

# Finding support outside the clinic—the intersection of instagram and miscarriage

December 9 2019, by Karuna Meda

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About 10-20 % of all known pregnancies unfortunately end in miscarriage or the loss of a fetus. Despite its common occurrence, there is still a lot of stigma surrounding miscarriage and many women find that their emotional and psychological needs are unmet as they go through a devastating grieving process. In 2014, Dr. Jessica Zucker, a clinical psychologist specializing in women's reproductive and maternal mental health, started a campaign on social media using the hashtag #ihadamiscarriage to address this cultural silence.

Amy Henderson Riley, DrPH, MCHES, assistant professor at the Jefferson College of Population Health, came across this campaign when she was seeking out support for her own experience. As a health communication researcher, she was struck by the breadth and honesty of people's stories on this public platform. In order to find out more about what women and men were sharing about their miscarriage experiences, she teamed up with Rebecca Mercier, MD MPH, assistant professor and OB-Gyn doctor at Thomas Jefferson University to conduct a qualitative research study on 200 posts of text and pictures shared by Instagram users. They published their findings in *Obstetrics & Gynecology* on December 5.

Their study found that the content posted by Instagram users included rich descriptions of the medical and physical experiences of miscarriage, and the emotional spectrum of having a miscarriage and coping with those emotions, the [social aspect](#), and family identity.

"I find it endlessly fascinating that women are opening up to essentially strangers about things that they hadn't even told to their partners or families," says Dr. Riley. "But this is how powerful this community is."

*"I think it's normal to be pissed at your body—especially when it feels like it failed you and even more so when it feels like it keeps failing you"—post #130.*

"What surprised me the most was how many women and their partners identified as parents after their miscarriage and how the miscarriage lasted into their family identity after a successful [pregnancy](#)," says Dr. Mercier. "The extent to which this loss affects women and their families, and the longevity of their grief is a blind spot for clinicians."

*"Every time I see a pregnant woman, I'm reminded of what should have been"—post #104.*

These personal accounts also provided insight into patients' perspectives of typically defined experiences. For example, in the clinic, the typical definition of recurrent pregnancy loss is after three pregnancies. However, the researchers found that many patients who had had two or more miscarriages identified with having recurrent pregnancy loss.

"There is a push in the OB-Gyn field to redefine recurrent pregnancy loss. The findings from this study could help the field come to a new consensus," says Dr. Mercier. "This is a clear example of looking at a clinical problem through a public health lens and why this collaborative research is so important," adds Dr. Riley. "These testimonials can inform how providers care for patients with very specific needs, like recurrent pregnancy loss, and address it sooner rather than later."

"As clinicians, we're trained to provide for women's medical needs as they go through a miscarriage. We don't always have the tools to address

the emotional needs," says Dr. Mercier. "I'm hoping that this study will encourage clinicians to point patients to [social media](#) as a potential coping tool, as well as to approach this subject with bereaved and expecting parents with more respect and empathy."

Social media is becoming a common avenue for patient testimonials. For example, the social media platform TikTok has recently become a home for some users to make videos sharing their personal health struggles. The platform has also become an avenue for doctors to interface with their patients and rapidly disseminate information from vaping to reproductive health. Dr. Riley cautions that more quantitative and qualitative studies, like this one, are needed to properly evaluate the benefit to both patients and providers.

"As far as we know, this is the first study to look at the intersection of Instagram and [miscarriage](#)," says Dr. Riley. "But this is a drop in the bucket. Social media platforms are evolving rapidly and theoretically grounded research must follow."

**More information:** Rebecca J. Mercier et al, Instagram Users' Experiences of Miscarriage, *Obstetrics & Gynecology* (2019). [DOI: 10.1097/AOG.0000000000003621](#)

Provided by Thomas Jefferson University

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