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Experiences with misoprostol-only used for self-managed abortion and acquired from an online or retail pharmacy in the United States☆

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ABSTRACT

Objectives: This study aimed to understand individual experiences with medication abortion using misoprostol-only among people living in the United States.
Study design: We conducted 31 semistructured anonymous in-depth interviews with individuals who used misoprostol-only for self-managed medication abortion. Participants were recruited from Aid Access, an online telemedicine organization that provided prescriptions for misoprostol to eligible people in all 50 states in May and June 2020 when a combined mifepristone and misoprostol regimen was unavailable. We coded transcripts with a flexible coding approach and focused on perceptions and experiences with use.
Results: Participants were knowledgeable about misoprostol. Previous abortion experiences shaped perceptions of misoprostol-only by allowing comparison to the mifepristone and misoprostol regimen. Most participants expressed an unwavering desire for an effective abortion method, regardless of the medications or regimen. Individual physical experiences with misoprostol, including bleeding, cramping, nausea, and diarrhea, varied in intensity and duration. Participants proactively managed symptoms with self-care strategies and drew extensively from their prior experiences with menstruation, miscarriage, abortion, and childbirth. Clear instructions and information on potential complications and what to expect throughout the abortion fostered a sense of preparedness, and personalized interactions with an online help desk brought comfort.
Conclusions: Misoprostol offered an essential abortion method for study participants. This regimen was physically challenging for some, and there is potentially a greater need for communication and support for individuals using misoprostol-only regimens. Prior reproductive experiences informed participant's knowledge, preparedness, pain management, and ability to both recognize and manage potential complications.
Implications: As restrictions on mifepristone continue, more people may use misoprostol-only regimens. All regimens can be supported with detailed instructions, clear expectations, information on signs of potential complications, and personalized support. To achieve reproductive autonomy, people must have access to a range of abortion care options that meet their needs.

1. Introduction

The World Health Organization recommends two medication abortion regimens: either mifepristone used with misoprostol or misoprostol-only [1]. Both regimens are recognized as safe and effective [1]. In settings where mifepristone is inaccessible or unaffordable, millions of people globally use misoprostol-only for medication abortion [2]. Misoprostol is viewed as an essential abortion care option because of its straightforward instructions for use, relatively low cost, and far fewer restrictions on prescription and availability [3,4]. Using misoprostol only for self-managed medication abortion, defined as ending a pregnancy outside of the formal health care setting without direct clinician supervision, increased worldwide after this practice was pioneered by Brazilian feminists in the 1980s [5].

Medication abortion in the United States typically involves the combined regimen of mifepristone and misoprostol. However, legal restrictions limit access to mifepristone. The Food and Drug

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Administration (FDA) Risk Evaluation and Mitigation Strategies restrictions on mifepristone limit where and how mifepristone can be dispensed [6]. The pending court case *Alliance for Hippocratic Medicine vs. Food and Drug Administration* seeks to withdraw the FDA approval of mifepristone, potentially limiting nationwide access to the medication, even in states where abortion is legally protected [7]. The 2022 US Supreme Court ruling in *Dobbs vs. Jackson Women's Health Organization*, which overturned *Roe vs. Wade,* further exacerbates these present and potential restrictions. After this ruling, at least 15 states enacted near or total bans on abortion [8], effectively making the provision of mifepristone used for medication abortion impossible in these states.

Given this restrictive policy context and potential nationwide restrictions on mifepristone, misoprostol-only medication abortion regimens pose an opportunity to expand abortion access in the United States. Misoprostol is subject to fewer abortion-related legal restrictions than mifepristone [9] and is widely stocked in US pharmacies because of the multiple uses for reproductive health [1,10], early pregnancy loss [11], and stomach ulcer prevention [12]. Despite these benefits, there is little qualitative research on people's experiences using misoprostol for abortion in the United States. This research aims to understand people's experiences using misoprostol-only for self-managed medication abortion.

