Social technologies for digital wellbeing among marginalized communities

Michael A. DeVito
Ashley Marie Walker
Jeremy Birnholtz
Kathryn Ringland
Northwestern University
Evanston, IL 60208, USA
devitom@u.northwestern.edu
amwalker@u.northwestern.edu
jeremyb@northwestern.edu
kathrynringland@northwestern.edu

Kathryn Macapagal
Ashley Kraus
Northwestern University Institute for Sexual
and Gender Minority Health and Wellbeing
Chicago, IL 60611, USA
kathryn.macapagal@northwestern.edu
ashley.kraus@northwestern.edu

Sean Munson
Calvin Liang
University of Washington
Seattle, WA 98195, USA
smunson@uw.edu
cliang02@uw.edu

Herman Saksono
Northeastern University
Boston, MA 02115, USA
hsaksono@ccs.neu.edu

ABSTRACT

Discussions of online social technologies focus on their negatives in relation to wellbeing, prioritizing offline relationships and reduced screen time. However, many communities depend on

online social technologies for building community, gaining social support, and even exploring identity. This makes the use of these technologies crucial for the wellbeing of these communities. Numerous CSCW-related disciplines examine marginalized people's use of social technology and its relationship to wellbeing. Yet opportunities to converse across domains and engage in thinking around these topics are scarce. We aim to bring together health, design, communication, HCI, STS, and a spectrum of diversity science researchers to discuss what digital wellbeing looks like for marginalized populations, share the state of knowledge in respective fields, and identify opportunities for leveraging social technologies for wellbeing across these communities. We will engage in exercises intended to foster mutual understanding, identify commonalities between areas of inquiry, and bridge gaps between research areas. Our goal is to stimulate interdisciplinary collaboration, with the hope of advancing a research agenda regarding digital wellbeing for marginalized populations.

INTRODUCTION & TOPICS

Recently, there has been pushback against the role that social technologies, play in people's everyday lives. Companies such as Apple and Google have released suites of tools largely focused on giving users an accurate sense of the amount of time that they spend on different apps [15], with an eye towards allowing users to make informed decisions about how to limit their time on their devices. This follows years of scholarship focusing on the negatives of social technologies in terms of attention, connection, and addiction [4, 6, 32]. This push aims to curb some of the documented negative impacts of technology overuse [4, 15, 16, 24, 31]. However, it can often turn to advocating the reduced use or abandonment of these technologies [15, 24, 31, 32], despite the fact that, for marginalized communities specifically, these technologies are often essential [7, 9, 10, 14, 19]. In this workshop, we intend to problematize the current narrative of pursuing digital wellbeing through limitation of social technologies by considering the unintended consequences of this approach for marginalized populations and better understand how social technologies can be used to support marginalized groups.

Online social technology plays a distinct role for many marginalized communities that can be different from the role it typically plays for dominant groups. The LGBTQ+ community serves as a prime example. As offline LGBTQ+ community spaces have disappeared, LGBTQ+ people increasingly turn to online spaces for important information around their own identity development, safe sex practices that are not taught in schools, and social support they may not have access to in their offline lives [5, 7, 12, 13].. Compared to heterosexual and cisgender youth, LGBTQ+ youth spend more time online and are more likely to have close, supportive online friendships (50% vs 19%), including with other LGBTQ+ people [9], bringing into question using screen time as the primary metric for digital wellbeing.

This wellbeing of social technologies is not limited to the LGBTQ+ community. For children with autism, online spaces such as Minecraft can play a foundational role in allowing a space to play comfortably in a safe environment and build relationships with other people with similar life experiences [27]. Similarly, for people, and especially children, experiencing chronic illnesses,

ORGANIZERS

Michael A. DeVito is a PhD candidate at Northwestern. Their work explores how users adapt to complex online environments, understand social media ecosystems to protect themselves while expressing their identity.

Ashley Marie Walker is a PhD candidate at Northwestern. Their work focuses on the community health and how technology can help make responses to public health crises impacting marginalized populations more efficient, effective, and just.

Jeremy Birnholtz is an Associate Professor of Communication Studies at Northwestern University. He is interested in self-presentation online and has focused on the experiences of LGBT populations using social media and dating/hookup platforms.

Kathryn Ringland is a postdoctoral scholar at Northwestern. She is interested in social media as a means of access and inclusion to social support and care for marginalized individuals.

