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Pain experiences during intrauterine device procedures: a thematic analysis of tweets

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ABSTRACT

Introduction In June 2021, high-profile testimonials in the media about pain during intrauterine device (IUD) procedures in the UK prompted significant discussion across platforms including Twitter (subsequently renamed X). We examined a sample of Twitter postings (tweets) to gain insight into public perspectives and experiences.

Methods We harvested tweets posted or retweeted on 21–22 June 2021 which contained the search terms coil, intrauterine system, IUD or intrauterine. We analysed the dataset thematically and selected illustrative tweets with the authors' consent for publication.

Results Following deduplication and screening, we included 1431 tweets in our analysis. We identified testimonials with descriptions of varied pain experiences. Twitter users reported that clinicians had not warned them that pain could be severe or explained the options for pain relief. Some raised concerns about pain being minimised or dismissed and linked this to the management of women's pain in medicine more broadly. Twitter users described connecting to an online community with shared experiences as validating and used this as a springboard for collective action.

Conclusions While we acknowledge the limitations of our sample, this study highlights important perspectives and accounts relating to pain during IUD procedures. Our findings attest to the need for strategies to improve the patient experience for those opting for IUD as a clinical priority. Further research should explore IUD users' experiences, expectations and wishes around pain management.

INTRODUCTION

The intrauterine device (IUD) is an umbrella term for a range of copper and hormonal devices which act as effective,

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ There are gaps in the research literature on patient experiences and expectations of pain management during intrauterine device (IUD) procedures.

WHAT THIS STUDY ADDS

⇒ Our analysis highlights important perspectives and accounts relating to IUD procedures, including concerns about missing information about pain and analgesia options, and dismissal of pain.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ These findings should inform quality improvement strategies and highlight the need for more research exploring patients' lived experiences.

long-acting, reversible contraception.¹ All types of IUDs, which have an estimated 159 million users worldwide,² require insertion by a provider. Pain is a recognised risk of IUD insertion, with users' experiences of pain varying from minimal to high.^{3,4} Improving experiences of pain during IUD procedures has been identified as a national healthcare priority in England, as laid out in the Women's Health Strategy.⁵

A series of events in 2021 prompted public discourse about the management of pain during IUD procedures in the UK. Activist Lucy Cohen created a petition to health ministers in England, Scotland and Wales advocating for changes in practices around counselling about pain and analgesia provision during IUD procedures, which was circulated in a newsletter by



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author Caroline Criado Perez and has since had over 35 000 signatories.^{6,7} Following this petition, public figures within media and broadcasting in the UK including Caitlin Moran and Naga Munchetty shared personal accounts via news outlets and radio of their experiences of severe pain during IUD procedures.^{8,9} There was a substantial response to these events on multiple online platforms including Twitter (subsequently renamed X), with many IUD users sharing their own experiences of insertion and/or removal.¹⁰

In this study, we set out to examine Twitter posts (tweets) shared online at the time of this public conversation about pain during IUD procedures. This study is situated within a growing body of research highlighting the possible benefits of analysing social media data about contraception, including the potential to explore healthcare experiences and inform quality improvement.^{11–13} Recognising and addressing individuals' reports of negative healthcare experiences or care which did not meet expected standards also offers the opportunity to critically examine current practices and to support public trust in the healthcare community.^{12,14} Our analysis is driven by the overall aim of sharing, considering and learning from accounts shared by Twitter users with an open and reflexive approach, in the interest of improving patient care for those who opt to use IUDs.

METHODS

We collected publicly available tweets shared following high-profile testimonials discussing pain during IUD procedures. We identified appropriate search terms by hand-screening 50 relevant tweets to identify common words and phrases used by Twitter users. This process resulted in the following search terms: coil, intrauterine system (IUS), IUD and intrauterine. We used NodeXL to harvest all tweets containing any one of these search terms from Twitter's application programming interface (API). We limited our search to tweets shared on 21–22 July 2021. This period was chosen to capture the peak of discussion immediately following Naga Munchetty's discussion of this subject on BBC Radio 5, which has a weekly listenership of over 5 million.¹⁵ We downloaded data into Microsoft Excel for deduplication and screening. One author (NT) hand-screened this dataset to remove tweets which did not contain any reference to IUDs.

