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The Ethical Implications of Using Social Media to Engage and Retain Justice-Involved Youth in Behavioral Health Research

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Abstract

Given its popularity among youth ages 13–17, social media is a promising avenue for engaging and retaining historically hard-to-reach youth in longitudinal research. Social media use in longitudinal research involving youth, however, has preceded development of best practices for ethical use. This article describes the ethical challenges and considerations of using social media to engage and retain youth within the context of a randomized controlled trial of a group-based adolescent substance use intervention. Best practices for addressing ethical challenges are also provided using the Belmont Principle as a guiding framework. As social media becomes more commonly used to engage and retain youth in clinical research studies, researchers must address emerging ethical concerns within project protocols.

Keywords

research ethics; social media; behavioral social science research; justice/participant selection/inclusion/recruitment; risks; benefits; burdens of research/beneficence and non-maleficence

Longitudinal research has been critical in advancing our understanding of developmental changes occurring during adolescence. Yet longitudinal research studies involving youth often face challenges with maintaining high retention, thereby impacting study validity (Hansen et al., 1985). Retention rates in longitudinal research involving youth range from approximately 38–98% (Teague et al., 2018), with rates among historically hard-to-reach subgroups including justice-involved, unhoused, and lesbian, gay, bisexual, and transgender (LGBT) youth frequently on the lower end of the range. Among justice-involved youth (i.e., youth who have contact with the juvenile justice system), out-of-home placements (CJJR, 2015), transfers to/from detention facilities (Redding, 2010), and restricted access to reliable communication methods, are all factors that can interfere with researchers maintaining contact with these youth, and thus affect participant retention. Low retention rates not only

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affect power for statistical analysis, but can greatly limit the generalizability of findings regarding the efficacy of evidence-based treatments for justice-involved youth (Burlew et al., 2011).

Understanding factors that hinder or promote sustained contact between participants and researchers has contributed to improvements in the retention of other historically hard-to-reach groups in longitudinal research. Some strategies for retaining hard-to-reach youth include communicating with social networks for LGBT youth (Liu & Mustanski, 2012), employing peer outreach workers to conduct motivational interviewing with youth living with HIV (Naar-King et al., 2009), and engaging in multiple tracking procedures (i.e., contacting collateral contacts, searching internet databases and collecting driver's records for address updates, mailing letters home, and conducting community visits) for youth experiencing housing instability (Hobden et al., 2011). Less is known about effective strategies for retaining justice-involved youth in longitudinal clinical research (Montanaro et al., 2015) and novel strategies are needed.

Given its popularity among youth ages 13 to 17 (Anderson & Jiang, 2018; Madden et al., 2013), social media is a promising retention tool in longitudinal research (Guillory et al., 2018). The use of social media in longitudinal research involving youth, however, has preceded development of best practices for ethical use. Research involving social media is, in general, lacking in discussions about ethics (Henderson et al., 2013) and much of the existing literature on social media research ethics focuses on adult or researcher perspectives on how to ethically use social media for research purposes (Golder et al., 2017; Samuel & Buchanan, 2020; Weller & Kinder-Kurlanda, 2014). There are unique developmental considerations for using social media as a retention tool with adolescents. Adolescence is a time of increasing autonomy, individuation, and engagement in risky behavior (Arain et al., 2013; Balocchini et al., 2013). Social media has the potential to influence identity formation and perceptions of privacy, which are more fluid and evolving during adolescence (James et al., 2011). Parental authorization or consent is still generally required for youth to participate in research in addition to their own assent (Buchanan & Zimmer, 2021; Leikin, 1993). However, parental authorization is not required for youth 13 years and older to use social media, so conducting social media research with youth brings its own host of separate ethical issues to consider, including parental underestimation of youth social media involvement (Blackwell et al., 2016), parental concerns about revealing youth identity and location to researchers online (Spriggs, 2009), and youth completing online parental consent forms themselves (Hokke et al., 2018). Existing research on social media with youth focuses on the ethics of using social media to analyze their posts (Lunnay et al., 2015), examining their attitudes about participating in social media research (Monks et al., 2015), and using social media for recruitment, intervention delivery, or health measurement (Park & Calamaro, 2013). Thus, there remains a critical gap in understanding how researchers can ethically use social media as a retention strategy for youth who present with unique developmental considerations relative to adults.