Kathryn Macapagal is an Assistant Professor at Northwestern's Institute for Sexual and Gender Minority Health and Wellbeing. As a clinical psychologist and adolescent health researcher, she is interested in the role of social media in LGBT health and wellbeing.

Ashley Kraus is a postdoctoral scholar at Northwestern's Institute for Sexual and Gender Minority Health and Wellbeing. Her research interests involve the intersection of sexual and gender minority health, multimedia technology, and social media.

having access to online communities via social platforms can be one of the few reliable ways they can find others to share the emotional burden of chronic illness with [22]. Online platforms are also a crucial way of maintaining a sense of normalcy through connections with friends and loved ones while moving in and out of treatment [19]. This potential for connection also boosts wellbeing, and even traditional health metrics, for low-socioeconomic status populations. For example, in predominantly racial minority neighborhoods, social sharing of healthy eating moments can evoke a feeling of hope [11], empowering community members to collectively take control of the health disparities in their neighborhoods. Similarly, social sharing can increase comfort and help provide a feeling of safety when exercising in low-income neighborhoods where fitness resources are limited and crime rates are high [28]. Overall, online social technologies play an instrumental role in the lives of people from many different marginalized groups, roles that are not well-served by offline counterparts. Focuses on decreasing screen time or overall usage as a way to promote digital wellbeing may actually disproportionately harm already marginalized groups who rely on social technologies for important support and resources.

At the same time, these marginalized groups may be vulnerable to some of the current worries about online social technologies generally and may in fact have additional concerns about how these technologies impact wellbeing. Consider the case of LGBTQ+ youth: though online spaces are a key site of social support and education, they also can enable fixation on validation through "likes", unhealthy relationships with body image, sexualization of innocent images [2], and potentially risky behaviors than their offline counterparts [14]. Though these behaviors are motivated by the desire to seek friendships and romantic relationships, they also have the potential to compromise these youth's safety and well-being. For instance, one study found the majority of gay/bisexual adolescent boys had used online sexual networking apps intended for adult men [20]. Others have shown that youth out online are more likely to experience bullying [9]. Similarly, autistic youth often find themselves the target of online harassment and bullying. Many of the built-in safety measures for these and other people with disabilities tend to take away functionality of the system, with a result of infantilizing the user with disability [23]. We must also consider issues of access, adoption, and adherence to wellbeing technologies, in order to avoid further marginalizing disadvantaged populations [33]. To define and support wellbeing for marginalized people via social technologies, we must explore both the unique positives and unique negatives these technologies present for such groups.

This workshop aims to draw out and focus on the tension between the value and drawbacks of social technologies regarding the wellbeing of marginalized populations. Building off the expertise of the organizing team in working with different marginalized populations, we will catalyze a broader discussion to identify opportunities for learning across disciplines and domains. A key goal is to establish points of solidarity and commonality across marginalized groups. From this basis, we will develop a research agenda for future work, identify useful collaboration opportunities across contexts, and ultimately, produce an article about future directions for this research area.

Starting themes for discussion include:

ORGANIZERS (CONTINUED)

Sean Munson is Associate Professor of Human Centered Design & Engineering at the University of Washington. In his research, he works to support people in understanding and acting on their health data and in applying design to make existing health interventions more accessible, equitable, and effective.

Calvin Liang is a PhD student in Human Centered Design & Engineering at the University of Washington. His work centers around queer health and how technology might address tensions that arise for anyone who is marginalized, harmed, or treated as other when navigating healthcare.

Herman Saksono is a Ph.D. candidate at Northeastern University. His research focuses on understanding digital health interventions in low-SES populations. He investigates how fitness trackers can help low-income families stay active despite the multiple barriers they face to exercise.

Promises and pitfalls of social technology for connection and identity. Social technologies introduce questions around self-presentation and attention, as marginalized communities, in addition to facing structural discrimination, are also often stigmatized by larger society. This common experience of stigmatization can lead to heightened concerns around context collapse when disclosing and presenting marginalized identity, especially on algorithmically-driven social platforms which can be difficult to navigate [21]. Key topics in this area include best practices for creating and moderating spaces for these groups to foster connection, parental awareness and monitoring among young users, ensuring maximum inclusion while balancing the need for safety and boundaries, tensions between self-identification with minoritized groups and opening oneself up to victimization, implications for online privacy, and concerns about managing the disclosure of and claiming a marginalized identity.

