Conducting Sensitive Research with Teens in the U.S. Foster Care System

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Abstract

My (Karla's) dissertation research will include an investigation of: 1) how foster parents mediate foster teens' technology use at home, 2) how foster youth experience sexual risks online, and 3) foster youth's designs for effective interventions that can protect them from serious online risks. Thus far, I interviewed 29 foster parents on their experiences with mediating their foster teens' technology use. In conducting this research, my advisor and I have encountered several challenges related to: 1) recruitment, consent, and assent, 2) sensitive data, 3) confidentiality and privacy, and 4) embedding inclusivity in design. My goal in attending this workshop is to find a support network of researchers that can mentor me on actionable ways to incorporate new research practices to address the challenges outlined in this position paper.

Author Keywords

Sensitive Research; Adolescent Online Safety; Online Risks; Foster Care System; Ethics.

ACM Classification Keywords

K.4.1 [Public Policy Issues]: Ethics, Human safety, Privacy.

Introduction

While there are several different meanings for "sensitive research," we define the term using Lee's [7:4] definition: "research which potentially poses a substantial threat to those who are or have been involved in it." This definition highlights the idea that all stakeholders (e.g., participants and researchers) related to the research are susceptible to potential harms. In my (Karla's) current research about youth in the foster care system [1,2,3,4], many of these teens have "mixed maturity" levels, where they are sexually mature but emotionally stunted, leading to extreme attention-seeking behaviors that put them at higher levels of online risk. As a researcher, working with this highly vulnerable population may involve collecting extremely sensitive data (e.g., sexually explicit material, drug use, criminal behavior). Handling these data can be difficult, especially if the content violates the teen's rights or my personal values. My goal in attending this workshop is to critically engage with a community of researchers who are more experienced (than I am) in conducting sensitive research and could provide me guidance in dealing with the challenges I have outlined in this position paper. I am interested in learning about best practices that I can apply in my own research as well as making strong connections with other researchers of sensitive domains. By attending this workshop, I hope to gain the following:

- A support network of researchers with whom I can share my experiences and build a collaborative relationship.
- Actionable ways to incorporate new research practices that can meaningfully address the research challenges presented below.

Experience Conducting Sensitive Research

Foster teens are some of the most vulnerable youth to serious risks, such as sex trafficking. However, very little research has studied how the internet plays a role in these risks, nor how we can develop effective interventions to empower foster youth against becoming victims of online risks. For my dissertation research, I will investigate: 1) how foster parents mediate foster teens' technology use at home, 2) how foster youth experience sexual risks online, and 3) foster youth's designs for effective interventions that can protect them from serious online risks. I recently conducted a study with 29 foster parents to understand their experiences with mediating their foster teens' technology use at home. I found that foster parents felt a great tension between providing these teens with a sense of normalcy (i.e., giving more technology access) and trying to keep them safe, as foster youth experience very high risks online. My findings confirmed that online safety is a great challenge within foster families. It also highlights the need for more research with foster youth, as they have unique sets of characteristics and challenges that create substantial nuance and require a deeper understanding beyond that of the general population. In conducting this research, I was exposed to several sensitive topics and unexpected situations that I never experienced before. For example, foster parents shared stories about extremely sexual online risks their teens faced: "*First things she did was post naked pictures of herself! She was 14, and she had posted some very, some nude pictures of herself that, you know, it was pornography.*" In addition, in one of my interviews a foster parent began crying uncontrollably, because she felt strongly about the topic and it was difficult for her to share. In both situations there is emotionally sensitive

information that is being shared. As the researcher, I would like to ensure that my practices result in positive outcomes, not just for myself, but for my participant as well.

Other experiences with sensitive research include visiting the University of Maryland, College Park. My advisor and I teamed up with the members of Kidsteam on a project about stranger danger. We were interested in understanding children's perspectives of online stranger danger and their ideas on designing social media features for combating online stranger danger. From our sessions, we gathered that children understood the severity of stranger danger situations and in most cases wanted help resolving the issues themselves instead of relying on their parents.

