

An updated review: women's concerns following miscarriage on multiple social media platforms

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Running title

Women's concerns following miscarriage on social media

Abstract

This study explored concerns and unsolicited advice relating to miscarriage shared on multiple social media platforms for mentions of questions, advocacy, medical advice, conflicts of interest, and terminology used to describe miscarriage.

Public social media posts in English from January 1st, 2019 to June 30th, 2021 were searched using keywords related to miscarriage. A dataset of questions, advice, conflicts of interest, and terminology used was created from eligible posts determined by inclusionary and exclusionary criteria. The dataset was analyzed to identify themes and calculate statistics.

Approximately 1000 posts were reviewed and 149 posts were found eligible for analysis. Of the total, 116 posts included advice and a subset of 71 posts offered questions. A total of 152 mentions of advice were identified from the total eligible posts with 82.9% of advice related to advocacy for destigmatizing miscarriage, enhancing community support, or expressing grief. 17.1% of posts offered medical advice eligible for evaluation of which 73% were accurate across all platforms. From the dataset, 103 questions were analyzed for common themes. The four most common themes of questions included grief, self-blame, quality of post-miscarriage counseling in different care settings, and inadequate medical counseling.

This study indicates that women who experience miscarriage have many unanswered questions and powerful feelings relating to grief and self-blame that could have long-term impacts. Social media has become a place for women to self-advocate and connect with others for support, from which clinicians could increase their understanding of women's unmet needs.

Introduction

Miscarriage, also known as early pregnancy loss, is the loss of a pregnancy before the 20th week of gestation. Approximately 9-20% of all pregnancies in the United States end in miscarriage.¹ Women report feeling isolated, guilty, depressed, and/or anxious; these feelings can persist for at least six months to one year following a miscarriage.^{2,3,4} Shorter et al found that approximately 25% of women experiencing early pregnancy loss are at an increased risk for major depressive disorder within the first month post-treatment.⁵ Wong et al surveyed post-miscarriage women and found that they felt inadequately supported by their healthcare providers and that many felt they lacked enough information.⁶ There have been no prior studies using multiple social media platforms to investigate women's specific concerns and questions following miscarriage.

For women and families experiencing miscarriage, social media has become a popular outlet and resource for support. The 2014 “#IHadAMiscarriage” campaign led by Jessica Zucker, Ph.D. started a movement to destigmatize miscarriage, provide support to the many women who suffer in silence, and reject the self-blame ideology many women face.⁷ In recent years, there has been an increasing number of public figures publicizing their personal experiences with miscarriage to normalize the experience. There are communities of women utilizing social media platforms within Facebook, YouTube, Reddit, Instagram, and Twitter to share their experiences, unanswered questions, and frustrations.

Prior studies have investigated individual social media platforms including Instagram, Twitter, or YouTube to identify themes in perceptions or emotions following a miscarriage and the use of social media as a part of the grieving process or as an educational tool.^{7,8,9} However, social media has not always been found to be a reliable source for patient education on miscarriage.⁹ Based on prior surveys, women have expressed dissatisfaction with the care they have received following a miscarriage and have turned to social media for support, yet their unanswered questions have not been studied to identify areas of improvement for providers in miscarriage counseling to patients.^{6,10} The specific concerns elicited from the unanswered questions women have following a miscarriage and potential conflict of interest in the medical advice shared online have not yet been researched nor compared across multiple social media platforms. This study investigated unanswered questions and advice posted on social media to identify any unmet patient needs and areas of improvement for providers in post-miscarriage counseling.

Materials and methods

Public social media posts on five different social media platforms originally published between the dates of January 1st 2019 and June 30th 2021 using the keywords of “miscarriage”, “preterm birth”, “pregnancy loss”, “early pregnancy loss”, “early fetal loss”, “spontaneous abortion”, “spontaneous pregnancy loss” and “#IHadAMiscarriage” were searched by our team. The team of research investigators coordinated so that only one person searched under specific keywords to avoid duplicate data entries. IRB approval was waived by the Ethics Committee of Western University of Health Sciences as only public posts were searched, no user information was collected, and thus no informed consent from users was obtained. A secure Google form was created to enter data for each public post identified. Mentions of multiple questions and advice (medical and non-medical) were recorded in the form, alongside the use of terminology related to miscarriage, and if any conflict of interest was identified. Ultimately, the data was consolidated to identify major themes and statistics.

