Title: Foregrounding pain in self-managed early medication abortion: A qualitative study

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Abstract

Objective

To explore experiences of pain in the context of early medication abortion in the UK and to guide best practice around anticipatory guidance on pain.

Methods

From late 2020 to early 2021, we recruited people from across the UK who had undergone abortion during the COVID-19 pandemic to participate in in-depth, semi-structured telephone interviews. A storytelling approach was used and data analysed thematically using Nvivo12.

Results

Focused coding and thematic analysis addressed accounts of pain, which were prominent in many interviews. We constructed the following sub-themes: expected pain is manageable for some; the problem with unexpected pain; pain (co)produces fear; problematising 'period-like pain'. The key issue which our analysis draws out is that, while early medication abortion (EMA) pain experience might vary, for some it may be much worse than anticipated. Moreover, the common trope of likening it to 'period pain' can be misleading and a source of additional uncertainty at a potentially already challenging time.

Conclusions

For some, pain experienced in EMA will be severe and/or worse than expected. Insufficient preparation for pain can result in extremely negative experiences of EMA. Alongside development of improved analgesia, improvements should be made to anticipatory guidance on pain, particularly for those self-manging EMA at home. Framings of 'period-like pain' do not clarify expectations and should be avoided.

Key messages

WHAT IS ALREADY KNOWN ON THIS TOPIC

- Pain in early medication abortion is a known issue which potentially limits acceptability and has particular implications for home self-management.

WHAT THIS STUDY ADDS

- Our analysis highlights the nuances and varaibility of EMA pain experiences, including where pain contributes to an extremely unpleasant overall experience.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- Our findings suggest that the 'period-like pain' analogy should be avoided, and that those seeking EMA should effectively be made aware of the spectrum of possible pain experiences.

Keywords

Pain, early medication abortion, self-management, EMAH, EMA,

Word count: 2500

Introduction

Early medication abortion (EMA) under 14 weeks' gestation is safe, effective and acceptable, and constitutes an increasing proportion of abortions in the UK and worldwide.[1-3] In some contexts, such as the USA, the number of medication abortions are rising exponentially, as abortion rights and access are rolled back.[4] Pain in EMA is a known issue, although attention to the need for more effective pain management has, until recently, been relatively minimal.[5]

While pain experiences vary,[5,6] a growing literature highlights intense pain as common to EMA,[7-9] and associations with anxiety, dysmenorrhea, nulliparity, and inadequate information provision.[7,8,10,11]

Guidance from the Royal College of Obstetricians and Gynaecologists and World Health Organisation specifies that those undergoing abortion should be offered pain relief.[12,13] However, evidence on the most effective pharmacological interventions is minimal and unclear,[14] and current approaches vary.[11,15-18]

The shift to self-managed EMA at home (hereafter EMAH) necessitates reconsideration of how pain is addressed. Qualitative evidence suggests EMA pain experiences can be intense, linked to feelings of punishment,[19] and other forms of psychological distress.[20] Worse-than-expected pain can reduce EMA's acceptability and have lasting impact.[17,20] For example, while reported patient satisfaction and acceptability (as well as safety) of EMAH in the UK are high,[21-24] it is also evident that some patients would not choose this model for a subsequent abortion,[22,25,26] at least in part due to unexpected or unmanageable pain. Understanding how EMAH pain is experienced is thus essential to improving quality of abortion care, and attending to pain would move beyond a focus on quality-as-efficacy, in favour of more truly patient-centered care. Alongside increasing proportions of EMAH, rising UK abortion rates – as well as currently policy focus on 'women's health'[1] - mean that effective analgesia and expectation-setting are relevant to more patients and are thus more important than ever.

Our qualitative study captured experiences of abortion during COVID-19. Addressing a dearth of qualitative evidence, this paper explores descriptions of pain embedded in those accounts, in order to address the question of how those with lived experience talk about pain in EMA. As such, this paper is the first to focus on EMAH pain experiences in the UK, and to problematise its framing, in

[1] Women's health plan - gov.scot (www.gov.scot); Women's Health Strategy for England - GOV.UK (www.gov.uk)

particular its alignment with 'period pain'. We identify key ways in which expectations and experiences of pain could be improved, with a view to contributing to abortion care best practice.