2. Materials and methods

2.1. Methods

We conducted this study with individuals who used Aid Access, the only online telemedicine organization that provides medication abortion pills and support for self-managed medication abortion to people in all 50 states in the United States [13]. Self-managed medication abortion in this study is defined as obtaining medications outside of the formal health care setting and using these medications without direct clinician supervision. Aid Access typically provides the combined mifepristone and misoprostol medication abortion regimen. However, due to challenges shipping mifepristone internationally in the beginning of the coronavirus disease 2019 pandemic, the service temporarily adjusted the model to prescribe misoprostol only. Misoprostol was available to people up to 10 weeks' gestation, determined by the last menstrual period. Users completed an online consultation. A physician reviewed consultations for any contraindications to medication abortion. Physicians prescribed eligible individuals three doses of 800 μg of misoprostol. The prescription was mailed directly to the individual or available for pick-up at a local pharmacy. Aid Access requested a $35 sliding scale donation based on individual need. An online help desk was available for questions and support *via* email communication.

2.2. Sample and data collection

We conducted semistructured, in-depth interviews with a convenience sample of individuals who obtained misoprostol only in May and June 2020. Participants were recruited by an email invitation sent by Aid Access and inviting people to participate in an in-depth interview study conducted by the University of Texas at Austin. The invitation was sent on November 1, 2021, and interviews were conducted in November and December 2021. Interviews were completed in the English language and with individuals aged ≥18 years. Verbal consent was obtained for all participants. Participants were sent a $50 digital gift card to thank them for their time.

We conducted interviews via phone using an encrypted messaging application that ensured both the participant and the interviewer remained anonymous. We did not collect identifying information. Interviews lasted between 30 and 90 minutes. We used a semistructured in-depth interview guide designed to capture experiences with misoprostol only. Select interview questions relating to the focus of this manuscript are in Appendix 1. The final sample size of 31 interviews reflected the research team's determination that a balance between thematic saturation and available resources had been reached. The Institutional Review Board at the University of Texas at Austin approved this study.

2.3. Data analysis

Interviews were transcribed verbatim using an in-house transcription service. Two members of the research team co-developed the initial coding guide. We coded transcripts with a flexible coding approach [14] using ATLAS.ti 7 (Atlas.ti) software. We collaboratively established intercoder consistency [15,16] by coding the first three transcripts together and then comparing codes. Guided by a focus on the core categories of perceptions of and experiences with misoprostol, we conducted a second round of axial coding concentrating on the subcategory of physical experiences using misoprostol. We iteratively developed major themes [17] based on code summaries, field notes, and group discussions.

3. Results

3.1. Participants

Thirty-one people participated in interviews, and participant demographics are summarized in Table 1. Participants self-reported demographic information. All participants identified as women, and no participants identified as transgender, nonbinary, gender expansive, or gender nonconforming. At the time of the abortion, participants were aged 17 to 44 years, and most (n = 22) were aged 25 to 39 years. Over half (n = 16) identified as non-White, and most (n = 20) self-identified as heterosexual. The majority (n = 23) were working full time, had health insurance (n = 28), and were living in a state classified as hostile to abortion rights (n = 18) [18]. Eleven participants received misoprostol from an online pharmacy, and 20 participants picked up misoprostol at a local retail pharmacy (Fig. 1).

3.2. Perceptions

Most (n = 28) participants knew about medication abortion pills before using Aid Access. Over half of the participants had previous abortion experiences, and this subgroup explicitly compared their experiences between misoprostol-only and mifepristone and misoprostol regimens. One participant, who had recently had another medication abortion at a clinic, said:

> "During my second experience having an abortion…I was given mifepristone too. So, I've experienced both sets…and with mifepristone, it was a world of difference. It really was just so incredibly different. The pain amount, the ease."

Another compared using misoprostol-only to a medication abortion she had seven years prior: "this was way more intense… just those contractions or cramping feeling, it was way intense…"

Among those with no previous abortion experience, misoprostol-only regimen perceptions were less uniform, and some participants were open minded about receiving just misoprostol. As one participant recalled: "I felt good about just the one." Another participant said: "I was just like…this is as much as they can, you know, give to me. So, I thought maybe it would work just as well."