Five different social media platforms were chosen to capture information from as diverse a population as possible and to capture a wider number of users based on the popularity of the platforms.¹¹ Since our

standards for determining the accuracy of information were based on guidelines from the American College of Obstetricians and Gynecologists (ACOG), only data from public posts in English were captured. The user demographics ranged per social media platform, Instagram users were the youngest (majority ranging from 18-24 years of age) while YouTube users were the oldest (majority ranging from 15-35 years of age).¹² Due to the varying activity on different social media platforms, predetermined minimum cutoffs were used for the inclusion of popular posts. The criteria for popular posts varied by platform: posts in public Facebook Miscarriage groups, YouTube videos with ≥ 1000 views, Reddit r/Miscarriage with ≥ 175 upvotes, Instagram photos with ≥ 50 likes, and Tweets with ≥ 1 interaction were analyzed for mentions of questions, advice, conflicts of interest, and preferred miscarriage terminology. Only posts from persons directly experiencing miscarriage were included; posts from partners were excluded. Posts were excluded from the data set if a question or advice was not mentioned. There was no limit for thematic saturation. The comments of a post were not analyzed. Questions were distinguished by the syntax and use of question marks in the post. Advice was distinguished by action verbiage and suggestions for readers. Every post was reviewed in its entirety in which both questions and advice were included in the data pool if mentioned in a single post.

Major themes were identified by comparing the number of mentions for each topic. The collected advice was classified into categories of “completely accurate” if it was supported by current professional association guidelines, including ACOG. “Insufficient evidence” was advice only supported by published reports but not in professional guidelines, and “inaccurate” if any part was found to be contrary to published clinical guidelines and was unsupported. Potential conflicts of interest were noted when posts mentioned products or specific ads were featured from which the user would be expected to gain profits.

From the systematic rules, major themes of the unanswered questions, advocacy trends, and medical advice were identified by comparing the number of mentions for each topic. The data was organized within each of the five different social media platforms, allowing comparison between the social media platforms. Ultimately, all themes were pooled to evaluate the most common questions posed during the specified time frame. Mentions of advice unrelated to medical care were categorized as advocacy trends and excluded from the accuracy grading. Medical advice was grouped into three categories (accurate, insufficient, and inaccurate) and compared among the different social media platforms. The number of conflicts was compared to the number of posts on each social media platform. The terminology used to describe miscarriage was tallied in each post collected.

Results

Approximately 1000 posts were reviewed of which 149 posts were found to be eligible for analysis of both questions and advice. Of the eligible posts, 103 unique questions were identified to study their common themes. The major themes of questions included grief, self-blame, the quality of post-miscarriage counseling in different care settings, and inadequate medical counseling, see Table 1.

Table 1. Themes of questions expressed by at least 1.9% posts across all social media platforms.

| Theme | % of mention (N=103) |
|------------|----------------------|
| Grief | 20.4 |
| Self-blame | 19.4 |

| | |
|--|------|
| Inadequate medical counseling | 14.5 |
| Quality of counseling in different care settings | 13.5 |
| Next pregnancy | 8.7 |
| Fear and stigma | 4.9 |
| Bleeding | 3.9 |
| Support for partner | 3.9 |
| Calling in sick | 1.9 |
| COVID restrictions | 1.9 |
| Other, Miscellaneous | 7 |

Our study identified that across all platforms, the majority of women publicly posting about their miscarriage struggled with grief and loss. Patients expressed their grief and frustration by seeking the advice of fellow women who have experienced miscarriage.

“What went wrong?” [Text with post #21]

“Can't I just be sad?” [Text with post #10]

“How do I cope when women that are close to me are getting pregnant?” [Text with post #65]

Despite prior campaigns to mitigate the self-blame ideology associated with miscarriage, women continue to place blame on themselves. Our research found that the self-blame nature of miscarriage was the second most common theme found in questions posed online. Women asked:

“Am I a failure for not being able to carry a child?” [Text with post #74]

“Do you blame yourself for your loss?” [Text with post #18]

“How am I supposed to love a body that continues to fail me?” [Text with post #52]

There was a range of posts voicing concerns about feeling inadequately supported by their provider. In particular, women shared that the medical terminology used by providers felt sterile and impersonal. Additionally, the site of miscarriage diagnosis made a difference in how the news was accepted. Women questioned these discrepancies online.

“Why is medical terminology so unempathetic?” [Text with post #23]

“Why do we say ‘pass the fetus?’” [Text with post #23]

“Why did my doctor say it was too early to even know I was pregnant?” [Text with post #12]

“Why did the ER doctor address the situation so abruptly and quickly?” [Text with post #112]

Questions regarding post-miscarriage counseling claimed that women were not given information on what to expect about pain, bleeding, contractions, and passing tissue. Women posed questions wishing they had a clearer understanding of what to expect.

