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Perceived Risks and Benefits in a Text Message Study of Substance Abuse and Sexual Behavior

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To inform ethical procedures for human subjects research using mobile health (mHealth), we examined perceived risks and benefits of study participation among emerging adults ($N = 54$) with drug use who completed text message assessments of substance use and sexual behaviors. Most participants reported comfort with participation and some reported perceived benefits, such as improved relationships. Perceived risks were infrequently reported, including negative emotions

and legal or financial concerns. In conclusion, participants from a vulnerable population reported few perceived harms of participation in longitudinal mHealth assessments of sensitive behaviors. Researchers should continue characterizing participants' perspectives on ethical aspects of mHealth research.

Keywords: emerging adults, mHealth, sexual behavior, substance abuse, text messaging

INTRODUCTION

Mobile technology tools such as text messaging, smartphone applications, and social media are increasingly used in research and treatment for substance use (Keoleian, Polcin, & Galloway, 2015; Molfenter, Boyle, Holloway, & Zwick, 2015; Quanbeck, Chih, Isham, Johnson, & Gustafson, 2014). Given the narrowing of the "digital divide" (Zickuhr & Smith, 2012), mobile health (mHealth) can enhance research, particularly among understudied populations. In addition to providing a mechanism for intervention, mHealth tools can be used to track behaviors closer to or in real time, thereby decreasing recall bias and enhancing ecological validity (Stone, Shiffman, Atienza, & Nebeling, 2007). Such data improve researchers' understanding of proximal factors associated with socially sensitive behaviors (e.g., substance use, sexual behaviors), which can inform interventions.

Empirical examination of ethical issues tied to the use of mHealth research for such sensitive behaviors has not progressed at the same pace as the implementation of mHealth technologies, which is especially relevant for vulnerable populations. Therefore, for the present article we explored the perceived risks and benefits experienced by urban emerging adults who participated in a prospective study involving 28 days of daily text message surveys of their substance use and HIV-related risky sexual behaviors.

Ethical Considerations in mHealth Research on Substance Use and HIV Risk

A key foundation in the ethical conduct of research dictates that the benefits of participation outweigh the potential risks encountered by participants (Emanuel, Wendler, & Grady, 2000) and that participants have accurate informed consent, including information about potential risks (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Investigators, in consultation with their ethical review boards, create risk and benefit descriptions for use in informed consent procedures, that are presumably influenced by available scientific evidence. Research qualifies as posing minimal risk if the "probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests" (HHS Protection of Human Subjects, 2010, §46.102 Para. i). Relatedly, guidance from the *Belmont Report* suggests that risks and benefits can occur across five domains: psychological, physical (i.e., health), legal, social, and economic. Behavioral studies typically qualify as minimally risky by ethics committees because the primary risk involves a potential breach of confidentiality. mHealth methods may introduce unique concerns about informational risk, for example, electronic breaches of privacy of confidentiality, that should be considered (Burden, Schuck, & Aubusson, 2012; Hall & McGraw, 2014).

Researchers have rapidly deployed mHealth technologies in substance use and HIV-related research, but very little empirical data exist on perceptions of risks and benefits among vulnerable populations participating in these studies. The small amount of available research suggests

that young participants have few concerns about risks. For example, when pilot testing a Facebook-based sexual health intervention, Bull et al. (2011) reported that during the informed consent process youth did not express concerns about sharing sensitive information or about what would be done with their data. In an online survey study of men who have sex with men (ages 18 and older), fewer than 2% of the sample indicated that their participation became inadvertently disclosed to someone else (Khosropour & Sullivan, 2011), and only one individual reported distress about this, but did not experience other harm.

Other research has addressed young people's perceptions of risks and benefits related to text messaging about other sensitive topics. Qualitative work with female adolescents indicated no "major concern" about privacy in reference to participating in a text message intervention for dating violence (Ranney et al., 2014). In another study, among 120 African American college students, risk beliefs and privacy concerns did not significantly limit intentions to use a text message-based sexual health intervention (Carter, Corneille, Hall-Byers, Clark, & Younge, 2015). Specifically, risk beliefs assessed in this study involved perceived uncertainty about and potential for loss of personal information provided over text message and privacy concerns included concern that private text message information could be misused or posted to the Internet. With regard to sexual health intervention delivery, compared to in-person group sessions, female emerging adults noted several benefits of text messaging such as convenience, comfort discussing sensitive topics, and privacy, with a few noting concerns about risk if a partner saw and questioned the text messages (Broaddus & Marsch, 2015).