Four members of the research team used reflexive thematic analysis to analyse the resulting dataset of tweets.¹⁶ Each read the entire dataset and independently coded 50 tweets to construct an initial draft codebook, which was discussed and agreed by the whole team. Each researcher then used this codebook iteratively to code a quarter of the overall dataset using qualitative analysis software (QSR NVivo). We used regular group discussions to reflect on our individual responses to the data, refine the codebook (e.g., incorporating new codes) and develop themes and subthemes.

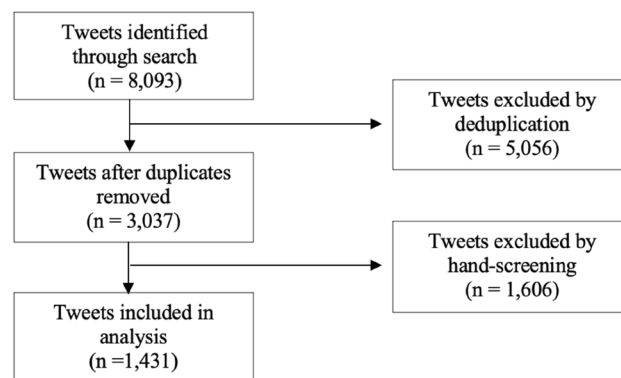


Figure 1 Flowchart of data screening.

We illustrated thematic findings with selected quotations, for which we obtained informed consent. This aligns with best practice for social media research since users may be identifiable from their data, and quoting tweets in research may draw attention to users beyond what they would normally expect from their use of Twitter.¹⁷ To request consent to quote, we contacted users from a designated Twitter account created for this study via direct message, or a tweet in cases where direct messaging was not enabled; we sent a maximum of one further reminder where there was no response. Prior research has taken the same conservative approach to the reporting of Twitter data.¹⁸

RESULTS

Our initial search resulted in 8093 tweets; we excluded 5056 duplicate tweets (retweets) and 1606 tweets which contained no reference to IUDs. This resulted in 1431 unique tweets from 1276 unique accounts which we analysed (figure 1).

Table 1 summarises the themes and subthemes developed through analysis of our sample of tweets with illustrative quotes.

Pain testimonials

In response to high-profile testimonials about pain during IUD procedures, Twitter users shared their own experiences or those of their peers, providing descriptions of varied levels of pain:

"I consider myself to have a really high pain threshold, I've sat for hours and hours of tattoos and broken countless bones but I can still safely say my IUD being inserted was the most painful and traumatic experience of my life"

"I actually really love my coil and didn't experience that much pain when it was put in. But I've heard so many horrible stories from friends who were in agony that it is clearly an issue that is not being adequately dealt with"

Many tweets described IUD procedures as *mildly painful* or *uncomfortable*. However, in our sample, such experiences were outweighed by accounts of pain described as *severe* or the *worst pain*.

