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Online Support Groups for Perinatal Loss: A Pilot Feasibility Study for Women of Color

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Abstract

We tested use of an online support group for women of color who had experienced stillbirth or early infant loss. We recruited recently bereaved mothers and asked them to participate in an existing online community for pregnancy and infant loss hosted on a commercial platform. Participants were asked to go online at least three times weekly for 6 weeks to read posts. Using a mixed-methods approach, we assessed attitudes toward online support, mental health, and experiences pre- and postintervention using written surveys and a brief phone interview. We used summary statistics for quantitative data and a deductive coding approach for qualitative data. Twenty participants completed the study. We found nonsignificant improvements in all four mental health domains (depression, post-traumatic stress disorder, moderate-severe generalized anxiety, and perinatal grief). Women reported the group allowed them to help others and feel less alone. They also reported that at times, posts could increase the intensity of their loss emotions. This study demonstrated feasibility to recruit, retain, and track participation in an online support group for perinatally-bereaved mothers of color. Although the study was not powered for outcome, all mental health measures showed nonsignificant improvements, suggesting value in further investigating online social support for improving women's mental health after perinatal loss.

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Keywords: online communities, social media, perinatal loss, pregnancy loss, Internet support groups, bereavement

Introduction

NEARLY 80 PERCENT of U.S. adult women use social media, and millions access informal social support through online communities (OCs) such as message boards, forums, support groups, blogs, and vlogs.¹ Among U.S. adults, 3.6 percent reported participating in Internet support groups to help with mental health through social support.² In the United States, peer support for bereavement started in the early 1970s, and social networks helped protect against depression and post-traumatic stress disorder (PTSD) among grieving individuals.^{3,4} Access to OCs for grief and mourning support has expanded dramatically,⁵ particularly during the COVID-19 pandemic.^{6,7}

The death of a baby occurs in 1 of 80 live births in the United States,⁸ and is associated with stigma, social exclusion and isolation, “disenfranchised” grief, guilt, and shame, making recovery difficult.^{9–16} Losses are often minimized by health care staff as well as friends and family, and support drops off rapidly after delivery which can make it more challenging for parents to integrate and make meaning from the loss.^{17,18} Online support is particularly appealing as it helps with stigmatized losses. The 24/7 availability may benefit individuals with limited transportation, childcare, job duties, or those without local support groups. The ability to engage or disengage with grief sites reflects Stroebe and Schut's Dual Process Model of coping with bereavement that proposes that the bereaved oscillate between grieving and restoration.¹⁹

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Although pregnancy loss OC users are predominantly Caucasian, women of color have twice the risk for pregnancy and infant loss and similar mental health outcomes.^{20,21} Our prior study (unpublished) found that bereaved women of color are interested in accessing online support groups but are often unaware of these resources postloss; a study of African American women using Facebook breastfeeding support noted that the women found strong support and normalization online.²² Most existing studies on OC mental health and grief lack randomization or controls,^{23–25} or create a special community for study participants that cannot mimic real-world conditions.^{25,26} We sought to (a) test feasibility of a brief pilot intervention for women of color with perinatal loss and (b) understand participants' experience in an OC.

Methods

Recruitment

The study was reviewed and approved by the institutional review boards at the University of Michigan and the Michigan Department of Health and Human Services (MDHHS) and registered with ClinicalTrials.gov #NCT 04600076. Using similar methods as prior research,²⁷ MDHHS used vital records data to identify parents with recent losses (within 6 months), including stillbirth (fetal death after 20 weeks gestation or weight ≥ 400 g) or infant deaths in the first 28 days of life. Michigan residents identified by the vital records as non-Caucasian and/or Hispanic, age 18 years or older, without baby adoption plans preloss were included. To protect confidentiality, the state mailed all study materials.

We sent mails to 200 women based on response rates from prior research with bereaved women of color, with a goal of 50 participants.²⁷ Mothers could return a decline card with a random study ID, not respond, or complete consent online. This ensured the study team only knew the identity of participating mothers. Mails included a hand-written condolence card sent at least 3 weeks postdeath, followed 2 weeks later by a study invitation. Nonresponders were sent up to two more invites and a reminder card per survey protocol.²⁸ As a feasibility study, this was not powered for health outcomes.