For a few participants' (n = 3) misoprostol-only perceptions informed explicit preferences for the combined mifepristone and misoprostol regimen. One participant said she would have opted for

Table 1
Self-identified demographic characteristics of individuals who acquired misoprostol only for self-managed medication abortion in the United States in May and June 2020 (N = 31)

Characteristics	Frequency, n (%)
Age (y)	
< 18	3 (10)
18–19	1 (3)
20–24	4 (13)
25–29	7 (23)
30–34	6 (19)
35–39	9 (29)
40–44	1 (3)
Race/ethnicity	
Asian	1 (3)
Black/African American	6 (19)
Hispanic/Latinx	6 (19)
Native American	1 (3)
Native American & Hispanic	1 (3)
West Indian	1 (3)
White	15 (50)
Gender	
Female or woman	31 (100)
Other	0 (0)
Sexual identity	
Asexual	1 (3)
Bisexual	6 (19)
Heterosexual	20 (65)
"I like men"	1 (3)
Pansexual	1 (3)
"Lesbian"	1 (3)
Refused	1 (3)
Number of children at the time of their abortion	
0	16 (52)
1+	15 (48)
Highest level of education at the time of their abortion	
High School	5 (16)
Associates	3 (10)
Some college	13 (42)
Bachelor's degree	5 (16)
Graduate degree	5 (16)
Employment at the time of their abortion	
Working full time	23 (75)
Working part time	1 (3)
In school/full-time student	2 (6)
Working and in school	1 (3)
Full-time caregiver	4 (13)
Insurance at the time of their abortion	
Affordable care act	1 (3)
Employer	14 (45)
Medicaid	6 (19)
"Public insurance"	1 (3)
Parent/guardian	2 (6)
Partner/spouse	2 (6)
Uninsured	3 (10)
Veterans affairs	1 (3)
Missing	1 (3)

Table 2
Previous abortion experiences among individuals who acquired misoprostol only used for self-managed medication abortion in the United States in May and June of 2020 (N = 18)

Abortion site and type of abortion	Frequency, n (%)
Aid Access (mifepristone and misoprostol)	2 (11)
Clinic (medication abortion)	6 (33)
Clinic (D&C or vacuum aspiration)	6 (33)
Clinic (not specified)	6 (33)
Pills from another source (not Aid Access)	1 (6)
Total number of people with previous abortion experience	18 (100)

Some people had more than one previous abortion experiences.

the combination if it had been an option at the time because she knew "all about" medication abortion from her work as a doula. When asked if she wanted to use both medicines, she responded:

> "I definitely would have, if that had been an option for me. I knew enough about the medicine that I was pretty secure at the time in my pregnancy that it was going to work fine and be fine. But since I did not get the second medicine, that is why I went and made sure that I got checked out just to make sure that I didn't need to have something else done."

These prior perceptions prompted her to seek a postabortion ultrasound at a doctor because as she explained: "I worry about everything" and wanted the extra peace of mind confirming a complete abortion.

> Apart from three participants whose perceptions and experiences led them to express a clear preference for the combined regimen, most participants held an unwavering desire for an effective abortion method, regardless of the medications or regimen. One participant said: "I mean if they got it done, they got it done. That's really what I was worried about."

> Another participant reflected that: "I really didn't have any thoughts of it. I mean, it didn't matter to me either way, just as long as it did what it was supposed to do." And another explained:

> "Honestly, I didn't really think about it because at that point I was just doing the research and when Aid Access explained to me what the process was, the medication and how to take it, I thought well ok if they are just giving me misoprostol, then this works on its own. I wasn't really concerned about getting both pills or just getting the one."

3.3. Experiences

Participants discussed physical experiences that varied in intensity and duration, including bleeding, cramping, nausea, diarrhea, fever, or chills. Some participants described intense symptoms, and others felt that symptoms were manageable. Among these symptoms, some lasted for days or weeks, while others lasted only a few hours.

From their experience, participants most frequently discussed bleeding, and participants used menstrual bleeding as a benchmark. As one participant said:

> "I have pretty heavy period cramps…so it wasn't more or less than what I expected. I think I probably changed my pad every couple [of] hours and I think the whole thing probably took like 6–8 h well actually probably 4–6 h for the worst part of it and then the rest just kind of eased less and less."

> Another participant bled for 3 days after taking the misoprostol, recalling: "there was bleeding but nothing that my pad couldn't handle. And I actually went and got the 'Always' diapers."

Other participants experienced bleeding up to 4 weeks after taking misoprostol. Aid Access informs people that bleeding is expected and advises that if an individual is bleeding through more than two maxi pads an hour for over 2 hours to see a doctor.

> Participants frequently mentioned cramping, and, like descriptions of bleeding, they compared cramping to menstrual cramps. One woman said: "I felt the intensity of the cramps, it was just hurting. Like it feels like I had my first time with my period." Another said: "I normally get bad period cramps, and it was pretty much kind of like, on par with that, if not, like, slightly worse."