Considering potential psychological risks in assessment research, Decker, Naugle, Carter-Visscher, Bell, and Seifert (2011) concluded that written questionnaires about sensitive topics rarely cause distress among participants, and research on sensitive behaviors also results in some perceived benefits (e.g., learning something about oneself, altruism/helping others). However, whether these findings extrapolate to mHealth assessments about sensitive topics remains unknown. To date, research has not documented emerging adults' experiences with other types of risks (e.g., economic, social, legal, or physical) related to their participation in mHealth research about socially sensitive behaviors. These early investigations provide initial data about participants' perspectives on the risks of sharing information about substance use or other sensitive behaviors via mHealth; however, research has not attempted comprehensive assessments across all domains of risks.

Empirical Assessment of Risks and Benefits in mHealth Research

Despite calls for evidence-based research ethics (Anderson & DuBois, 2007), ethics committees' and researchers' decision-making regarding risk level in the emerging area of mHealth typically occur in the absence of much empirical data. In this vacuum, ethics committee members' subjective beliefs can influence decision making (Klitzman, 2013). Known biases in human judgment and decision-making, such as familiarity, risk availability, affiliation, and affect, can exert undue influence (Pritchard, 2011). In addition, given the extent to which technologies have become increasingly available, emerging adults' perceptions of the risks associated with their participation in mHealth research may be markedly different than perspectives of older individuals charged with making determinations of risk level and authoring or approving consent forms. As Allison and colleagues (2012) suggested, the absence of data on ethically relevant aspects of mHealth research may lead to significant delays in research and could result in failure to approve important studies due to lack of familiarity or inaccurate perception of risks.

The Current Study

Given the lack of empirical data based on actual participants' experience in mHealth research for socially sensitive behaviors, we designed the current study. Using a retrospective survey design, our goal was to systematically assess the perceived risks and benefits of 18- to 25-year-olds who had just concluded participation in a prospective research study that assessed substance use and risky sexual behaviors on a daily basis, over a 28-day interval, via mobile phone text messages. Participants provided information on their perceptions of risk and benefits across the economic, legal, social, physical, and privacy domains. These data may be useful to researchers using mHealth data collection methodologies and could provide useful information as well to ethics committees that evaluate study protocols. Although the study was designed to be descriptive, we expected that participants' reports of risks would be minimal and that they would report some benefits of participation.

METHOD

Study Setting

Data were obtained from a subsample of participants completing a longitudinal research study (Bonar et al., under review). We initially recruited participants between November 2014 and September 2015 from the Emergency Department (ED) at Hurley Medical Center in Flint, Michigan. Hurley Medical Center serves about 85,000 patients annually and is the only Level 1 trauma center and public hospital in Flint, a mid-sized midwestern city with poverty rates around 3 times the national average (U.S. Census Bureau, 2015a, 2015b, 2015c, 2015d, 2015e). The study received Institutional Review Board (IRB) approval from both Hurley Medical Center and the University of Michigan. We sought and received a Certificate of Confidentiality from the National Institutes of Health.

Study Population

Patients 18 to 25 years of age presenting during day and evening recruitment shifts qualified for screening. Exclusion criteria included cognitive problems precluding fully informed consent (e.g., psychosis); medical conditions precluding informed consent (e.g., unconscious, intoxication); presenting for care that required immediate intensive mental health intervention (e.g., sexual assault, suicidal ideation); living with a significant other already enrolled in the study; hearing or visual impairment precluding participation, illiteracy, and/or inability to understand English; or ongoing participation in other longitudinal research at the site.

Study Protocol

Research assistants (RAs) identified potential participants in an electronic patient medical record system and approached them in waiting and treatment areas to complete a 15-min tablet-based self-administered screening survey. Participants provided written, informed consent and received a token gift valued at \$1 (e.g., candles, headphones).

Baseline eligibility criteria included past 4-week illicit drug use or nonmedical use of prescription drugs (opioids, sedatives, stimulants), past 4-week sexual intercourse without a condom, and having a cell phone with text messaging capability. RAs obtained separate written informed consent for the longitudinal study. The informed consent document included descriptions of the following: the purpose the study, voluntariness, tasks associated with the research (e.g., surveys, urine drug screens), duration of participation, descriptions of potential risks and measures taken to minimize risk, potential benefits to the participant and society, how to cease participation if desired, study-related costs/payments, description of the Certificate of Confidentiality, and IRB and study team contact information. Enrolled participants ($N = 111$) completed additional self-report measures on the tablet computer, followed by an audio-recorded, semistructured adapted Timeline Follow Back Interview (TLFB) for recent substance use and sexual behaviors (Scott-Sheldon, Carey, & Carey, 2010; Weinhardt et al., 1998).