“You have contractions when you miscarry?” [Text with post #8]

“Why did no one prepare me for the physical pain of miscarriage?” [Text with post #80]

“Why I am experiencing immense bleeding after my miscarriage? Should I go to the hospital?” [Text with post #61]

Common themes varied by the social media platform. YouTube yielded the most posts collected,

totaling 54 mentions of questions. The most common themes included self-blame (22.2%), post-miscarriage counseling (22.2%), implications for next pregnancy (14.8%), grief/frustration (11.1%), fear and stigma around miscarriage (9.4%), lack of medical support/follow-up (7.4%), bleeding (5.5%), support for partner, and difficulty dealing with COVID restrictions in the healthcare setting (3.7% each).

Facebook yielded 23 mentions of questions eligible for evaluation. The most common themes of questions on Facebook included self-blame (34.8%), lack of medical support/follow-up (30.4%), grief/frustration (8.7%), postpartum counseling (8.7%), implications for next pregnancy, support for partner, molar pregnancy, and statistics of miscarriage (4.3% each). The majority of posts screened were posted by miscarriage groups or businesses and thus excluded.

Collectively, Instagram, Twitter, and Reddit contributed only 25 posts. Across these three platforms, grief/frustration was the most common theme. On Instagram, the most common themes following grief/frustration were lack of medical support/follow-up, calling in sick for miscarriage, postpartum counseling, and mental health. The majority of posts screened on Instagram did not include mentions of questions or advice, but rather personal stories and advocacy for destigmatizing self-blame culture related to miscarriage. The community of users on Instagram supporting others in their losses was qualitatively large in comparison to other platforms like Twitter and Reddit. Twitter and Reddit yielded the least amount of data and were not particularly useful given the large amount of product advertisements noted on these platforms.

152 mentions of advice were extracted from 116 posts of which 82.9% were categorized as advocacy trends due to the focus on destigmatizing miscarriage, community support, or grief/loss, see Table 2. The two most common platforms for miscarriage advocacy were YouTube (48.7%) and Instagram (34.7%). YouTube, Instagram, Facebook, and Twitter all showed that the majority of advice collected was non-medical and thus was not gradable for accuracy.

Table 2. Most common advocacy themes across all social media platforms.

| Advocacy Themes | % of mentions (N=126) |
|------------------------------------|-----------------------|
| Grief/Mental health | 54.8 |
| Word-choice related to miscarriage | 12.7 |
| Isolation | 8.7 |
| Destigmatizing miscarriage | 8.7 |
| Other, Miscellaneous | 15.1 |

The overwhelming trends around advocacy focused on how to handle grief/mental health (54.76%), word choice related to miscarriage (12.7%), isolation (8.73%), and destigmatizing miscarriage (8.73%). The theme of destigmatizing miscarriage included many women urging others to connect with the online community, to share their stories, and to show others they are not alone. While many women advised others to share their experiences online, others shared a feeling of obligation or sense of duty to publicly share their stories. One user wrote:

“Is it my responsibility to go public with news of my miscarriage to normalize it?” [Text with post #62]

In advocating for themselves, women shared that they wanted to stop hearing commentary like:

"At least you weren't that far along" [Text with post #19]

"Maybe if you hadn't..." [Text with post #20]

"You can try again and have another baby" [Text with post #7]

"It's a blessing in disguise" [Text with post #19]

17.1% of eligible posts offered medical advice eligible for evaluation, in which accuracy across all platforms was calculated to be 73%. Overall, due to the small subset of eligible advice, accuracy could not be compared across platforms. YouTube accounted for the majority of advice. The majority of posts on YouTube, Instagram, and Reddit posts were considered to be the most accurate (>66%).

The most popular term used was "miscarriage", totaling 75% of all posts. The second most popular term was "pregnancy loss" (37.5%). The third most popular term used was "#IHadAMiscarriage" (16.4%). Early pregnancy loss and early fetal loss were terms used the least (0.8% each). This information showcases the popularity of each term but does not speak to the preference of terminology explicitly.

Of all posts collected, 14.7% included a conflict of interest. YouTube was the social media platform with the largest number of conflicts of interest. Within YouTube itself, 42.3% of videos included a conflict of interest. Although the content of the video did not explicitly advertise a product, there were video commercial ads from which the creator profited based on the number of views of the video received.

The dataset was collected during the height of the COVID-19 pandemic. As such, many women posed questions about how new restrictions would impact their quality of care. Women shared concerns about isolation from their partners. The COVID-19 protocols may have impacted patients' perceptions captured in this study about loneliness and the quality of care received.