In this article, the authors describe their experiences using social media to enhance retention of youth currently involved or at-risk for involvement in the juvenile justice system in the context of a randomized controlled trial (RCT) of a group-based adolescent substance use

intervention. Due to difficulties contacting youth to complete post-intervention assessments (e.g., frequent changes in residential placement, displacement from communities, competing priorities, changing phone numbers, loss of phone privileges, and limited or inconsistent cellular service), using social media became essential to bolstering retention and facilitating assessment completion. Ethical considerations in using social media to improve retention of underserved youth in longitudinal research and recommendations in alignment with the principles of the Belmont Report are discussed.

Project VOICES

Project VOICES was an RCT testing the efficacy of a group-based substance use intervention for adolescent girls and young women aged 12–24 years who were either on probation or at-risk for justice involvement due to substance use. Participants ($n = 132$) were recruited from public schools, community-based organizations serving justice-involved youth, and juvenile courts in northern California, and were randomized at baseline to either the VOICES intervention (Covington, 2004) or an active psychoeducational comparison group matched for time and attention. Group conditions consisted of 12 1-h group sessions with pre- (baseline), mid- (1 month), and post-intervention (3, 6, and 9 months) assessments. Caregivers were also invited to complete longitudinal assessments. As part of baseline assessment procedures to obtain follow-up contact, youth were asked to provide social media account information for Facebook, Twitter, and Instagram. The primary methods used for contacting youth were phone calls and text messages; in the event that youth could not be reached through these methods, researchers attempted contact via social media. The Children's Online Privacy Protection Act (COPPA) of 1998 restricts children under 13 years of age from using social media, so, researchers did not collect social media information or have any social media contact with youth under 13 years of age. Although individuals enrolled in the VOICES trial ranged from 12 to 24 years of age, the discussion in this paper is limited to those aged 13 to 17 years to focus on the ethical issues as they relate to social media use among adolescents.

The Belmont Report

The Belmont Report (1978) serves as the foundation for ethical conduct in human subjects research and provides a useful framework for ethical use of social media in research with youth participants. The Belmont Report (1978) lays out three primary ethical principles: justice (i.e., equitable distribution of the benefits and burdens of research), beneficence (i.e., obligation to do no harm and maximize benefits), and respect for persons (i.e., acknowledgment of an individual's autonomy and a need to protect those with diminished autonomy). Existing frameworks on the ethics of social media research, such as the Privacy by Design framework for online health research recruitment (Bender et al., 2017), focus extensively on risk and privacy concerns as they pertain to minimizing harm and maximizing benefits, but fail to center equity or autonomy (Moreno et al., 2013; Townsend & Wallace, 2016; Williams et al., 2017). Thus, the Belmont Report was selected as the framework for this discussion because ethical use of social media with youth, and in particular youth involved in or at-risk for involvement in the juvenile justice system, requires a framework that addresses not only minimizing risks and maximizing benefits, but also fair treatment

for all participants and the preservation of autonomy throughout study participation. Considerations for ethical use of social media in alignment with each principle of the Belmont Report are outlined below, using experiences from Project VOICES to illustrate; specific suggestions for researchers are presented in Table 1.

Justice

According to the Justice principle, no individual or group should disproportionately bear the burden or acquire the benefits of research. Researchers collected youth social media information during the informed consent/assent discussions, and requested updated information at every follow-up time point. Systematically requesting and using youth social media information to assist with retention is one way of creating an equitable opportunity for all youth to participate in the research study. Not every youth in Project VOICES provided social media account information; however, asking all youth to provide social media information at multiple time points throughout the study allowed for the same opportunity to be contacted for the group intervention sessions and survey assessments. Moreover, using social media or providing account information was not eligibility requirements for participation; youth were not pressured to provide this information, and for youth who did not provide social media information, researchers proceeded with standard contact attempts via phone calls, text messages, collaterals, and letters. Of note, social media platforms can be accessed on any electronic device (e.g., computer, tablet, mobile phone) with Wi-Fi capability and therefore served as an additional way of reaching youth with less reliable cellular service for their group sessions and follow-up assessments.

Beneficence

Researchers have an obligation to minimize risks to individuals' privacy and safety. This can be challenging when using public platforms such as social media as terms of services (e.g., using data for research, targeted advertisements, selling and sharing information to third parties) can change frequently, be difficult to interpret, and inadvertently lead to data/privacy breaches. Unanticipated disclosures (e.g., social media platform selling data to a third party) can have cascading effects with wide-ranging implications for youth (e.g., reputation, discrimination, legal status, employment). Furthermore, connecting with youth over social media potentially gives researchers access to more information than may be necessary for the project. For example, researchers may inadvertently view content over social media that indicates youth are at-risk of harm to themselves or others, which might necessitate mandated reporting (e.g., child abuse) or follow-up (e.g., suicidal ideation). Mandated reporting may then lead to unintended negative consequences (e.g., exacerbating family tensions and mistrust toward adults, out-of-home protective care placement).