RAs provided participants with a 5- to 10-min training on the text message survey protocol (including written and verbal instruction for ways to maximize privacy) and sent a practice version of the survey via text messaging. Participants received \$20 in cash for completing the baseline survey and the interview, \$5 cash for completing a urine drug screen, and a \$10 credit card gift card to offset the cost of the longitudinal text messaging. Baseline enrollment, data collection (including the TLFB interview), and text message training lasted 1–1.5 hr and took place in ED waiting, treatment, and discharge rooms where privacy could be ensured.

At 10:00 a.m. local time the morning after the ED visit, participants received a text message prompt to text “START” to begin the daily survey, a practice repeated for 28 straight days. Automated text reminders went out at 6:00 p.m. daily for incomplete surveys. Participants had until midnight to complete the daily surveys. Each day, 27 survey items inquired about the previous day’s behaviors and motivations related to marijuana use, alcohol use, other drug use, sexual behaviors, and affect (a copy is available in Bonar et al., [under review](#)). Survey questions used a branched structure, so that if participants did not report a target behavior (e.g., marijuana use) on a specific day they did not receive further questions about that behavior (e.g., motives for marijuana use). Instead, they received an equal number of questions assessing other daily behaviors (e.g., exercise, seeing friends).

Daily survey completion earned weekly compensation of \$2 per day, and a \$5 gift card bonus for participants who completed at least six out of seven daily surveys. Completed surveys generated two messages that stated the study phone number, compensation structure, and a reminder to delete study messages in order to maximize privacy. After the 28-day survey period, participants completed follow-up survey measures and a semistructured interview that mirrored baseline measures (compensation = \$25 cash), including the urine drug screen (\$5 cash compensation). In April 2015, we received IRB approval to add questions at the follow-up appointment to assess participants’ perceptions about the risks and benefits associated with participation; these provide the focus of the present analyses. The data presented come from the subsample ($n = 54$) of participants who completed the follow-up assessment after adding questions on perceived risks and benefits. Among these 54 participants, 48 follow-up assessments occurred in a mutually convenient community location (i.e., study hospital, fast-food restaurant) where privacy could be ensured. The remaining six participants completed follow-up procedures over the phone due to moving or other difficulties with meeting in person. The follow-up procedures typically lasted 1–1.25 hr.

Measures

Study assessments included questions assessing demographics, substance use, and sexual behaviors (Bonar et al., [under review](#)). The measures summarized next reflect the data presented in this article focusing on risks and benefits of participation.

Screening/Baseline Assessment

We adapted items from previous research (Johnston, O'Malley, Bachman, & Schulenberg, 2010; United States Department of Health and Human Services, National Institutes of Health, & National Institute on Drug Abuse, 2008, 2010) to assess demographics such as participants' age, gender, race, and educational status. We also screened participants to determine whether they had a cell phone (yes/no) and, if so, whether the phone had text messaging capability. Screening items assessed (a) the number of days of substance use (in the past 28 days; alcohol, marijuana, cocaine/crack, street opioids, hallucinogens, inhalants, methamphetamines, and nonmedical use of prescription substances [sedatives, opioids, stimulants]; Humeniuk et al., 2008; Smith et al., 1996; Smith et al., 2006; WHO ASSIST Working Group, 2002), and (b) past 4-week condom use with main and/or casual partners (Bonar et al., 2016; Johnston et al., 2010; Weinhardt et al., 1998). Participants were qualified for the study if they reported substance use (any drug other than alcohol), sex without a condom, and having a cell phone with texting capability. Eligible participants completed interviews about their substance use and sexual behaviors using a modified version of the TLFB interview for the day of the ED visit and the 28 days prior to baseline (Scott-Sheldon et al., 2010; Weinhardt et al., 1998).

28-Day Daily Text Messaging Surveys

Participants received daily prompts to complete a 27-item daily assessment containing questions that focused on substance use (e.g., quantity/frequency, motives) and sexual behaviors (e.g., number of partners, condom use, motives; Bonar et al., [under review](#)).

One-Month Follow-Up Assessment

In addition to repeating questions assessed at baseline, additional questions assessed perceptions of risks and benefits of daily text surveys. In consultation with scientists familiar with studying HIV and drug abuse research ethics and with an advisory group consisting of four emerging adults (two men, two women), we developed the following measures to assess perceptions of risks and benefits of participating in the current study. We integrated these items into the 1-month follow-up survey completed via tablet computer.

Informational risk and privacy measures. We asked participants the yes/no question, "Did anyone around you see the [study name] messages you sent or received on your phone, when you did not want them to?" For affirmative responses, follow-up items queried who saw the messages (e.g., spouse/significant other/sex partner, friend, parent(s), child(ren), boss/coworker). For each selection, participants rated on a 4-point Likert scale how bothered they were that the messages were seen by this person (response options: *not at all*, *a little*, *somewhat*, *very*

bothered). We asked those choosing at least “a little bothered” to indicate which types of viewed messages (i.e., drug use, alcohol use, sexual behavior) bothered them. We also asked if participants deleted the survey messages after each survey and whether they used a password/code on their phone during the study.