Methods

Study design and participants

Between late 2020 and early 2021, we recruited 20 participants from across the UK who had sought abortion since the beginning of COVID-19 restrictions. Aged 22-43, all participants self-identified as cisgender women. (Hence, we use gender-neutral terms such as 'patient' and 'pregnant person' in describing abortion generally, but 'woman' when referring to our participants specifically.) We excluded one participant who underwent surgical abortion from the analysis presented here, leaving a final sample of 19.

Participants were recruited via the My Body My Life project website, related social media, and an online classified advertisement. Anyone aged 18 or over who had undergone abortion in the UK since the beginning of Covid-19 restrictions was eligible to participate. All eligible people who opted into the study were interviewed. EMA was obtained via NHS clinics (Scotland), independent providers (England) and verified online providers (Northern Ireland).

Data production

All interviews were conducted by telephone by researchers experienced in qualitative abortion research (LH, FB, CP). All participants provided verbal consent which was audio recorded prior to commencing the interview. Existing literature and the primary research question (namely, 'what were the experiences of those who sought abortion during the Covid-19 pandemic?') informed a flexible topic guide. Participants were asked to recount their 'abortion story' - from learning they were pregnant to the time of the interview - in as much detail as possible. Follow-up questions clarified key information if absent from initial accounts. Interviews lasted an average of one hour, and were audio recorded for verbatim transcription.

Data analysis

Interviews were professionally transcribed, pseudonymised, and data management facilitated by Nvivo 12.[27] Inductive thematic analysis[28] from the broader study highlighted pain as a prominent feature of the data. Through new coding focused on pain (conducted by CP), and an iterative process of interpretation involving all co-authors, we developed four sub-themes: expected pain is manageable for some; the problem with unexpected pain; pain (co)produces fear; problematising 'period-like pain'.

Patient and Public Involvement statement:

Given pandemic restrictions at the time, no patients were involved in the study's design or conduct.

Results

Expected pain is manageable for some

Some participants explicitly described pain expectations set by providers:

> the pain wasn't as bad as I thought […] I guess maybe I anticipated it being like a really, really horrible experience in terms of pain and stuff like that. And it definitely could have been worse, but at the same time it didn't feel great, […] I remember them saying oh for some people it's only like as much pain as a period or as much bleeding as a period, and I was thinking OK, I don't know if I believe that, to be honest, but ok... (Jack, EMAH ~8 weeks)

Jack's questioning suggests this framing may have introduced an element of distrust in the health professional. Moreover, for Jack, the pain's manageability was at least in part down to her highly negative expectations.

Hannah aligned pain with punishment:

> [The pain] was easy to manage because I had these painkillers. Later on, I decided not to continue with painkillers, I don't know why, I was like, I made the decision, am I supposed to feel the pain, kind of punishing myself for things I've done. (Hannah, EMAH ~9 weeks)

For some who described manageable pain, there was a sense that pain was normalised, assumed to be an unquestionable part of EMA process, and just something to be endured: "Obviously, as you're aware it was extremely painful […] I knew the pain was just part of the process" (Debs, simultaneous EMD[2] ~6 weeks).

The problem with unexpected pain

Where pain emerged as a problem was often where it was worse than expected. Brid described her detailed plan to use the pain relief provided, but that this had nonetheless been insufficient, with enduring implications:

[2] EMD – 'early medical discharge' model which preceded EMAH, where mifepristone and misoprostol are administered at the abortion clinic / hospital, with the woman returning home to pass the pregnancy. Two of our participants were given simultaneous mifepristone and misoprostol, rather than at the more typical 1-2 day interval.