Intervention

BabyCenter (BC) is a global commercial platform owned by Johnson & Johnson offering pregnancy and parenting information through 15,000 groups, of which ~ 300 have been active in the past 3 months (pers. comm.). Our prior study suggests women preferred anonymous groups²⁹ and women of color may particularly value digital privacy, so we chose this site as it has frequent daily traffic and is designed for anonymous posting and commenting.³⁰

We asked participants to sign on and read postings at least three times weekly for 6 weeks on a specific OC for pregnancy and infant loss site.³¹ They could write comments or submit new posts, but this was optional. We sent text reminders thrice weekly, and BC sends e-mail "Daily Digests" to all group enrollees to encourage participation. Participants could earn up to \$50 for study completion.

Instruments

Online surveys assessed demographics and digital access, loss type, attitudes toward online support, and mental health.

We used the 8-question Patient Health Questionnaire-8 for depression, using a score of 10+ to indicate a positive screen³²; the 33-question Post-Traumatic Stress Disorder Civilian Checklist (PCL-5) with scores of 35+ representing positive^{33,34}; the 7-item Generalized Anxiety Disorder Scale, using a score of 10+ for moderate/severe anxiety³⁵; and the 33-question Perinatal Grief Scale-Short (PGS), using >40 to indicate more severe grief.^{36,37} Two PGS questions were inadvertently dropped in our surveys that allowed pre-post analysis but limits comparison with other studies.

Data collection

After consenting, women registered on BC, shared their self-created screen name, and BC collected information on page views, posts, comments, and reactions for these participants. We had access to the group postings, but the content was not the study focus. BC staff did not see participant surveys data or participate in data analysis or interpretation. We conducted brief (13–35 minutes) semistructured phone interviews postintervention to explore user experiences. These were recorded and transcribed verbatim. Enrollment started in December 2020, and data collection was complete by May 2021.

Data analysis

Quantitative data from surveys were evaluated with summary statistics, using McNemars test to compare pre-post data on Likert-style categorical questions about attitudes and Wilcoxin Rank Sum test to compare pre-post mental health scores. We used deductive coding for qualitative analysis.³⁸ Coding was informed by our survey questions on whether participants felt posting could help others, whether they felt less alone, and whether posting would make people feel too sad, while we remained open to other relevant themes emerging from the data. The first and last authors independently conducted a first round of closely reading the data and discussed observations. Coding was completed by the last author.

Results

Demographics

Invitations were mailed by MDHHS to 200 women. One declined, 22 consented, and 177 did not respond. Of consenters, two withdrew before the intervention. Nineteen women completed the final survey and phone interview. Participants self-identified as Black ($n=12$), two or more races ($n=3$), White Hispanic ($n=2$), Asian ($n=1$), and Native American/Alaska Native Hispanic ($n=1$). One participant self-reported Caucasian race and Middle Eastern ethnicity.

Thirteen (59 percent) had public insurance and nine (41 percent) had private insurance. Education included high school or less ($n=5$, 23 percent), some college ($n=7$, 32 percent), bachelor's degree ($n=4$, 18 percent), or masters/doctorate ($n=6$, 27 percent). Fifteen (75 percent) reported mental health preloss as "excellent" or "very good." The group we utilized averaged 18 posts and 326 comments weekly that was lower than anticipated due to unrelated digital platform changes by BC.

TABLE 1. MENTAL HEALTH SCORES FOR PARTICIPANTS COMPLETING BOTH PRE- AND POST-TESTS

| | Pretest (mean ± SD) | Post-test (mean ± SD) | p |
|-------------------------------|------------------------------|--------------------------------|--------------|
| Depression (PHQ8) | 8.9 ± 6.4 | 8.1 ± 5 | 0.505 (n=17) |
| Post-traumatic stress (PCL-5) | 38.6 ± 15 | 35.8 ± 14 | 0.383 (n=19) |
| Anxiety (GAD7) | 12.8 ± 5.7 | 11.9 ± 6 | 0.100 (n=18) |
| Grief (PGS) | 91.9 ± 18.9 | 88.2 ± 20 | 0.365 (n=19) |

GAD7, 7-item Generalized Anxiety Disorder Scale; PGS, Perinatal Grief Scale-Short; PHQ8, Patient Health Questionnaire-8; PCL-5, PTSD Checklist for DSM 5; SD, standard deviation.