Perceived physical health risks and benefits. Participants received three items (separate for drug use, alcohol use, and condom use) asking them to compare their current behaviors to the month preceding enrollment and if they believed the surveys caused them to change these health-related behaviors. For example, “Did your drug use change because of the [study name] surveys?” with response options (a) No, the surveys did not change my drug use (or my drug use changed, but not because of the surveys); (b) I used less or quit using because of the surveys; or (c) I used more because of the surveys. Next, seven yes/no items queried whether participants engaged in various health-seeking behaviors “because of the [study name] daily surveys” (see Table 1 for items).

Perceived psychological risks and benefits. Participants rated how often they felt each of 12 emotion-related words when completing the daily surveys (response options from 0 [*never*] to 4 [*always*]). Negative emotions included upset, worried, angry, embarrassed, stressed, and paranoid. Positive emotions included pleasant, satisfied, hopeful, happy, and calm. The word *neutral* also appeared in the survey. We selected words by reviewing established affect measures (e.g., the PANAS-X; Watson & Clark, 1999) and through discussion with scientific and community advisors. We combined positive and negative items and computed Cronbach’s alphas (α positive = .84, α negative = .84). Second, we assessed the frequency of “desire, urge, or craving to use” alcohol, marijuana, and other drugs when completing the surveys with three items on the same 5-point scale. Third, we queried support-seeking for drug use, alcohol use, and sexual relationships with three yes/no items.

Perceived social risks and benefits. To assess potential improvement in or harm to social relationships, participants rated their responses to the item, “How much did completing surveys improve [harm] your relationships with each of these people?” We sought ratings for significant other/sexual partner(s), friend(s), parent(s), child/children, other family member(s), and “other.” Response options were on a 4-point Likert scale from *not at all* to *a lot* and included a “does not apply to me” option.

TABLE 1
Proportion of Participants Reporting That They Engaged in Health-Seeking Behaviors Due to Study Participation

<i>Health-Seeking Behavior</i>	<i>% (n)</i>
I decided to get treatment for drug use.	1.9 (1)
I decided to get treatment for alcohol use.	0.0 (0)
I talked with a sexual partner about using condoms.	11.1 (6)
I decided to find out more about how to stay safe when having sex.	16.7 (9)
I talked with a sexual partner about getting tested for HIV or sexually transmitted infections.	33.3 (18)
I decided to get tested for HIV or sexually transmitted infections.	31.5 (17)
My sexual partner and I decided not to have sex with anyone except each other.	35.2 (19)

Perceived legal harms. We asked participants to check all that apply from the following three statements reflecting (a) no legal concerns, (b) worry that the messages would cause trouble with police/probation, and (c) other legal concerns (with a fill-in response option).

Perceived economic costs and risks. Participants were reminded of the compensation structure for the study-related tasks; then, they were asked if participating cost any extra money. If so, they could select which portion of the study (e.g., texting, transportation to the follow-up appointment, etc.) caused additional costs, and we asked them to enter a corresponding dollar amount. We also asked (yes/no) whether (a) completing text surveys caused them to lose a job or hours at a job or any financial assistance they receive and (b) whether they believed the surveys could cause financial problems in the future.

Other perceived risks and benefits. Using items adapted from prior research (Fisher, 2003; Mustanski, 2011; Newman, Willard, Sinclair, & Kaloupek, 2001), participants rated their agreement with statements reflecting benefits of participation in the current study (see Table 2 for nine items) on a scale from 1 (*strongly agree*) to 5 (*strongly disagree*). Two items (Newman et al., 2001) assessed perceived overall risk/benefit ratio on the same Likert-type scale. At the end of the survey, we asked participants whether they experienced anything else good or bad due to their participation that the survey had not already addressed. Affirmative responses resulted in a computerized prompt for RAs to further inquire, in a semistructured manner, while audio-recording at the end of the interview.