> I just had no idea it was going to be that sore. I don't know if I could ever do it again, to be honest, it was so physically painful[…] looking back that's one of the things that I think about most, that I'm really angry about, is that we're not really told what, in practice, what it can be. It's all the instructions everywhere saying, oh you might feel a bit of cramping. This wasn't a bit of cramping, it was excruciating. (Brid, EMAH ~7 weeks)

Others described hours of intense pain, while the speed at which pain intensity accelerated from bearable to unbearable was also an issue for some:

> the pains did come on quite suddenly and went from being mild to quite strong. I'd describe them as being like labour cramps. It did go from bearable to unbearable within literally the space of minutes. (Ginny, EMAH ~6 weeks)

Several participants described how worse-than-expected pain combined with other medication side-effects to generate a highly unpleasant experience:

> It was also quite a lot more painful than the literature had implied. I mean it was incredibly painful and no painkillers of any kind made the slightest dent in it. It got steadily worse but within, I would say, two hours I was completely bent double on the toilet in incredible pain. The blood flowing very fast out of me along with very explosive diarrhoea and vomiting.[…] It was really very rough indeed. (Claire, EMD ~6 weeks)

Brid highlighted the impact of lacking a benchmark for her pain, and a perceived tension in making visible the reality of EMAH:

> It was really traumatising, it was horrible, and the thing is I don't really know what other women's experience of it is like[…] I didn't know if that's 'normal' or if that is not normal[…] And that troubles me, that I could be in my mid-30s where one in three women have definitely had a pregnancy termination and we've not talked about it[…] I sort of understand that, when we're still fighting for abortion services, that we don't want to scare people either as though it's this terrifying thing. (Brid, EMAH ~7 weeks)

Pain co-produces fear

Descriptions of worse-than-expected pain fed into concerns about the abortion process going wrong. Immy described how her pain's intensity caused significant concern, as a medical process going according to plan would presumably not be so painful:

> It was the most painful thing I've ever gone through both mentally and physically[…] I was convinced that something had to have gone wrong because it couldn't be this painful. And then about five a.m., after nine hours of excruciating pain and codeine not working, my boyfriend was like I've had enough, we're taking you to hospital. (Immy, EMAH ~6 weeks)

Several, like Kim, reflected that information on pain could be improved:

> The main thing that I remember is that I was not expecting it to be that painful. And I was quite worried about the pain and that kind of was a bit scary.[…] In the pain section, I remember it was just like 'oh paracetamol…' but I think they should offer codeine or just emphasise that it can be extremely painful for some people. (Kim, EMAH ~7 weeks)

Problematising 'period-like pain'

Pain experiences were often framed in comparison with period pain which, for some, created discord:

> I knew from the literature that came with all of the pills and from [provider] that you should start bleeding within four hours, and that most people said really it's not much more than a painful period. For me the experience was actually really different to that and was quite scary as a result. (Steph, EMAH ~9 weeks)

Steph's description highlights fear generated by feeling unprepared for intense pain. While, for some, the 'bad period' comparison was borne out, these were for women whose baseline was 'quite painful periods', and also reported very early gestations, as Judi describes:

> I think I have quite painful periods anyway. So for me it was just very much like a normal period. Possibly even less painful but a lot more blood.[…] I think I took two paracetamol and nothing else. And that was fine. (Judi, EMAH ~4 weeks)

In contrast, despite having taken the codeine provided, Ayda's pain on passing the pregnancy was notably worse than period pain, becoming more similar after its peak:

> After about an hour it got very heavy very suddenly, which they say can happen when you're passing the actual pregnancy. And that bit was extremely painful, I was curled up on the bathroom floor and I vomited a couple of times from the pain.[…] But then it ebbed away quite quickly, after the main clots had come out. And then I was just in what I would call high-level period pain, the pain that you get from a really bad period. (Ayda, EMAH ~6 weeks)

For Mali, not knowing what to expect about any physical element of EMA was a particular challenge:

> I think what was most difficult for me in the lead up was not really knowing too much about what to expect. Because obviously they say it's going to be different for everybody, so I was thinking I'm not sure how painful it's going to be, I'm not sure how much I'm going to bleed, how bad the cramps are going to be[…] it's hard to find a lot of information about that. I would have loved to have been able to talk to someone who'd had an abortion, and be like oh what happened to you, what was yours like? (Mali, EMAH, gestation unknown)

Mali's point highlights an acknowledgment of the subjectivity of pain and likely variability in its experience, while also foregrounding a need for more (particularly experiential) information.