To protect the youth's safety and stability, the following strategies were integrated into the Project VOICES protocol (see Table 1). When gathering youth's social media account information, youth should type their username into the search bar of the social media platform on the researcher's encrypted work cellphone. Researchers should refrain from clicking on the youth's profile to respect their privacy and ensure search history has been cleared before and after the youth searches for their social media account. Staff should

record the username into a secure research participant enrollment and retention tracking database. Contact with youth over social media should be limited to direct messages (i.e., avoid posting publicly on youth's accounts and scrolling through youth's social media posts) and focus on a clear project-related goal (e.g., scheduling follow-up assessment). Researchers should also stress they are reachable only during standard business hours (e.g., 9am to 6pm). This boundary is necessary in case the youth attempt to disclose harm to themselves or others via social media messaging at a time when no licensed clinician is available to help guide the youth to safety. Unless there is reason to suspect the youth is at-risk of harm to themselves or others, researchers must keep all information confidential. Informed consent should clearly explain how researchers will use social media to communicate with youth and describe mandated reporting requirements as they apply to online communication. Given the potential risk of data breaches associated with social media platforms, all social media-based communication were recorded into a Research Electronic Data Capture database and direct messages were cleared from the lab social media account every few weeks.

Respect for Persons

The Belmont Report outlines specific provisions to ensure participants' autonomy in research by protecting them from coercion and undue influence. For example, youth must be given the opportunity to make informed decisions about participation and to provide assent separately and privately from parental consent. During the informed consent process, researchers should be transparent with youth and caregivers about how they gather and verify social media accounts, and how and when staff engage with them using social media (e.g., via direct messages only). This will allow youth and caregivers to make an informed decision about providing consent for contact through social media.

In Project VOICES, youth were not always willing to share their social media information when caregivers were present. During several informed consent meetings, caregivers reported their youth did not want them to see their social media profiles or know their usernames. It is developmentally appropriate for youth who are expanding their autonomy to want to keep their social media information private from their caregivers; however, depending on age and situation, data also suggest parents should be monitoring social media accounts by, for example, following their youth's account or becoming their "friends" (Khurana et al., 2015). Researchers must respect the youth's autonomy and privacy while balancing family's norms about their youth's social media use. First, researchers should address caregiver norms for social media involvement (e.g., when do caregivers follow and not follow their child's accounts, how much access caregivers have to their child's accounts). Second, explain potential issues of youth privacy and reemphasize the researcher's role in maintaining participants' confidentiality. Third, with the caregiver's approval, ask for youth's social media accounts during the assent process, when staff have the opportunity to speak to the youth independently from their caregiver. Finally, researchers must respect that even when a youth is active on social media, they may elect not to respond to the researcher's direct messages. For example, Instagram allows users to see when those they have previously direct messaged are active online. Researchers can recognize this without directly looking at the youth's profile and may elect to alter the frequency

of their contact attempts. In Project VOICES, when youth regularly read messages and did not reply, staff waited a few days before attempting to reach out again, or reached out through a different communication method (e.g., email, parents, backup contacts) to respect the youth's decision of whether or not to respond on social media. Researchers should strive for an ethical balance between maintaining high retention rates and respecting the autonomy of youth, while also considering family involvement for safety and open parent-child communication.

Conclusion

Social media offers researchers an opportunity to overcome barriers that have previously hindered the retention of youth in longitudinal research. It is imperative researchers remain vigilant to potential threats to safety and its impact on young research participants. In sharing our recommendations, we encourage researchers to evaluate the ethical issues that may arise when using social media as a retention strategy in order to justly expand their reach with youth and other underserved, hard-to-reach populations.

Best Practices

Researchers must create guidelines in accordance with the Belmont Report for ethical use of social media with youth participants at all stages of research (e.g., pre-consent, consent, post-consent; see Table 1). They must also ensure all research staff are familiar with rapidly evolving functionality, terms of service, and security level of all social media platforms used to communicate with youth.