Minimal risk. Six items assessed perceived comfort (i.e., more comfortable, about the same, less comfortable) in answering the daily text questions compared to “your typical day-to-day text

TABLE 2
Proportion of Participants Agreeing and Disagreeing With Statements Reflecting General Benefits of Participation

<i>Participation Benefit</i>	<i>Strongly Agree/ Agree % (n)</i>	<i>Neutral % (n)</i>	<i>Disagree/Strongly Disagree % (n)</i>
I felt like I was part of something important.	72.2 (39)	27.8 (15)	0.0 (0)
Participating made me feel like I am helping my community.	79.6 (43)	14.8 (8)	5.7 (3)
Participating helped me to have a way to share my experiences.	75.9 (41)	18.5 (10)	5.7 (3)
Participating helped me feel like people care about other young people like me.	87.0 (47)	13.0 (7)	0.0 (0)
Participating made me feel like I am helping other people in my age group.	83.3 (45)	14.8 (8)	1.9 (0)
Participating made me want to reach out to other people my age in my personal life.	54.7 (29)	34.0 (18)	11.3 (6)
Answering the text message questions made me feel better about myself.	49.1 (26)	35.9 (19)	15.1 (8)
Participating in [study name] made me feel supported.	52.8 (28)	41.5 (22)	5.7 (3)
I learned more about myself by answering the text message questions.	47.2 (25)	32.1 (17)	20.8 (11)
Overall risk/benefit perceptions			
Knowing what I know now, I would participate in this study again if given the chance.	79.3 (42)	17.0 (9)	3.8 (2)
If I knew in advance what participating would be like, I still would have agreed to participate in [study name].	88.7 (47)	11.3 (6)	0.0 (0)

message conversations” and “talking to a doctor, therapist, counselor, social worker, or case worker about these topics.” Items queried comfort separately for texts about drugs, alcohol, and sexual behaviors and were modeled after items used in previous research (Mustanski, 2011).

Adequacy of informed consent. After a brief heading listing information reviewed during the informed consent process (e.g., study purpose, possible risks/benefits, length of study, etc.), participants rated agreement from 1 (*strongly agree*) to 5 (*strongly disagree*), with the following statement: “I was well-informed about the potential risks and benefits of participating in the [study name].” Instructions for protecting the privacy of text messages (e.g., passcode/password on phone, complete survey in private, delete surveys from phone) were reviewed and participants indicated their agreement with the statement “The researchers prepared me well to protect the privacy of my text message surveys,” on the same 5-point Likert scale.

Data Analyses

The present analyses of quantitative data are descriptive in nature. We used SAS version 9.4 to calculate means, standard deviations, and proportions to summarize the responses to the questionnaires regarding perceived risks and benefits of participating in the text messaging study. Qualitative data from audio-recorded responses to flagged items assessing general risks and benefits were transcribed. Given that these items were infrequently endorsed ($n = 7$), we briefly summarize participants’ responses in the Results section next. The first author read these responses for key themes and coded responses by themes. A master’s-level research coordinator coded the responses and had 100% agreement with the first author’s assigned codes.

RESULTS

Subsample Characteristics and Daily Survey Completion Rates

Fifty-four participants completed at least one daily text survey and completed the follow-up measures containing items assessing perceived risks and benefits. In this subsample, the mean age at baseline was 22.2 years ($SD = 2.3$); 57% were male. About half (48%) were African American, 35% were Caucasian, and 17% reported another racial background. The majority were single (83%), and 57% reported receiving public assistance. Regarding education, 39% indicated having a high school diploma or GED, 24% reported completing some high school or working on a GED, 37% reported enrollment in college or completion of a college degree. On average, participants completed 20.1 ($SD = 7.1$) out of 28 daily surveys (71.4%), with 70% indicating that the surveys took 15 min or less on average. Almost all (96%) owned a smartphone; 67% had unlimited data plans, and 61% had unlimited text messaging plans.

Based on the TLFBS, participants used marijuana an average of 16.7 days ($SD = 11.2$) at baseline and 16.2 days at follow-up ($SD = 10.2$). They reported consuming alcohol an average of 3.7 days ($SD = 6.0$) at baseline and 3.4 days ($SD = 3.8$ days) at follow-up. Other drug use was infrequently reported among the sample at baseline with $M = 0.3$ ($SD = 1.2$) days of other illicit drug use and $M = 1.1$ ($SD = 4.1$) days of prescription drug misuse (at follow-up, $M = 0.3$,

$SD = 1.0$ and $M = 0.4$ and $SD = 1.2$ days, respectively). The majority of participants (74%) reported having one sexual partner during the 4 weeks prior to baseline, and 26% had multiple partners during this time frame. Most (87%) indicated having a “main” partner, and 88% reported unprotected sex with a main partner in the past month. Thirty percent reported they had a casual partner in the 4 weeks prior to baseline, with 83% of those reporting unprotected sex with a casual partner.

Informational Risks and Privacy

Only one participant indicated that someone else (a significant other/sexual partner) saw the study text messages when they did not want the messages to be seen. He reported feeling “a little bothered” by unintentional disclosure of messages pertaining to sexual behavior only, not drugs or alcohol. On other survey items this individual reported that he did have a password on his phone and that he always deleted his study messages. Notably, 69% of participants indicated always deleting their survey messages after daily survey completion, 24% sometimes deleted, and 7% never deleted. Almost two thirds (63%) had a password/code on their phone during the study.

