BCS HCI 2020 Doctoral Symposium

Juan F. Maestre

Indiana University

Bloomington, Indiana, USA

Abstract

My research area lies at the intersection of stigma, technology, and HCI research methods. My dissertation work addresses (1) remote access to stigmatized populations in order to conduct HCI research via the Internet; and (2) co-design of technology to help people cope with stigma. My prior work has already explored the first aspect by employing a methodology to conduct HCI research remotely. At the moment, I am in the process of designing a final study for my dissertation that would involve the use of methodology, protocols, and instrumentation for co-design workshops to be conducted remotely with people living with HIV.

Keywords

Stigma, stigmatized populations, HIV-related stigma, HCI methods, remote research, co-design.

My Research Area

Stigma involves the real or perceived existence of personal traits or *marks* that could be visible or invisible and that are undesirable to a particular social group. For example, someone could be stigmatized due to physical appearance (e.g., facial disfigurement), sexual orientation (e.g., being gay), occupation (e.g., trash collector), etc. Regardless of the type of *mark,* stigmatized individuals often experience negative effects in the forms of self-isolation, discrimination, and violence (Meisenbach, 2010; Goffman, 1979).

My research area lies at the intersection of stigma, technology, and HCI research methods. The motivation to conduct research in this area derives from my own experiences with the negative effects of stigma in the forms of discrimination and erosion of self-esteem due to my non-normative sexual orientation. As a result of my personal experiences with stigma, I feel committed to working with and for groups who are impacted by the effects of stigma in their lives. In this sense, upon joining a Ph.D. program, I wanted to learn how to conduct research with stigmatized populations and be able to design technological interventions for them.

Researchers in the HCI field have worked with different stigmatized populations such as people living with certain conditions (e.g., eating disorders, people living with depression, homelessness), and occupations (e.g., sex work). The majority of this work has not focused on how to help people cope better with stigma specifically, but rather it mentions stigma as another aspect of the population and has looked more into the use of technology to manage or treat their particular condition. In addition, most of the work has relied on studies in order to conduct research face-to-face using methods that are commonly used in HCI research like photo elicitation, vignettes, and co-design workshops. Thus, my dissertation work focuses on addressing two key aspects: 1.) Access to a stigmatized population via the use of remote HCI methods for data collection; and 2.) Co-design of technology that could help people cope with stigma more directly.

As a member of the LGBTQ+ community, I have experienced the impact of stigma in my life first hand. Thus, in my research I have been working with the LGBTQ+ community and the associated stigmas within this community in order to explore how individuals use technology to cope with stigma. In particular, I have been paying attention to the stigma associated with the Human-Immunodeficiency Virus (also known as HIV-related stigma). HIV-related stigma can have a detrimental impact on an individual's physical and psychological health (Corrigan, 2014; Chesney and Smith, 1999).

During my research journey, I have been able to get access and conduct research with people living with HIV. My dissertation work focuses on people living with HIV for the following reasons: (1) HIV is a highly stigmatized condition, (2) this is the group that I have been able to have access to via previous and ongoing research; and (3), HIV-related stigma affects members of the LGBTQ+ community disproportionately.

I have been able to complete studies and publish about how to access and conduct HCI research with people living with HIV remotely (see Maestre et al., 2018 and Maestre et al., 2020). I have been using the Asynchronous Remote Communities (ARC) method (MacLeod et al., 2016) to conduct research remotely. In this prior work, I found that the method proved helpful at recruiting and encouraging participation and engagement from participants (Maestre et al., 2018). I plan on using this method again to conduct co-design workshops. At the moment, I am designing and preparing protocols and instrumentation for co-design workshops to be conducted remotely. The goal of these co-design workshops will be to explore the co-creation of technology that could help people cope with HIV-related stigma and protect them from the deleterious impact of stigma in their lives.

Why Am I Applying for the Doctoral Symposium?

I am originally from Ecuador. I graduated in Computer Science and then worked as an instructor in the departments of Communication and Multimedia Design in two colleges in Quito, Ecuador for about five years. Then, I obtained a Fulbright scholarship to come to the U.S. to complete postgraduate studies. I completed a Masters program in Informatics at the University of Iowa and then moved to Bloomington, Indiana to pursue a PhD degree in Human-computer Interaction Design and Health Informatics in the Luddy School of Informatics, Computing, and Engineering at Indiana University. I work with Dr. Patrick Shih as my advisor. I have already completed my qualifying exams in 2018 and defended my dissertation proposal successfully in the spring semester of 2020. Next year will be my sixth and final year of my PhD program. I plan to complete my dissertation and defend in the summer of 2021.