Research Agenda

Ethical use of social media to engage and retain hard-to-reach adolescents, such as justice-involved youth, requires considerably more research. Future research should explore the barriers and facilitators to youth ages 13–17 providing social media information to researchers, as well as their attitudes regarding researchers communicating with them over social media. Furthermore, since communicating with minors for research purposes requires parental authorization, researchers must investigate family norms and expectations around parental involvement in teen social media use to ethically protect research subjects while respecting family boundaries.

Educational Implications

Enrolling youth in research requires the informed assent of the youth and the informed consent of their caregiver. Researchers must therefore ensure all staff receive training on how to clearly explain to families the guidelines for social media use in the research study for communicating with the youth, as well as the confidentiality measures in place for doing so. Furthermore, there must be distinct guidelines for explaining social media use during the informed consent (with caregiver) and youth assent processes to preserve autonomy of all parties and address family norms for youth social media use. Finally, researchers should receive training on the history and current context of the juvenile justice system to ensure use of social media in research does not contribute to further exploitation or marginalization of youth and families.

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Table 1.
Issues to Consider and Potential Recommendations Using the Belmont Report Framework.

Topic	Specific issue for consideration	Recommendations
Justice		
Justice-Involved Youth	Longitudinal studies of justice-involved youth often have low retention rates; youth move often, lose or have limited phone/data access, and change phone numbers. Social media accounts can be accessed from electronic devices even when youth do not have a cellular plan or personal cell phone.	<ol style="list-style-type: none"> 1 Pre-consent: Create a generic lab account on each social media platform for researchers to communicate with youth. 2 Consent: Ensure youth understand research staff will use social media as a means of communication so youth who have any issues with cellular service will still have the opportunity to complete the research.
Beneficence		
Data Breach	Social media sites may experience data breaches, which are out of the research staff's control. Devices used by staff for recruitment and retention purposes may be stolen or hacked.	<ol style="list-style-type: none"> 1 Pre-consent: Make sure all devices used by project staff comply with university encryption standards. 2 Project phase: Send messages that avoid using protected health information (names, addresses etc.) or limit that information if necessary. 3 Project phase: Log all important communications on a separate, secure server that includes any protected health information that may have been collected over text or social media. 4 Pre-consent/Project phase: Develop a plan to wipe data from devices used by research staff
Boundary setting	Youth may divulge personal information to research staff on social media	<ol style="list-style-type: none"> 1 Pre-consent: Outline how social media will be used in the project. 2 Consent: Be clear about research staff's role during the recruitment and consent process, including that the researcher will not be reachable beyond standard work hours. 3 Project phase: Make sure staff use social media only to speak about research.
Mandated reporting	Researchers may inadvertently see updates on social media, or youth may choose to share information with researchers, that could require follow-up	<ol style="list-style-type: none"> 1 Pre-consent: Know federal, state, website, and institutional reporting regulations. 2 Pre-consent: Establish internal disclosure protocols and ensure staff training around social media-specific reporting. 3 Consent: Inform caregiver/youth about mandated reporting during the consent and be specific about what that entails with regards to in-person disclosure and social media content. 4 Consent: Ask youth to type username into search bar and confirm the account without clicking on it. Clear search history immediately after recording username to secure, external database. 5 Project phase: Direct messages only. Avoid viewing participant profiles unless necessary, and use social media strictly as outlined in the project protocol.
Respect for Persons		
Youth's privacy	Youth may be unwilling to share their social media account information in the presence of their caregiver.	<ol style="list-style-type: none"> 1 Consent: Discuss how and why social media will be used as a method of communication with both youth and caregivers. Then, ask the youth independently for their social media account information during the assent, when research staff have a chance to talk to youth independently from the caregiver.

Topic	Specific issue for consideration	Recommendations
Youth's right to non-response	Sometimes youth are unresponsive because they do not want to talk to the research team.	<ol style="list-style-type: none"> 1 Pre-consent phase: Outline clear research protocols about how many times it is acceptable to reach out to participants using different methods during each time point. 2 Consent: Ensure youth and caregiver understand participation in the research project is voluntary. 3 Project phase: Send direct messages only and follow the outlined research protocol with regards to how many times to follow-up with participants for each time point. Allow multiple days between contacts when possible and engage youth using a variety of retention strategies. After multiple attempts via social media have failed, and it is clear youth are reading messages but not responding, then respect their boundaries. Wait to follow-up with youth until the next time point or send a final message indicating there is one last opportunity to complete research requirements. Allow the youth space to reach out themselves.