Perceived Physical Health Risks and Benefits

Regarding perceived changes in health-related behaviors due to daily text questions, 87% reported no change in their drug use due to the surveys, 11% said they used less or quit using, and 2% ($n = 1$) indicated using drugs more frequently. This individual reported using marijuana on 7 days prior to baseline and on 24 days during follow-up. Regarding alcohol, 87% reported no changes in consumption due to the survey, whereas 13% reported decreased use. For sexual risk behaviors, nearly all (93%) reported no changes in condom use; however, 4% ($n = 2$) reported increased condom use and 4% reported decreased condom use because of the surveys. Among the two individuals reporting decreased condom use, one had unprotected sex on three of six sexual events at baseline but reported no sex events at follow-up. The second participant had seven out of seven unprotected sex events at baseline and only one sex event during follow-up, which was unprotected. As shown in Table 1, about one third reported that because of the surveys they engaged in discussions with their partner(s) about HIV/STI testing, decided to get tested, and/or committed to mutual monogamy with their partner. In contrast, no participants reported seeking alcohol treatment and only one reported seeking drug treatment because of the surveys.

Perceived Psychological Risks and Benefits

Regarding emotional valence while completing the surveys, participants’ mean ratings for positive emotions rated between “rarely” and “sometimes” ($M = 1.8$, $SD = 1.0$) and negative emotions rated between “never” and “rarely” ($M = 0.6$, $SD = 0.7$). Participants reported feeling neutral “sometimes,” which had a mean rating of $M = 2.3$ ($SD = 1.3$).

Although craving could potentially occur as a result of responding to questions about substances, few participants reported perceived craving; six (11%) individuals indicated craving for alcohol and 10 (19%) indicated craving for marijuana. Two participants (4%) reported craving for other drugs.

Few participants indicated that they engaged in support seeking because of their involvement in the text surveys. Two participants (4%) reported deciding to talk to someone about their drug use for support, one (2%) sought support related to alcohol use, and four participants (7%) discussed their sexual relationships with someone for support.

Perceived Social Risks and Benefits

Participants reported benefits across relationship types as follows: significant other/sex partner (32%; $n = 17$ of 53 responding), friend(s) (21%; $n = 11$ of 53), parent(s) (12%; $n = 6$ of 52), children (13%; $n = 6$ of 47), other family members (9%; $n = 5$ of 53). Few participants reported at least a little harm to the following relationships: significant other/sex partner (2%, $n = 1$ of 52 responding), friend(s) (6%, $n = 3$ of 52), parent(s) (2%, $n = 1$ of 52), and other family members (2%, $n = 1$ of 53). Note that some individuals did not provide a response for each relationship type because it did not apply to them (e.g., no children).

Perceived Legal Harms

Six participants (11%) worried that the text messages might cause a problem with police or probation officials, but otherwise participants reported no legal concerns. Due to a programming error, only 32 participants received an item assessing concern that government or police might access their responses. Most (66%) were not at all concerned, 22% were not too concerned, 13% were somewhat concerned, and no one was very concerned.

Perceived Economic Costs and Risks

Regarding economic costs of the study, only five participants reported incurring extra costs (one spent \$10 on extra text messages, four spent \$5–\$15 for transportation to their follow-up appointment). One participant reported that completing the text surveys caused lost hours at a job or a lost job. No one reported losing any financial assistance due to participation. All participants indicated they did not think the text surveys could cause any future financial problems.

Other Perceived Risks and Benefits

Responses about general benefits of research participation appear in [Table 2](#). Agreement was high with statements reflecting: feeling like young people are cared about (87%), helping other young people (83%), helping the community (80%), having a way to share personal experiences (76%), and feeling a part of something important (72%). About half of participants indicated agreement with wanting to reach out to others their age (55%), feeling better about themselves (49%), feeling supported (53%), and learning more about themselves (47%). Regarding participants' overall perceptions of risk versus benefits, most (79%) said they would participate in this study again if given the chance; similarly, 89% would have still participated if they knew in advance what participating would actually be like.