Mental health

We limited analysis to women completing both pre- and postintervention measures. Depression screens were positive for 6 of 17 (35 percent) preintervention and 5 of 17 (29 percent) postintervention. PTSD screens were positive for 8 of 18 women (44 percent) preintervention and 7 of 18 (39 percent) postintervention. Moderate-severe generalized

anxiety was found in 14 of 19 (74 percent) preintervention and 10 of 19 (53 percent) postintervention. Perinatal grief screening was positive for all 19 of 19 women (100 percent) both preintervention and postintervention. Mean scores for depression, PTSD, anxiety, and perinatal grief all declined postintervention, but changes were not statistically significant (Table 1).

Preintervention, most women (14/20, 70 percent) reported awareness of online groups, but only 9 of 20 (45 percent) women had participated in an OC since their loss. Postintervention, 4 of 19 women who had not previously sought outside help added one of these supports, and women were more likely to believe that posting allowed them to help others and to feel less alone but also to agree reading posts could make them feel sad or be unhelpful (Table 2).

Engagement

Most women (19/20) electively chose to initiate a post (n=11), add comments (n=14), or react to a post (n=16). Thirteen (72 percent) planned to return to the group post-study. Only 4 participants logged in at least three times weekly for 6 weeks, but most (n=15) participated for at least 5 weeks and 12 participated for all 6.

TABLE 2. ATTITUDES TOWARD READING AND POSTING IN LOSS ONLINE COMMUNITIES

| | Pretest | Post-test | Sample quotes |
|---|-------------|-------------|---|
| “Posting a response on one of these sites will make me feel like I am helping someone else.” | 13/19 (68%) | 17/19 (89%) | “I just enjoy bein’ able to help other people and seein’ that they was concerned about me and the way that I felt.” (ID 250) “I... appreciate the opportunity to support other people, uh, eventually.” (ID 150) “I felt like I was actually there helping other people who were recently going through it.” (ID 140) |
| “Reading stories or experiences from other moms will make me feel less alone.” | 15/18 (83%) | 17/18 (94%) | “Like... they was there when you couldn’t really talk to your family, like you think about it, like they understood, ‘cause they was goin’ through the same thing you know I was goin’ through.” (ID 230) “...after I read a, a few, other moms sharing their experience, actually I felt, oh, I was not alone. Because for me, to be honest too, I thought that’s who, that’s, you know, if you’re a woman, that’s your... what else you can do...you woman, you have womb, then you, you making baby, and then, it’s like a natural thing...So I kinda like you know, question myself. So, but when I first like read a few other moms, you know, they share experience, and I would say oh, so I’m not alone. There are a lot of other moms being through the same situation, you know like what I’m being through.” (ID 187) |
| “Reading stories or experiences from other moms will make me too sad and would not be helpful.” | 3/18 (17%) | 7/18 (39%) | “It’s hard for me. I haven’t been able to like read the stories lately, because readin’ the stories, it does trigger me back to the loss and the whole experience of it.” (ID 129) [going through the forums] “opened up a lot of wounds... that I’d already buried.” (ID 103) “... initially when I started looking at posts, ... I was a little uncomfortable. I think I was worried about, um... maybe seeing or hearing things that I might not really wanna think about at the time, because I was trying to maintain like a really positive and optimistic outlook...I started to feel like, maybe it was medically affecting my outlook on pregnancy in general to see so many losses.” (ID 184) |

Numbers represent those who “strongly agree” or “somewhat agree” and completed questions both pre- and postintervention.

