of artifacts found in self-harm communities can often be very intense – for example the images depicting activities like cutting, burning, branding, and purging can be, and often are, very disturbing. The text that is embedded in these communities is also sometimes very graphic in nature. As a researcher, how do you dissociate yourself from such evocative content? We have IRB's in place to ensure that we are protecting the emotional, physical, and spiritual well being of our research participants, but what about the individuals conducting the research? Other research communities like those that work with the terminally ill, disaster recovery, political unrest, and other domains potentially share this issue. What can we learn from each other? Are their best practices that can be shared within disciplines?

### **Conclusion and Next Steps**

Several types of ethical challenges arise in the context of the behaviors that have been discussed in this paper. As we continue to uncover social computing uses of individuals who are underage or otherwise a vulnerable population based on health issues, like self-harm, what is our ethical burden as researchers? How are we to evolve our community norms and practices to reflect the ethical challenges outlined here and beyond?

Continuing a dialogue of ethical challenges within the community is essential as we continue to evolve as a field of social computing researchers.

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