When asked if “anything bad” had happened because participants enrolled in the study, apart from content elicited in prior questions, all 54 participants responded “no.” Seven (13%) individuals reported that something “good” occurred. Qualitative interview data from the participants revealed themes shown in [Table 3](#), accompanied by illustrative quotes. As shown,

TABLE 3

Participants' ($n = 7$) Qualitative Responses Describing Additional Perceived Benefits of Study Participation

<i>Theme and No. of Participants Whose Responses Reflected Each Theme</i>	<i>Illustrative Quotations</i>
Increased self-knowledge ^a	“A lot of the questions that would ask like why I do certain things like made me actually think of why I did certain things so, I don't know, I feel like, not in a major way but just in a little bit, helped me realize what my reasonings are behind why I choose to drink or why I choose to have sex. I just kind of understand myself a lot better. And then I feel like that helps me explain myself better to other people.”
Reducing risk behavior ^b	“I cut back on smoking weed and found an alternative way to receive the same benefits that weed gave me without getting high. . . . I guess this kind of opened my eyes to get me to explore other options and ask my doctor, y'know, what other routes I can take besides getting high all the time so I'm not just fried all day long.”
Financial benefits ^c	“And after losing my job after the one day I was in the hospital, the money that you guys gave me each week really did help me drive around, look for a new job, use it for gas. So it really did help me out a lot.”
Increasing other positive behaviors ^d	“When I would get up in the morning and do my text or whatever and if it, say, asked me if I went out and looked for a job or something like that, it would instill in me that morning to, hey, you know what, I should probably go out, I haven't done it in a day or two or something like that and went out and dropped off some resumes or something like that.”
Altruism ^e	“I felt like that helped improve me all the way around because I really want to help you all understand what goes on and how what we might think as being younger, and we might, could get help with some of the things . . . so I enjoy it, helping.”
Social support ^f	“I felt like I could talk, let people know what's really going on, that everything was confidential and nobody else was going to know but me in the text surveys, so that was awesome to be able to talk to someone about stuff like that”

^a $n = 3$, ^b $n = 2$, ^c $n = 2$, ^d $n = 1$, ^e $n = 1$, ^f $n = 1$.

some participants found the study payments beneficial in assisting with their daily needs, others commented that learning more about themselves and their patterns of behavior was a benefit, and a few thought that the text messages helped them reduce use. Another participant found the filler items, which asked about daily activities (e.g., work, exercise), to be beneficial because an item about looking for work served as a prompt to apply for jobs.

Adequacy of Informed Consent

All participants agreed (9%) or strongly agreed (91%) that they felt “well informed” about the risks and benefits of the daily text surveys during the informed consent processes.

Regarding specific instructions during consent and text message training, 98% of participants indicated agreement/strong agreement that they felt well prepared by the research staff to protect the privacy of their text surveys (one individual chose “neutral” on this item).

TABLE 4
 Participants' Ratings of Comfort With Text Messages by Subject Type Compared to Typical Daily Life Events

<i>Message Subject</i>	<i>More Comfortable % (n)</i>	<i>About the Same % (n)</i>	<i>Less Comfortable % (n)</i>
Compared to day-to-day text message conversations			
Drugs	40.7 (22)	53.7 (29)	5.6 (3)
Alcohol	38.9 (21)	57.4 (31)	3.7 (2)
Sexual behavior	29.6 (16)	51.9 (28)	18.5 (10)
Compared to medical/therapist visit			
Drugs	63.0 (34)	35.2 (53)	1.9 (1)
Alcohol	63.0 (34)	35.2 (19)	1.9 (1)
Sexual behavior	57.4 (31)	38.9 (21)	3.7 (2)

Comfort With Surveys Compared to Typical Daily Events

As shown in Table 4, for all topics most participants (82%–98%) indicated they felt more comfortable or at about the same comfort level answering the text message survey items compared to their typical daily text message conversations with others, or with medical or therapy providers. Of note, 19% of participants indicated that texting about their sexual behaviors felt less comfortable than their typical texting topics, but only 4% reported that texting about sex felt less comfortable than discussing this topic with a medical/therapy provider.

DISCUSSION

In the present study, we assessed the research-related perceived risks and benefits among emerging adults who completed daily mHealth-based text message assessments of drug use and sexual behaviors. As hypothesized, our findings demonstrate that very few emerging adults who used drugs experienced harm associated with completing a text message-based study of sensitive behaviors; instead, perceived benefits (e.g., altruism) were more often reported than risks. Together, these novel data provide support for the use of text messaging as a data collection methodology for sensitive behaviors among emerging adults, although research is needed to determine whether patients would have similar perspectives about the use of these methodologies as part of clinical care.

Although harms were infrequent, concerns were mentioned by a few participants. Specifically, a few individuals reported discomfort with study text messages and/or personal financial costs. Although nearly all participants felt appropriately prepared for the research study, some reported experiencing negative emotions (although not frequently) while completing the surveys; however, positive emotions were endorsed, too. Legal concerns were mentioned by approximately one in nine participants, probably related to the fact that they were asked to report on illegal drug use. In this regard, such concerns may explain the negative affect experienced by some participants (e.g., worry, paranoia). It is unclear the extent to which such concerns could lead to underreporting, as the number of participants with legal concerns was too small for statistical comparison, although completion rates were similar between those with and without legal concerns. Although less than one in five participants reported increased craving due to

substance-use-related questions, only one participant reported perceiving that he or she had increased their substance use from baseline to follow-up. Similarly, only two individuals reported using condoms less frequently due to the surveys; both had fewer sex events during follow-up compared to baseline and may have perceived using condoms less frequently due to decreased sexual activity.