Discussion

Social media is a free and accessible source that provides patients an outlet to share experiences and connect with others. It also provides an inside look at women's unfiltered experiences with miscarriage and the unanswered questions they have about early pregnancy loss. However, one drawback of social media includes its unregulated nature in which unqualified clinical recommendations may spread. McNamee et al identified YouTube as an unreliable source for patient education unless posted by medical institutions.⁹ However, our findings do not support this conclusion yet were limited as only a small subset of advice was gradable for accuracy. We found Twitter and Reddit contained levels of advertising, which could allow physicians to steer patients away from these platforms for medical advice.

This qualitative study identified the most common themes of questions including grief/frustration, self-blame, quality of post-miscarriage counseling in different care settings, and inadequate medical counseling. Women are turning to social media platforms after their miscarriage for guidance and connection.^{7, 8, 10} McNamee et al found that YouTube was useful as a source of community and miscarriage support, which is supported by our findings in this study.⁹ The well-known psychological impacts and remaining unanswered questions of women following miscarriage highlight the need for a routine yet individualized post-miscarriage follow-up to evaluate the patient's physical and mental well-being.

The differences noted in the language used in varying healthcare settings (Emergency Room vs. outpatient clinics) posed the question of how to improve and individualize counseling in all care settings. The frustrations highlighted in this study revealed that women perceive medical language as sterile and

unempathetic when addressing miscarriage. Clinicians may proactively adopt more empathetic language to improve patients' perceptions of their miscarriage care. Based on our findings, women more commonly use the term miscarriage over early pregnancy loss. Despite ACOG's attempt to transition the terminology to early pregnancy loss, patients have not adopted this terminology.

A new theme emerged in this work surrounding the feeling of obligation to publicly share experiences with miscarriage. Prior qualitative social media studies have not included public sharing. Women posted that they feel a responsibility to share their miscarriage experience to uplift others. Moreover, women urged others to share their personal stories online to destigmatize miscarriage and to combat the sense of isolation and self-blame associated with miscarriage. While some women urged others to share in order to progress the movement of de-stigmatizing miscarriage, others asked why is it their responsibility to go public on the matter. The current social trend of sharing many personal experiences online has created an interesting environment for us to explore the potential motivations of patients.

Different social media platforms utilize unique limitations to word limits for posts and represent different demographics and communication styles. Although our study investigated five different platforms to diversify our data, there are other platforms and posts that our study did not represent. In particular, the popular social media platform, TikTok, had not matured to its current level of influence to have made major contributions at the time of our data collection. With TikTok's current popularity, our study may have benefitted from its addition. As part of our inclusionary criteria, only English posts were used in data collection. However, we were not able to determine what country of origin the posts originated from and thus there may be language and cultural barriers that influenced the interpretation of our findings. Due to the limited number of qualifying advice in our study, it was difficult to compare accuracy across multiple platforms. As no comments were included in the dataset of qualifying posts, this may have also limited our data collection. Despite these limitations, our qualitative study captured the unfiltered shared experiences and common concerns of women regarding their miscarriage care. Providers may use social media as a resource to understand the challenges, questions, and overall patient experience of miscarriage.

Ultimately, this study may help guide clinicians to better support women and their families by using the common concerns elicited from this study when counseling patients through a miscarriage. Conroy et al commented that although short-term exposure to miscarriage posts may be helpful, long-term exposure may trigger patients; we found support for this argument in many posts in which women advocated to have their own individual timelines for grieving.¹⁰ Moreover, there were women who wanted to maintain their privacy and others who urged women to continue to share, which supports our notion of individualized care. As the most common themes of questions and advice related to self-blame and grief, this could indicate a need to investigate if mental health counseling and resources may help women and their partners who recently have experienced a miscarriage.

Conclusion

Questions posed online most frequently related to grief, self-blame, quality of post-miscarriage counseling in different care settings, and inadequate medical counseling. This study indicates that women who have experienced miscarriage have many unanswered questions and powerful feelings related to grief and self-blame that could have long-term mental health impacts. Women are advocating for themselves by urging others to share their own personal experiences online to destigmatize miscarriage. Clinicians may consider the concerns outlined in this study when counseling grieving patients and direct

those who wish to seek support to platforms like YouTube and Instagram to help them connect with others for support, but not necessarily for medical advice.

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Conflict of interest

The authors declare that they have no conflicts of interest in this work

Availability of data and materials

All of the datasets for this study are available from the principal investigator and corresponding author upon request

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