

PERSONS WHO INJECT DRUGS' PERSPECTIVES ON THE RISKS AND BENEFITS OF PARTICIPATION IN A MOBILE HEALTH STUDY OF POLYDRUG USE

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Acknowledgements

Participants

Collaborators

- Drs. Richard Garfein & Richard Armenta
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Mobile Health (mHealth) Research

- mHealth research leverages the capabilities of mobile devices to monitor behavior and deliver health care
- The harms and benefits of using mHealth approaches have yet to be systematically assessed
- Best-practice guidelines are not yet available; such guidelines are particularly salient for research with vulnerable populations

Potential Risks in mHealth

- Theft of devices
- Stigmatization
- Participant burden
 - Behavioral assessments 2-5 times per day¹
 - Either pre-specified or random times^{1,2}
- Fairly generous compensation structures²⁻⁵

Study purpose

To explore participant perspectives on the potential risks and benefits associated with participation in a hypothetical mHealth study of polydrug use

Methods: Scenario

- Participants were informed they would have the opportunity to help researchers design a longitudinal study of polydrug use
- Polydrug use types
 1. Simultaneous
 2. Sequential
- Polydrug use is associated with negative health outcomes including drug overdose

Methods: Recruitment

- Participants were:
 - 1) ≥ 18 years of age
 - 2) Reported injecting illicit drugs in the past month
 - 3) Reported weekly polydrug use
- Recruitment occurred in San Diego, CA (N=18) and Philadelphia, PA (N=20)
- Participant demographics were similar in both cities
 - Mean age 44.5 years, 64% male, 56% white, 56% homeless

Methods: Data Collection & Analysis

- Completed simulations of a cell phone diary
- Interviewed about experiences

“How do you think completing diaries might impact your life?”

“Can you think of any bad [good] things that could happen as a result of answering the questions over time?”

- Qualitative analysis of interview texts for ethical themes



Findings: Potential Benefits

- All participants reported potential benefits associated with participation
- Many felt repeated behavioral assessments would be a positive influence
- Most indicated that the questions were not harmful to their mental or behavioral states
- Use of phone as economic benefit

Participant Perspectives on Benefits

Reflexivity

“It would make me reflect on my day-to-day activities...make it more clear as you’re answering the questions where you should be putting in effort to make a change. It’s like putting a mirror in front of you.”

(Steve, 43, San Diego)

Participant Perspectives on Benefits

Being recognized as an expert

“[If] you take heed to what I talk about...I’ll feel like, alright, I did something...I’ll feel good about myself...It makes me want to do other things to make me feel good about myself.”

(Rana, 34, San Diego)

Participant Perspectives on Benefits

Altruism

“If what we’re doing...is going to stop someone from getting on...or help someone get off heroin, let’s do it. I wouldn’t wish this on anyone.”

(Eddie, 65, Philadelphia)

Findings: Potential Risks of Participation

- Physical risks arise from carrying a study cell phone
- Behavioral and psychological risks stem from repeated disclosure of mood state or behavior
- Social risks were those that might arise if law enforcement obtained any information about participants
- Informational risks arose from unintentional disclosure of drug use or other stigmatized information more broadly

Participant Perspectives on Risks

Theft & the potential for physical risks

“It’s hard to keep stuff of value when you’re using drugs, you know what I mean? Some people have it harder than me, when you’re living with vandals you don’t have no security. I know people that wouldn’t sell their stuff and they get their stuff stolen just cause they nod out... [Once,] I fell asleep and when I woke up, I didn’t have my money. I didn’t have this. I didn’t have that.”

(Carlos, 40, Philadelphia)

Participant Perspectives on Risks

Triggers & potential psychological risks

“If a participant is constantly being reminded that they’re in the bottom of the barrel and feeling depressed, constantly having to go over how they feel could make them more anxious and want to commit suicide or overdose.”

(Mike, 40, Philadelphia)

Participant Perspectives on Risks

Mitigating harms

“Say, ‘Listen, you’re gonna have to constantly monitor your mood. I want you to be aware that during the course of what’s going on in your life, if something bad was to occur that would make you have a bad mood or irritated, that you need to be aware you will be constantly reminded of it.”

(Mike, 40, Philadelphia)

Limitations

- Small sample size
- Hypothetical study
- Magnitude of risks/benefits could vary
- Additional risks/benefits could surface

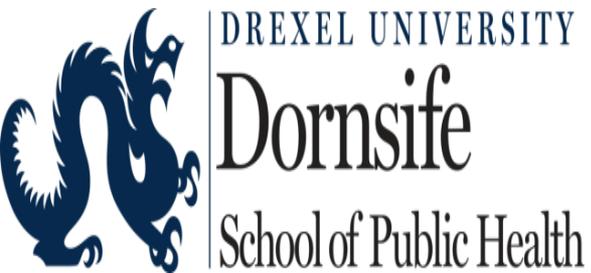
Conclusion

- Engagement in mHealth might confer important benefits
- Risks described as unlikely, however, it remains important for researchers to implement reasonable safeguards
- As mHealth becomes more widely used, it will be important to conduct research on harms and benefits
- Findings from this exploratory study are promising

References

1. Shiffman S. Ecological momentary assessment (EMA) in studies of substance use. *Psychological Assessment*. 2009;21(4):486-497.
2. Hensel DJ, Fortenberry JD, Harezlak J, Craig D. The feasibility of cell phone based electronic diaries for STI/HIV research. *BMC Medical Research Methodology*. 2012;12(1):75-86.
3. Johnson EI, Barrault M, Nadeau L, Swendsen J. Feasibility and validity of computerized ambulatory monitoring in drug-dependent women. *Drug and Alcohol Dependence*. 1/1/ 2009;99(1–3):322-326.
4. Oranskya M, Fisher CB, Mahadevana M, Singer M. Barriers and Opportunities for Recruitment for Nonintervention Studies on HIV Risk: Perspectives of Street Drug Users. *Substance Use & Misuse*. 2009;44(11):1642-1659.
5. Gunn JKL, Roth AM, Center KE, Wiehe SE. The Unanticipated Benefits of Behavioral Assessments and Interviews on Anxiety, Self-Esteem and Depression Among Women Engaging in Transactional Sex. *Community Mental Health Journal*. 2015; in press.

Questions?



Next steps: Roth & ethics research

- Paper outlining harms in press (waiting proofs)
- Paper outlining potential benefits (in preparation)
- Development of best practice guidelines in conjunction with other RETI fellows including Dr. Erin Bonar
- Paper describing mechanisms underlying improvements in mental health among sex workers completing a mHealth study of their sexual lives (in preparation)