My Research Challenges

My research presents several unique challenges that make it increasingly difficult to engage with my intended population. While we have been able to gain access to foster parents of teens within the state of Florida (where the research is being conducted), we have encountered several barriers gaining direct access to foster youth. This section outlines some of the challenges we have encountered during the research process that I plan to discuss during the workshop.

Recruitment, Consent, and Assent: According to FDA regulation 21 CFR 50.3(q), a ward, by definition, is "a child who is placed in the legal custody of the State or other agency, institution, or entity, consistent with applicable Federal, State, or local law." Federal, state, and local laws govern the participation of wards in research. Because foster youth are often considered wards of the state, the IRB consent and assent process

becomes complex. To our knowledge, in the state of Florida, no clear guidelines exist regarding consent and assent for youth in out-of-home placement to participate in behavioral research. There are regulations in place that require parental (i.e., biological parent) consent for the adolescent to participate [6]. However, obtaining consent from a teen's biological parent can prove difficult, if not impossible. Many of these teens are not in contact with their biological parents due to a variety of situations (e.g., parental incarceration). *How can we recruit foster youth and who provides legal consent for teens within the foster care system?*

Sensitive Data: As previously stated, working with highly vulnerable populations may involve collecting extremely sensitive data that can be difficult to handle, especially if the content violates the teen's rights or the analyst's personal values. For example, researchers must be conscious of disseminating research results in a way that the participant's confidentially and privacy are protected. We often try to accomplish this by removing all personally identifiable information and ensuring any publicly available comments, if retrieved from online platforms, are non-searchable. Unfortunately, with large social media data sets that contain photographs, there is limited flexibility for removing all identifiable information. Therefore, a researcher must make a tradeoff between the risks of exposing a teen's identity and conducting research to benefit this specific population of teens. Additionally, a researcher studying the sexting behaviors of a vulnerable teen may collect photos that affront their religious values and principles. *Even with consent, should the sensitive data collected from foster youth be considered accessible for research?*

Confidentiality and Privacy: While researchers often ensure confidentiality and privacy as a right reserved for research participants, the laws protecting foster youth may actually prohibit us from making such ethical guarantees. For instance, Florida law requires all individuals who suspect or become aware of child abuse, abandonment, or neglect to report the incident to the Florida Abuse Hotline as mandated child abuse reporters. Yet, many of the online risks teens in the foster care system face fall on a thin line between abuse and illegal activity (e.g., sexual solicitations).

Ironically, foster youth may be too forthcoming with researchers, which could cause unanticipated consequences for the teens. Foster youth are accustomed to repeating their life stories to multiple individuals (e.g., case managers, guardians, local authorities). Therefore, they may be open in expressing harmful situations (e.g., abuse from a caregiver) to a researcher without understanding the ramifications of their actions. Although respect for confidentiality and privacy is a major principle of research ethics, in a case similar to the one mentioned, a researcher must break confidentiality with a participant to report the incident. Researchers must be fully aware of their responsibilities and the protocols for reporting a situation. Clearly disclosing these mandates to participants in the informed consent documents can support transparency between the researcher and participant. However, this introduces our next challenge: *How can we simultaneously build trust with foster youth while being transparent as to our role as mandated reporters?*

Embedding Inclusivity in Design: Participatory design encourages the researcher to place value on the stakeholder's knowledge by allowing the stakeholder to share their perspectives. Researchers have proposed using participatory design techniques to involve the user in the research and design process [8]. This technique has been successful when working with teen populations [5]. Three principles that are known to facilitate the successful participation of teens are: 1) transparency – clearly expressing the objectives to the participant, 2) autonomy – the participant has control of what and how information is shared, and 3) literacy – the participant has both a technical and social knowledge of the problem. We are interested in understanding how we may apply this technique and are open to suggestions for other approaches, which might be appropriate for engaging in user-centric design processes with foster youth. *How can we include diverse perspectives and engage all stakeholders when we design interactive systems?*

Conclusion

We have not found a clear solution to the outlined challenges but hope that by participating in the CHI 2019 Sensitive Research in HCI workshop will help us address our questions.

Acknowledgements

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