It is important to state that the text message study was not designed as a behavioral intervention and that participants were not randomized and compared to those in a control group. When queried, a small minority of participants reported perceptions that they had made health-related behavioral changes due to their study participation. For example, some participants reported perceived health-seeking behaviors associated with the sexual behavior text message questions (e.g., seeking HIV/STI testing), but few reported such behaviors related to substance use questions (e.g., seeking treatment). This may be due to limited access to substance use services in the community, stigma associated with seeking treatment, and/or low levels of motivation to change. Comparatively, participants may encounter fewer barriers to acting to improve their sexual health and relationships. For example, HIV/STI testing may be free and accessible at local health clinics, and other behaviors such as talking to a partner about getting tested have no financial cost. These findings are consistent with the notion of assessment reactivity (Clifford & Davis, 2012; Simpson, Kivlahan, Bush, & McFall, 2005) and increased mindfulness; however, in the absence of an experimental design it cannot be concluded that responding to the text message survey items resulted in actual meaningful or sustainable behavior change. Further, the majority of participants reported no changes in their health-related or health-seeking behaviors, supporting the need for interventions in this population.

Findings from this study can inform future mHealth research procedures used by researchers and approved by ethics boards. First, this text message study was determined to be no more than minimal risk by two IRBs. Participants' survey responses supported this designation. Specifically, they felt as comfortable or more comfortable completing the daily texts about substance use and sexual behavior as compared to their day-to-day text messaging conversations, or to discussing the same topics in a healthcare-related visit. Similarly, participants most often felt "neutral" when completing the daily surveys, and positive emotions were reported more frequently than negative emotions. Their responses are consistent with the notion that they did not encounter risks greater than those normally occurring in daily life. Of course, findings from this single study require replication and extension to other populations. For example, individuals less familiar with technology (e.g., older adults) or late adopters of technology may be less comfortable with or perceive greater risks associated with providing data on sensitive behaviors via text messaging. Others may be more or less concerned with providing sensitive data via texting as part of clinical care.

Given the relatively few harms reported, results from this research suggest that participation in a daily study where participants are asked to share information about socially sensitive behaviors via mHealth modalities is acceptable to participants. Further, some individuals engaged in strategies to protect their privacy during the study (e.g., deleting messages, using a passcode); however, others did not and thus presumably felt less concerned about a breach of privacy. Despite these encouraging findings, it is also important to note that a few participants experienced discomfort and/or perceived harm from participation. There are always unanticipated risks to human participants in research, and consent procedures must include a disclosure of this fact. These findings also have broader implications for the use of mHealth to assess and

intervene upon sensitive behaviors in real-world, clinical settings. For example, clinicians considering these methodologies may review potential risks, including potential privacy and HIPAA-related concerns, financial costs to patients' data or text messaging services, and the risks of increased craving due to repeated assessments, while providing patients with informed consent and balancing potential risks against clinical benefit and utility.

Despite these potential implications and the useful knowledge gained from this study, there are limitations to consider. First, the assessment of risks and benefits was added for only a subsample of the parent study, thus the sample size is relatively small and not all longitudinal study participants' views are represented in these results. Due to the 1-month follow-up time frame, any harms or benefits that could have occurred after this point were not assessed. In addition, our measurement of risks and benefits was conducted using measures lacking established psychometric properties; however, to our knowledge no such comprehensive measures exist, likely reflecting the need for such measures to be tailored to the specific study methodology. Because these data were obtained from self-report, response biases (e.g., recall errors, social desirability) may have affected participants' answers; this concern is somewhat alleviated by study procedures in which participants self-administered surveys on tablet computers.

The present results based on participants' perspectives support future mHealth research studies using text messages to assess sensitive behaviors among vulnerable populations given the infrequent report of perceived harm and participants' perceptions of benefits. Future studies assessing risks and benefits from participation in mHealth studies are needed to provide additional information about unanticipated risks and benefits to better inform future participants and to improve research designs to minimize risks. Such data could facilitate accurate perceptions of risk and benefit and, most important, could enhance informed consent procedures. Although participants' perceptions of risks and benefits are often underassessed, researchers and ethics board members should consider these perspectives in concert with information from other sources (e.g., clinicians, data security experts, legal counsel).

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