Creating a Community with Mothers with Mental Illness Using Opioids

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- MMHRC – Key Partner

- No conflicts or disclosures
Objectives

• Following the presentation, participants will be able to explain the rationale behind mothers’ engagement in various stages of research.

• At the conclusion of the presentation, participants will be able to describe two different strategies for engaging mothers with mental illness and opioid misuse in research development, implementation and the dissemination of findings.
• Closing the gap between research & advocacy
• Social media & online – research4moms.com, blog, Facebook, Twitter, Instagram
• Patient Expert Advisors – share content, connect with community, involvement in research projects
Mothers, Mental Illness & Opioids Project

• To engage mothers & researchers in virtual community development (research4moms.com)
• To provide online resources & infrastructure for knowledge exchange
• To implement a tailored, in-person community engagement studio model
Theoretical & Conceptual Building Blocks

- Knowledge exchange
- Virtual teams, collaboratories
- Stakeholder engagement
- Co-creation of research
- Open Innovation
Research Questions re: Digital Technology

• Digital vs. in-person therapies?
• Common elements of therapy in digital interventions?
• Increase reach & access?
• Overcome isolation?

(Hollis et al., The Lancet Psychiatry, 2018)
How to engage mothers with opioid use & researchers in the MMHRC community?

• How to address mothers’ concerns, e.g., privacy, confidentiality?
• How to provide researchers with community engagement resources & support?
• Benefits & costs of virtual vs. in-person connections?
Community Engagement Strategies

• Social media initiative
  • Categorize, schedule & document postings
  • Manipulate the schedule
  • Explore response patterns with analytics
  • Dive deeper into comments
  • Engagement: likes, replies, shares & retweets

• Crowdsourcing with mothers & researchers to develop Research 101 and Mothers 101 resources

• Community Engagement Studios – in-person model
Social Media Summary Data so far...

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Social Media Example:

Personal Experience - MH
Research - Opioids

Social Media Example:

CDC: Number of Pregnant Women Addicted to Opioids Skyrocketed in 15 Years

Opioid addiction continues to impact the U.S. population at epidemic levels, and at a major cost to individuals and families as well as public health officials and even the labor force.

http://www.nytimes.com/2015/09/14/opinion/...
Example: Popular Press - Opioids

"Stigma is a common barrier to care for pregnant drug users. Many people at the needle exchange said doctors treat them poorly, they're brusque or don't give enough local anesthetic, for example when they realize they are injection-drug users." http://ow.ly/YZdl30IEopV

"You get what you deserve if you can't stop drugs for your baby or get on birth control to prevent getting pregnant while you're using don't deserve sympathy"

"Maternal Mental Health Research Collaborative - MMHRC This comment isn't helpful or necessary and is EXACTLY why mothers who use drugs have issues accessing care."

"Maternal Mental Health Research Collaborative - MMHRC then remove it if you don't like it. I stand by it. I don't believe in coddling people. Addiction is a crutch and making it seem like it's not in their power to change it is a disservice to people who actually struggle with addiction like me and like me, those who have overcome it and carry on with productive lives and become great parents. The only enemy is yourself the only one you can blame for your addiction is yourself, no matter what you went through or why you use its your fault entirely, you chose poor coping mechanism, chose to use and not get healthy and not seek treatment for mental health issues rather than using. If you feel guilty and ashamed that is on you and you probably should because you know what you're doing isn't right. If you find people judging you maybe it's not them it's you and your choices, taking responsibility is what needs to happen not a pat on the back and a good job. Sometimes the best thing that can happen to an addict is losing everything and especially those who enable the behavior by not setting ultimatums, the best thing that can happen is having people refuse to be around you and support your addiction. Sometimes its a kick in the gut but the truth isn't pretty and reality is harsh and a good dose of reality is what people need when it comes to addiction."

THEATLANTIC.COM
Pregnant and Addicted to Heroin
In Fresno County, drug use is about two times the state average. Pregnan...
Community Engagement Studios (CES)

- Promotes stakeholder input into research
- Community Navigator – orients mothers & researchers to CES process
- Facilitator - Guides group interactions
- Mothers provide input into researchers’ questions
Crowdsourcing

- Mothers generate questions about research
- Researchers submit questions for mothers
- Researchers & mothers respond
- Responses posted
- jnicholson@brandeis.edu
- mazel@brandeis.edu
Do mothers have to share things they might consider personal?
Thanks!
Volunteer to record a video or pose a question to mothers.
Contact us:

• [jnicholson@brandeis.edu](mailto:jnicholson@brandeis.edu)
• [mazel@brandeis.edu](mailto:mazel@brandeis.edu)
• [shannon@research4moms.com](mailto:shannon@research4moms.com)
• [Yaara@temple.edu](mailto:Yaara@temple.edu)

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