Helping others

Participants gradually found value in reading posts and in some cases posting about their own experiences (Table 2). One woman transformed her own pain:

The first week it brought... like a, like I said, like it brought like a lot of emotion. And things to deal with. The second week it was kinda okay, I can give this lady some advice, 'cause [she] was goin' through what I was goin' through (ID 228).

Healing through helping others, often referred to as “helper therapy principle,” is a well-established psychological phenomenon that occurred on this BC forum.³⁹

Feeling less alone

After reading others' stories, many participants felt less isolated, though one woman who got little feedback from others after posting noted that reduced the impact:

It's good that you know Baby Center is there. But it's kinda like, um... I'm still kind of alone, because nobody really, um... answers back or show their support. (ID 289)

Reading stories enabled some to reassess the stigma and self-blame they had long attached to their experiences.⁴⁰ Indeed, prior study⁴¹ suggests that seeing others' stories about pregnancy loss on nonanonymous social media (e.g., Facebook) reduces stigma; here we provide qualitative evidence for this outcome, extended to pseudonymous online spaces.

Unfortunately, when women felt stories did not reflect their own experiences with loss, they felt more isolated, emphasizing the importance of including a diversity of loss experiences.^{42,43}

I have trouble like relating to like the miscarriages, I've never had a miscarriage, I don't really know, how that is. I just had the one stillbirth... (ID 155)

Feeling sad

Women agreed the OC sometimes increased the intensity of loss and grief. Typically, such feelings were noted early after joining the forums as stories brought participants emotionally closer to their own time of loss. OCs may be most helpful if they cater to where an individual is in their loss journeys.

Social comparison

Participants used social comparison to feel better and some women found it helpful to know that their experience could have been worse.

And then also some other moms, they actually have been through like a, a tougher situation, like they... had a baby deliver like full term and then couldn't bring baby home. So, but you know, but me, mine was like 5 months... And, yeah, so I kinda like, when you go through more, reading more actually helps you more, like helped me more. (ID 187)

Participants also felt comfort seeing others further along in their grief process.

But, um, there are other parents that have gone through worse than me and my husband. So, there's other families that have struggled more... So it made me realize... we can get through this... through this grieving, through this process. (ID 289)

Complementing existing support systems

Some found the platform complementary to existing support, whereas others noted the community filled a void—a space where they could express feelings in depth.

Well of course friends and family are there right away, and then their support slowly drops off, so it'd be nice just to kinda... come in at that time. (ID 114)

Discussion

There are sparse data on mental health outcomes after use of an existing OC on a commercial platform, and this is one of few studies focused on women of color who are often marginalized in bereavement research.^{44–46} Although our pilot study was not powered for mental health outcomes, pre–post scores improved nonsignificantly on all four measures, suggesting the value of larger randomized controlled trials. Mental health and emotional sequelae after perinatal loss are substantial.^{20,27,44}

Our findings concur with prior research showing OCs for pregnancy loss help women feel less isolated and feel they can help others.^{40,47} We also report new insights into potential negative impacts of OCs (e.g., triggering content), evidence for social comparison leading to validation and feeling better, and OCs acting as a relief and complement of in-person support.

Limitations include small sample size. We anticipated challenges recruiting bereaved women of color and engaged prior successful strategies for enrollment but still recruited fewer participants than desired.⁴⁷ Owing to COVID-19, mailings planned for summer were delayed until Thanksgiving and the winter holidays—not an optimal time to recruit bereaved parents.

Grieving parents often find that friends and family are uncomfortable talking about their deceased baby and support dissipates quickly postloss, complicating the ability to make meaning and to redefine identity as a parent.^{9,11,14,40} BC and other OCs have the potential to fill this gap, and our mixed-methods approach contextualized quantitative findings to help explain the nuanced experiences of participants.

As OCs are free and accessible, they could augment traditional forms of care, particularly for parents with limited existing support or resources. Future larger trials have the potential to build on these preliminary and promising findings and should be powered for outcomes and utilize active OCs. As our participants addressed the difficulty in hearing stories of grief, interventions could consider the Dual Process Model and provide restoration-oriented text support to help balance difficult online content.¹⁹

Author Disclosure Statement

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