

Issue Brief

Mothers, Mental Health and Opioids: Engaging with Researchers @research4moms.com

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Abstract

Co-occurring mental illness and opioid misuse is a significant and rising public health issue for mothers in the US. In recent years, opioid misuse during pregnancy has increased a great deal.¹ Only a small subset of mothers will seek and receive help for themselves and their children.^{2,3} When it is sought, treatment is not necessarily targeted or tailored to meet the needs of mothers and families.¹ We are bringing mothers and researchers together to promote a shared understanding of mothers' experiences and needs, and to inform research that is relevant, meaningful and effective, with the goal of improving mental health/opioid misuse treatment and outcomes for mothers and children.

Key Words: mental health, opioids, mothers, community engaged research, social media

Creating Opportunities for Engagement

Co-occurring mental illness and opioid misuse is a significant and rising public health issue for mothers in the US. The prevalence of opioid use among women of child-bearing age is high.¹ Recent data from the National Surveys on Drug Use and Health indicate that about 21,000 pregnant women aged 15 to 44 misused opioids in the past month.⁴ The goal of the Mothers, Mental Health and Opioids initiative is to create an engaged community of mothers with lived experience of mental health challenges and opioid misuse and interested researchers to promote future partnerships in the development and study of treatment models, and the dissemination of research findings. Our thinking is that, if mothers and researchers work together to develop and study potential supports and solutions, the results will have greater impact – both in terms of a greater likelihood of effectiveness as well as a greater likelihood of being used to inform the decision-making of mothers and health care providers. The project builds on the Maternal Mental Health Research Collaborative (MMHRC; <https://research4moms.com>).

The Mothers, Mental Health and Opioids team is working together to create an online community of mothers through the MMHRC website and social media, including Facebook, Twitter, Instagram, LinkedIn and Pinterest. Our efforts now focus on bringing researchers together with mothers, both in online spaces and in-person, to foster the exchange of information and the co-creation of research. (See our project page on Research Gate: <https://www.researchgate.net/project/Creating-a-Community-with-Mothers-with-Mental-Illness-Using-Opioids>.)

Specific Project Objectives

1. Engage researchers and mothers in the research4moms.com online community using non-stigmatizing, interactive social media strategies to help mothers and researchers exchange information about their experiences and needs and support each other in their efforts to address mental health conditions and opioid misuse personally and professionally.
2. Develop online learning resources for mothers (Research 101) and researchers (Mothers 101), with representative mothers and researchers addressing questions generated through crowdsourcing. Mothers have provided questions for researchers like, “How do you decide what to study?” and “What do you do with the data I provide? Will anyone else see my information?” Researchers want to know answers to questions like, “What makes you as a woman/mother comfortable with speaking out about opioid use disorders?” and “If you participate in a research project, would you like to find out about results? What’s the best way to provide them to you?”
3. Implement in-person, tailored discussion sessions with mothers and researchers, to brainstorm and provide feedback on research ideas. We are working with community-based clinics and organizations to bring together mothers and prepare them for research partnerships and participation. We are approaching research colleagues to invite them to participate in preparing for and meeting with mothers to talk about their work in plain language, that is, talking about their work in ways that are understood by and have meaning to mothers who are non-researchers. We will learn from our experiences to prepare a guide for others who want to take advantage of this approach to inform their work.

First Steps

The MMHRC is an active presence on Facebook, Twitter, Instagram, and more recently Pinterest and LinkedIn. We have seen an increase in MMHRC Facebook followers to over 14,000 in the last few months. Part of our work includes implementing different content sharing strategies that see us posting a wide range of articles, photos, illustrations, and other visual content. Tracking responses to these postings allows us to tailor our content to include items that we know will resonate and build trust with our audience. While much of our community’s feedback is positive and supportive, we are also moderating and curating responses that are negative. From this work we have learned that barriers faced through the project’s social media engagement strategy may mirror barriers to treatment in the “real world”, such as stigma and shame.

Future Directions and Implications

Community-engaged Research

The Mothers, Mental Health and Opioids initiative has the potential to contribute to the way we do research, as well as the research we do. We are actively embedding design thinking practices into a participatory approach to research.⁵ A participatory approach to research implies that, by involving people dealing with health challenges in developing solutions to their problems, the solutions will more likely be used.^{6, 7} “Design thinking” involves bringing person-centeredness into the process and tells us how to do this by: (1) understanding the experience and needs of the user; (2) brainstorming to come up with a broad range of possibilities; and (3) building and testing out concepts to fit a solution to the problem.⁵ The unique contribution of our project is that we are considering both mothers and researchers as end users of the knowledge we hope to generate.

Peer Support

Online communities may take on the traditional role of peer support *for* mothers with mental health conditions and opioid misuse *by* mothers. With 24/7 availability and accessible information reviewed by the research team and other stakeholders, online communities have the potential to provide peer support via social networks.⁸ We are creating opportunities to explore the potential barriers to and contributions of online peer supports for mothers as compared with in-person peer supports.

Online opportunities to connect may be equally beneficial to researchers, as virtual collaborations become

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the norm. This has routinely involved researchers with other researchers. Our intention is to try out strategies for building networks of researchers with mothers, and to provide recommendations for creating online partnerships for stakeholders in other domains of health services research with other health conditions.

What You Can Do

We invite you to join this initiative on behalf of mothers with lived experience of mental health conditions and opioid misuse, the researchers who are committed to addressing these issues, and our policy and practice stakeholders actively working to craft solutions. We would appreciate your active participation in the MMHRC social media spaces. Follow us on [Facebook](#), [Twitter](#), [Instagram](#), [LinkedIn](#), [Pinterest](#) and [Research Gate](#). We encourage you to contribute information – scientific and experiential – and support the contributions of others to build the knowledge base and inform health decision-making to improve outcomes for all.

Ethical Considerations

The ethics of using publicly available social media data, especially regarding mental health and substance use, require careful consideration. Previous researchers have suggested avoiding using direct quotes from study participants, not disclosing identifying information of the user, and providing a clear justification for using the data.⁹ The MMHRC is a publicly accessible online community and the Mothers, Mental Health and Opioids project is specifically designed to bridge the gap between researchers and individuals with lived experience. This is stated in the MMHRC community guidelines, and participants on our social media pages acknowledge this mission when they join the MMHRC social media platforms.

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