Social technology for informational/instrumental needs. Many marginalized populations use online spaces as resources for important health and wellbeing information (e.g., information on safe sex practices, availability of low-cost clinics, access to job resources) [14, 20, 22, 28]. However, disinformation and misinformation remain highly salient concerns for all online information [1]. For example, online anti-vaccination campaigns have exacerbated people's fear of autism [8, 17, 30]. Key topics in this area include how to ensure that social technologies are delivering useful, correct, and relevant information, how to combat socially-spread misinformation, and how to ensure that sharing information does not expose marginalized individuals to the potential for further harm.

Designing for marginalized communities. Often, marginalized groups are using tools and platforms designed for a set of theoretical users who are rarely part of a marginalized group [3, 25]. While online social technologies have proven useful for marginalized groups overall, recent work has shown how these systems also contain problems that directly result from this lack of attention to marginalized groups during development [18, 25, 26, 29]. social media. This creates a situation where a social platform may be both psychologically helpful and harmful, such as a site that is physically accessible, but socially exclusive when autistic gamers are harassed out of virtual spaces [27] Key topics in this area include defining guidelines that help designers support wellbeing for a broad set of marginalized identities, what design tools would be useful for us to better move towards digital wellbeing that works well for marginalized populations, and how online spaces and technologies designed for marginalized groups may differ from the platforms that exist today.

REFERENCES

[1] Hunt Allcott, Matthew Gentzkow, and Chuan Yu. 2019. Trends in the diffusion of misinformation on social media. *Research & Politics*, 6, 2: 1-8.

[2] Jeremy Birnholtz. 2018. I don't want to seem trashy: exploring context and self-presentation through young gay and bisexual males' attitudes toward shirtless selfies on instagram. In *Proceedings of the 20th International Conference on Human-Computer Interaction with Mobile Devices and Services*, 34.

[3] Jed R Brubaker and Gillian R Hayes. 2011. SELECT* FROM USER: infrastructure and socio-technical representation. In *Proceedings of the ACM 2011 conference on Computer supported cooperative work*, 369-378.

[4] Justin Cheng, Moira Burke, and Elena Goetz Davis. 2019. Understanding Perceptions of Problematic Facebook Use: When People Experience Negative Life Impact and a Lack of Control. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1-13. 10.1145/3290605.3300429

[5] Shelley L Craig and Lauren McInroy. 2014. You can form a part of yourself online: The influence of new media on identity development and coming out for LGBTQ youth. *Journal of Gay & Lesbian Mental Health*, 18, 1: 95-109.

[6] Christopher R Engelhardt, Micah O Mazurek, and Joseph Hilgard. 2017. Pathological game use in adults with and without Autism Spectrum Disorder. *PeerJ*, 5e3393.

[7] Jesse Fox and Rachel Ralston. 2016. Queer identity online: Informal learning and teaching experiences of LGBTQ individuals on social media. *Computers in Human Behavior*, 65,, : 635-642.

[8] Gigi Garzio. 2018. *Values, Justifications, and Perspectives Connected to the Anti-Vaccination Movement.*

[9] CiPHR GLSEN, CCRC. 2013. *Out online: The experiences of lesbian, gay, bisexual and transgender youth on the Internet.* GLSEN, New York.

[10] Amy L Gonzales. 2017. Disadvantaged minorities' use of the Internet to expand their social networks. *Communication Research*, 44, 4: 467-486.

[11] Andrea Grimes, Martin Bednar, Jay David Bolter, and Rebecca E Grinter. 2008. EatWell: sharing nutrition-related memories in a low-income community. In *Proceedings of the 2008 ACM conference on Computer supported cooperative work*, 87-96.

[12] Benjamin Hanckel, Son Vivienne, Paul Byron, Brady Robards, and Brendan Churchill. 2019. 'That's not necessarily for them': LGBTIQ+ young people, social media platform affordances and identity curation. *Media, Culture & Society.*

[13] Gary W Harper, Pedro A Serrano, Douglas Bruce, and Jose A Bauermeister. 2016. The internet's multiple roles in facilitating the sexual orientation identity development of gay and bisexual male adolescents. *American journal of men's health*, 10, 5: 359-376.