I look forward to meeting colleagues involved in HCI and similar/related research from Europe and the United Kingdom. I am quite interested in applying for postdoc or academic positions in the UK. I would love to learn more about what other PhD students and faculty in our field are working on over there. I would like to meet and connect with people in academia. In particular, I would like to connect and share experiences with other researchers who may be working with marginalized populations or taboo topics; or with those who may be using similar or other methods to conduct research remotely (e.g., using social media, online platforms, etc.) I could contribute during the symposium by sharing my experiences working with a highly stigmatized population and the methods that I have used to recruit and collect data for HCI research. I could talk about key findings, lessons learned (i.e., what worked, what did not work) and best practices that have been useful during my PhD research journey.

During my research, I have been able to create rapport and gain access to a highly stigmatized population. The methods that I have used and that have allowed me to do research remotely with these populations have proven to be useful to learn more about the needs and views while respecting their privacy and confidentiality. Using a method to conduct HCI remotely can have several advantages. People can join from anywhere in the world without having to deal with barriers related to transportation, confidentiality or privacy issues. In particular, during the ongoing Covid-19 pandemic, remote research methods could further help researchers conduct research with participants without compromising their health and safety. Additionally, remote methods are less expensive to deploy and have allowed me to access highly stigmatized and marginalized populations that would otherwise be difficult to have access to in face-to-face settings. Nevertheless, while remote methods can be advantageous for research purposes, they can also hinder access to individuals who may lack access to technology that is needed for this type of remote research (i.e., access to Internet). The voices and perspectives of people without access to technology would be excluded. Thus, an important barrier that I have experienced thus far is gaining access to people who may lack the technology, but that would otherwise be willing to be part of an HCI-related research study conducted remotely.

Useful Resources

Since I am interested in conducting HCI research remotely, I would like to share a few resources that have helped me in conducting research remotely:

- The Asynchronous Remote Communites (ARC) method
    Paper: MacLeod, H., Jelen, B., Prabhakar, A., Oehlberg, L., Siek, K., & Connelly, K. (2016, May). Asynchronous remote communities (arc) for researching distributed populations. In 10th EAI International Conference on Pervasive Computing Technologies for Healthcare.

- Conducting research during a pandemic
    - Link:
      https://docs.google.com/document/d/1pUzToLjcBLwdp1dXw3k1oqhAQ1NCWD6PV6Sxp778KSA/edit?usp=sharing

In addition, here's a book that I just finished reading so I can pay attention to participants' values while involving them in participatory design workshops:

- Value Sensitive Design: Shaping Technology with Moral Imagination
    Book: Friedman, B., & Hendry, D. G. (2019). Value sensitive design: Shaping technology with moral imagination. Mit Press.

Open Questions

- What are other ways in which one could gain access to stigmatized, marginalized, or vulnerable populations in order to conduct HCI research remotely (i.e., co-design workshops)?
- Are there any other tools that I should be aware of in order to conduct HCI research remotely, and in particular for co-design workshops?
- Is there any other similar or related research in our field that has explored the design of technology for stigma?

References

Chesney, M. A., & Smith, A. W. (1999). Critical delays in HIV testing and care: The potential role of stigma. American behavioral scientist, 42(7), 1162-1174.

Corrigan, P. W. (2014). The stigma of disease and disability: Understanding causes and overcoming injustices. American Psychological Association.

Goffman, E. (2009). Stigma: Notes on the management of spoiled identity. Simon and Schuster.

MacLeod, H., Jelen, B., Prabhakar, A., Oehlberg, L., Siek, K., & Connelly, K. (2016, May). Asynchronous remote communities (arc) for researching distributed populations. In 10th EAI International Conference on Pervasive Computing Technologies for Healthcare.

Maestre, J. F., MacLeod, H., Connelly, C. L., Dunbar, J. C., Beck, J., Siek, K. A., & Shih, P. C. (2018, April). Defining through expansion: conducting asynchronous remote communities (arc) research with stigmatized groups. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (pp. 1-13).

Maestre, J. F., Kresnye, K. C., Dunbar, J. C., Connelly, C. L., Siek, K. A., & Shih, P. C. (2020, April). Conducting HCI Research with People Living with HIV Remotely: Lessons Learned and Best Practices. In Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems (pp. 1-8).

Maestre, J. F., Eikey, E. V., Warner, M., Yarosh, S., Pater, J., Jacobs, M., ... & Shih, P. C. (2018, October). Conducting research with stigmatized populations: Practices, challenges, and lessons learned. In Companion of the 2018 ACM Conference on Computer Supported Cooperative Work and Social Computing (pp. 385-392).

Meisenbach, R. J. (2010). Stigma management communication: A theory and agenda for applied research on how individuals manage moments of stigmatized identity. *Journal of Applied Communication Research*, *38*(3), 268-292.