Familiarity with cramping helped participants manage their pain, as one woman said:

> "There wasn't any pain coming from my lady parts aside from intense back cramps. I occasionally get those in a regular cycle…

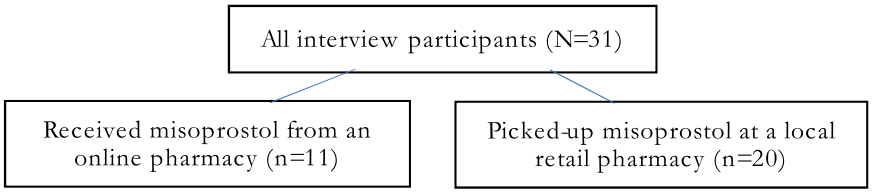

Fig. 1. How individuals obtained misoprostol only used for self-managed medication abortion in the United States in May and June 2020 ($N = 31$).

you just want to put your thumbs towards your spine in with your fingers wrapped around and just kind of massage."

Some participants also experienced common side effects of misoprostol, including diarrhea and nausea. Participants mentioned diarrhea that lasted "only for maybe half a day," and diarrhea that "…wasn't longstanding. It was probably just once or twice." Others mentioned: "I did experience a little bit of nausea. But that was it," and "a little bit of nausea…that's really it…no major complaints."

When we compared physical experiences between participants with previous abortion or miscarriage experiences to participants with none, both groups reported varied levels of pain and discomfort. However, these groups differed in their approach to potential complications. Those with a prior experience with abortion or miscarriage felt more confident in their ability to both recognize and manage possible complications. One participant, who previously had a procedural abortion, required a dilation and curettage procedure due to an incomplete abortion after using misoprostol. She explained:

"I knew mine wasn't complete because I didn't bleed a lot. I bled some, but I wasn't really bleeding like I should, like you would for a full abortion."

Overall, participants were proactive about caring for themselves and equipping themselves with what they needed during their abortion. Creating a comfortable and private space to take misoprostol was challenging for participants navigating work, childcare, covid-19 lockdowns, and privacy concerns. Across all participants, there was a clear need for physical comfort:

"I was able to be comfortable, lay down and just let it go. I took a nap too because I think it was better way for me to not feel the pain anymore from what was happening. After I woke up, I felt relieved, I think everything worked out."

Others strategically set up their bathroom:

"I just tried to take deep breaths. The toilet area of my bathroom is behind another door. So I had a pillow in there. I had blankets. I had a trash can with a clean liner in it. I had water in there. And I had my cell phone, but I only had it on the mode if I needed to call 911 because I didn't want to be disturbed."

Another woman turned to her cat for comfort, recalling: "I'm just gonna get through this with my cat."

Participants were also strategic about when they took the misoprostol, frequently waiting "till it was closer to the weekend to take the medication," affording them more time to rest and recover before returning to work. One woman explained: "I was really fortunate that I planned it in a certain time that we had a very long weekend, and then I just took an extra day." Another woman said: "I just made sure that I cleared my calendar for the day…and I just stayed home and rested."

Previous miscarriage or birth experiences also helped participants understand and prepare for pain management. All participants who mentioned pain management discussed taking medications to help ease the pain, and some also self-soothed with heating pads or baths. One woman recalled her miscarriage and used the same pain relief strategy for her abortion: "It helped that I was expecting it and the pain killers helped a lot too…I mean they weren't super strong. It was just Tylenol…but it helps ease it."

Another woman's previous miscarriage made her mindful of symptoms that were a sign of potential abortion complication:

"I knew based on the length of the pregnancy and the previous miscarriage what would feel like a regular miscarriage *versus* what would feel like, 'Oh, this is not what's supposed to be happening.' "

For her, this previous miscarriage experience also normalized the process, explaining:

"I think it did help me to feel like this access to pills would be safer and normal…I imagined that it would feel closer to what the miscarriage would feel like."

One participant, a doula and mother of three, felt prepared to take misoprostol: "I wasn't really surprised other than just the pain and nausea and vomiting, but I mean expected some pain." Another participant, a mother of two, echoed this as well: "I mean, cramps are expected. I've had two kids, so I know when you're giving birth you expect the cramps, but it was manageable."