[14] Lynne Hillier, Kimberly J Mitchell, and Michele L Ybarra. 2012. The Internet as a safety net: Findings from a series of online focus groups with LGB and non-LGB young people in the United States. *Journal of LGBT Youth*, 9, 3: 225-246.

[15] Anick Jesdanun. 2018. *Too much screen time? New phone controls for you and kids.* City.

[16] Jingjing Jiang. 2018. *How Teens and Parents Navigate Screen Time and Device Distractions.* Pew Research Center

[17] Anna Kata. 2012. Anti-vaccine activists, Web 2.0, and the postmodern paradigm–An overview of tactics and tropes used online by the anti-vaccination movement. *Vaccine*, 30, 25: 3778-3789.

[18] Os Keyes. 2018. The misgendering machines: Trans/HCI implications of automatic gender recognition. *Proceedings of the ACM on Human-Computer Interaction*, 2, CSCW: 88.

[19] Leslie S Liu, Kori M Inkpen, and Wanda Pratt. 2015. I'm not like my friends: Understanding how children with a chronic illness use technology to maintain normalcy. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*, 1527-1539.

[20] Kathryn Macapagal, David A Moskowitz, Dennis H Li, Andrés Carrión, Emily Bettin, Celia B Fisher, and Brian Mustanski. 2018. Hookup app use, sexual behavior, and sexual health among adolescent men who have sex with men in the United States. *Journal of Adolescent Health*, 62, 6: 708-715.

[21] Elizabeth McConnell, Bálint Néray, Bernie Hogan, Aaron Korpak, Antonia Clifford, and Michelle Birkett. 2018. "Everybody puts their whole life on facebook": Identity management and the online social networks of LGBTQ youth. *International Journal of Environmental Research and Public Health*, 15, 6: 1078.

[22] Mark Merolli, Kathleen Gray, Fernando Martin-Sanchez, and Guillermo Lopez-Campos. 2015. Patient-reported outcomes and therapeutic affordances of social media: findings from a global online survey of people with chronic pain. *Journal of Medical Internet Research*, 17, 1: 20.

[23] Rebecka Näslund and Åsa Gardelli. 2013. 'I know, I can, I will try': youths and adults with intellectual disabilities in Sweden using information and communication technology in their everyday life. *Disability & Society*, 28, 1: 28-40.

[24] Gwenn Schurgin O'Keeffe and Kathleen Clarke-Pearson. 2011. The impact of social media on children, adolescents, and families. *Pediatrics*, 127, 4: 800-804.

[25] Nelly Oudshoorn, Els Rommes, and Marcelle Stienstra. 2004. Configuring the user as everybody: Gender and design cultures in information and communication technologies. *Science, Technology, & Human Values*, 29, 1: 30-63.

[26] John R Porter, Kiley Sobel, Sarah E Fox, Cynthia L Bennett, and Julie A Kientz. 2017. Filtered out: Disability disclosure practices in online dating communities. *Proceedings of the ACM on Human-Computer Interaction*, 1, CSCW: 87.

[27] Kathryn E Ringland. 2019. "Autsome": Fostering an Autistic Identity in an Online Minecraft Community for Youth with Autism. In *Proceedings of the 14th International iConference*, 132-143.

[28] Herman Saksono, Carmen Castaneda-Sceppa, Jessica Hoffman, Magy Seif El-Nasr, Vivien Morris, and Andrea G Parker. 2018. Family health promotion in low-SES neighborhoods: A two-month study of wearable activity tracking. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, 309.

[29] Morgan Klaus Scheuerman, Stacy M Branham, and Foad Hamidi. 2018. Safe spaces and safe places: Unpacking technology-mediated experiences of safety and harm with transgender people. *Proceedings of the ACM on Human-Computer Interaction*, 2, CSCW: 155.

[30] Steve Silberman. 2015. *Neurotribes: The legacy of autism and the future of neurodiversity*. Penguin, New York.

[31] Morten Tromholt. 2016. The Facebook experiment: Quitting Facebook leads to higher levels of well-being. *Cyberpsychology, behavior, and social networking*, 19, 11: 661-666.

[32] Sherry Turkle. 2011. *Alone together: Why we expect more from technology and less from each other*. Basic Books, New York.

[33] Tiffany C Veinot, Hannah Mitchell, and Jessica S Ancker. 2018. Good intentions are not enough: how informatics interventions can worsen inequality. *Journal of the American Medical Informatics Association*, 25, 8: 1080-1088.