Discussion

Our analysis illustrates a suboptimal healthcare experience for some self-managing EMAH. We foreground ways in which pain, particularly when unexpected, interacts with fear and other EMA side-effects, to create a highly unpleasant experience. Nuances in these accounts highlight that, even when relatively 'manageable', pain is problematic, and add to an evidence base on the need for more effective expectation-setting on EMA pain.[29,30] Current guidance specifies that pain while passing the pregnancy will be '*worse than* during a period'.[12] However, our analysis suggests the potential severity of pain is not consistently made clear to UK abortion patients.

There are numerous potential explanations as to why women might find themselves experiencing worse-then-expected EMAH pain. For example, health professionals may have reservations about unduly frightening women, limited familiarity with the spectrum of pain experiences, or believe that sufficient information or analgesia has been provided. Crucial advice on pain may also be lost amidst the volume of information typically provided in EMAH consultations. Exploring potential explanations could be a useful focus of future research, as could developing and assessing impact of anticipatory guidance interventions presenting a range of potential pain scenarios.

While EMA pain might be framed as 'unavoidable',[30] the increasing proportion of self-managed abortions across the UK and elsewhere means that improved information on pain provided in initial consultations and support materials is essential. As well as engendering highly negative experiences insufficient preparation for potential pain has clear implications for informed consent, since the latter cannon meaningfully be provided without full understanding that EMA may comprise intense, severe pain.

Ultimately, our analysis suggests the 'bad period pain' trope can introduce additional uncertainty around EMAH. 'Period pain' means vastly different things to different people, and evidence from elsewhere suggests EMA sits anywhere between menstruation pain and childbirth.[30] Likening abortion to a familiar bodily process may support its normalisation.[19] However, this framing has problematic implications, not least in positioning EMA pain as something to be endured. There is an ongoing need to challenge gendered normalisation of pain in female reproductive embodiment.[29] Avoiding the 'bad period pain' analogy in favour of presenting best- and worst-case scenarios, could support this, as could asking patients in the consultation about their experiences of menstrual pain.

Pain in early medication abortion is, for some, significant and impactful enough to have lasting effect. Alongside better analgesia, improved information - that which emphasises the pregnant person's entitlement to pain relief - will not only enhance quality of care, but contribute to normalising abortion as routine reproductive healthcare through which pregnant people are not expected to suffer.

Strengths and limitations

We did not specifically ask participants to recount pain advice from health professionals, nor directly access consultations, instead relying on recall some weeks later. As is typical of qualitative research, our findings, based on a sample of 19 women, are not broadly generalisable, but present a nuanced picture of EMAH pain experiences. A key strength of this paper is its foregrounding of the lived experiences of EMA pain. Our data are grounded in the early uncertainties of COVID-19, when services had newly shifted to offering EMAH and had to adapt extremely quickly to do so. The aim of our exploration is not to criticise abortion provision in an intensely challenging landscape, but to highlight areas for improvement.

Conclusions

This paper is the first to sustain focus on the implications of EMAH pain experiences in the UK. While the severity of pain was acceptable and/or manageable for some, for others it was far worse than expected. Pain combined with fear and other EMA side-effects to create acutely unpleasant experiences, with potentially lasting impact. Since abortion is a common component of sexual and reproductive healthcare, unexpected and intense pain could potentially impact thousands of pregnant people every year.

In line with recent studies,[29] we advocate for provision of clear, realistic information and expectation-setting on pain and other abortion medication side-effects. Effective pain guidance which avoids minimisation or euphemism, will support health professionals striving for excellence in abortion care, and those seeking EMAH in future.

Data availability

The anonymised dataset is available on reasonable request from the study Principal Investigator Victoria Newton by contacting victoiria.newton@open.ac.uk.

Ethics statement

Patient consent for publication

Not applicable.

Ethics approval

The Open University's Ethics Committee approved the study (HREC/3560/Newton).

Contributorship statement

LH and VN devised the original study, in collaboration with CP and FB. LH, CP and FB conducted interviews. CP led the analysis presented here, in consultation with VN, LH and FB. All authors contributed to the drafting of this paper and approved the final version.

Competing interest statement

There are no competing interests for any author.

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