The expectations set by the self-managed abortion instructions and communications with the help desk reassured participants. As one woman described: "I knew what to expect because it also said that in the email." In addition to managing expectations, participants mentioned the necessity of information on potential complications:

"The website was pretty clear about what the reasons would be that you'd want to check in with a medical provider if things didn't work. But it progressed pretty much the way I expected it to progress based on having miscarried in the past."

Another relayed that the help desk felt personalized:

"It was an email thread, so… my response could have went to any number of people, but it was always the same person. And she had detailed knowledge about my specific situation. So I wasn't getting a generated response, from just another random person. I really appreciated that I was talking to one person the whole time."

4. Discussion

This study is the first in-depth, qualitative exploration of experiences using misoprostol-only for self-managed medication abortion among people living in the United States. We find that participants were knowledgeable about misoprostol, individual physical experiences varied in intensity and duration, and participants managed symptoms with strategies informed by prior reproductive experiences. These findings highlight that having clear

instructions for use, information on what to expect, and personalized support can assist those having misoprostol-only abortions.

Our findings on physical experiences with misoprostol are aligned with prior research on mifepristone and misoprostol. Like qualitative [19] studies on pain associated with the mifepristone and misoprostol regimen, we find that pain duration and trajectories vary, and people situate their pain within other reproductive events (including menstruation and childbirth).

We also find similarities to research on misoprostol-only used in international settings. Like a study of women who used misoprostol along the Thailand-Burma border [20], and the other studies on abortion preferences [21], we also find that previous abortions and the guidance of others shaped the experience. All participants in both the Thailand-Burma study (including those who remained pregnant after taking the misoprostol) would recommend the initiative to others, and in our US study, all but one person would consider this process again if they needed to end a pregnancy. Participant's strategies for self-care, need for privacy, and assurance brought by accurate information were also in line with findings from an in-depth interview study of misoprostol users in Buenos Aires, Argentina [22], as well as Cotonou, Benin, and Ouagadougou, Burkina Faso [23]. Furthermore, participant's reflections on cramping and comparisons drawn to miscarriage and childbirth were similar to a study in Nepal, Vietnam, and South Africa, where medication abortion was relatively less painful compared to giving birth and relatively more painful than menstruation [24].

This alignment with prior research is important and speaks to the range of abortion experiences people have. This study also underscores that there is potentially a greater need for communication and support for individuals using misoprostol-only because this regimen can be physically challenging for some.

We found that those with a prior experience with abortion or miscarriage felt more confident in identifying and managing potential complications. This finding highlights that people (such as adolescents) who have experienced fewer reproductive events in their lifetime may need additional support. Overall, the pain trajectories and awareness reported in prior studies and ours are notable because they contextualize and normalize abortion within the range of reproductive events people experience over the life course.

Finally, it is critical to note that some participants expressed a preference for the combined mifepristone and misoprostol regimen. This highlights the injustices inherent in a system in which individuals cannot access their preferred abortion method or model without interference, a violation of reproductive autonomy [25,26]. Misoprostol offered an essential medication abortion method, but it is not a panacea.

There are limitations to this study. First, this study examines one possible pathway for obtaining and using misoprostol-only for abortion. Therefore, our findings are not generalizable to the experiences of all people who have misoprostol-only abortions. Second, due to the length of time between the abortion and interview, participants may be subject to recall bias. Finally, participation was limited to those aged ≥18 years, who could participate in English, who had access to a mobile device with an internet or cellular data. However, misoprostol-only is not typically offered in US clinic settings, and therefore, it is difficult to capture these experiences with clinic-based interview recruitment methods. While not generalizable, this study fills a critical research gap by offering insights into the experiences of people using this regimen in the United States.

Our results highlight a need for comprehensive and democratized information on misoprostol-only used for medication abortion in the United States and throughout the world. Existing resources in the United States include the World Health Organization recommended protocols [1], a sample protocol for US providers [27], and evidence from the United States [28] and globally establishing the safety and effectiveness of misoprostol-only abortions [29]. This study adds to these resources by centering the knowledge of those directly experiencing misoprostol-only abortions. Given the highly restrictive US abortion access policy context and the potential for further nationwide restrictions on mifepristone posed by the case *Alliance for Hippocratic Medicine vs. Food and Drug Administration,* misoprostol-only medication abortion regimens are a crucial opportunity for abortion access. These findings inform how to support individuals who use misoprostol-only for abortion.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.contraception.2023.110345.

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