Table 1 Themes, subthemes and additional illustrative quotes

Themes	Subthemes
Pain testimonials	<p>Varied pain experiences <i>"Reading the discourse today around IUD insertion pain really shows how differently women react to the procedure."</i></p> <p>Negative impact of painful IUD procedures on mental and physical well-being <i>"... I had a very traumatic time having a coil fitted, meant to prevent painful periods. Both a trainee & GP "had a go". I was in excruciating pain & my body went into shock with low heart rate. My husband was called to collect me. I was told I was "unusual" 😞"</i></p> <p>Feeling at fault following painful experiences <i>"...I was told it was my fault I fainted from the pain - and I believed that for quite a long time too..."</i></p>
Missing or misleading information about pain	<p>Insufficient information about pain <i>"I received more information about the coil fitting from friends than my doctors! I was not prepared for the pain it caused, my doctors hadn't told me to take painkillers before hand and like so many others was told to expect "slight discomfort"."</i></p> <p>Insufficient information about pain relief options <i>"...My GP said that IUD fittings 'don't hurt'. She only offered a local anaesthetic (for this 'painless' thing!) once I'd refused due to pain..."</i></p> <p>Loss of trust in providers <i>"Does the RCOG not know what its own members are doing to women? IUD fitting is painful. Doctors lie about it, do not discuss pain relief options and carry on despite women being in pain. Is this genuinely the first they've heard of this? 😞"</i></p>
Dismissal of pain	<p>Minimisation or dismissal of pain <i>"The IUD pain gaslighting 🙄"</i></p> <p>Lived experiences not recorded or valued <i>"Not convinced 'experts' have spoken to women or clinicians. I'm on my 3rd coil. Insertion, removal & really painful each time despite taking pain relief. BTW [by the way] being forced to hold the nurse's hand for comfort doesn't help"</i></p> <p>Sexism in medicine <i>"...I vomited when I had a coil fitted and I had had a child by that point. No one cared as it was a woman's problem! If men had coils fitted or took contraception pills they would be better than those on offer to women!"</i> <i>"It's both empowering and heartbreaking to see more women speaking about their IUD experiences. It's 2021 and we must start taking gynaecological pain seriously - that we don't is such an insidious chapter of the patriarchy"</i></p>
Validation through collective experiences	<p>Sharing testimonials as validating <i>"Just got to wait for a second opinion with gynae. Still can't believe the clinic said that having an IUD fitted causes 'only ever mild discomfort'. Hearing that I'm not the only woman who experienced excruciating pain is so validating."</i> <i>[In response to a testimonial] "...It's made me realise there was no need for me to be so embarrassed as I sobbed while the GP removed my coil..."</i></p> <p>Peer advice as a helpful resource <i>"This brings back horrible memories about my first IUD fitting - the most painful thing I've experienced followed by 6 months of painful, heavy periods. I only found out you could get anaesthesia via forums - asking for that (plus great new doctor) made a HUGE difference..."</i></p> <p>Calls to action <i>"The coil may be 'worth it' for many people, but why is it normalised for (often very young) women to go through this level of pain with no anaesthetic or sedation? So happy to finally see this topic in the nationals."</i></p>

GP, general practitioner; IUD, intrauterine device; RCOG, Royal College of Obstetricians & Gynaecologists.

Accounts of the negative impact of painful IUD procedures on mental and physical well-being were shared, with some Twitter users reporting that they subsequently avoided gynaecological procedures or examinations, including removal and reinsertion of IUDs and cervical screening. Others shared accounts of enduring negative consequences following painful IUD procedures, including a sense of trauma:

"My failed coil insertion was without a doubt the most physically painful thing I've ever experienced, I felt so shocked and the feeling of violation lingered for ages. I didn't expect that sort of pain for such a 'routine' procedure."

Evident in some accounts was a sense of feeling to blame for experiencing pain during an IUD procedure. Linked to this, examples shared of communication from providers when debriefing with patients following a painful IUD procedure reveal how certain

language may lead to patients feeling at fault for experiencing pain, or other adverse outcomes:

"...The aftermath has been relatively ok, but thanks to my "reluctant uterus" the fitting was bloody awful 🙄 I've had 3 kids, I was told this would help and I'd probably get it fitted OK, I was not ok!!"

Tweets in our sample contained descriptions of the benefits of IUDs and expressions of support for its use including in cases where insertion experiences had been negative, distinguishing the device from the procedure:

*"Both my coil fittings were deeply unpleasant to the point of screaming pain, and while having contraception w/o hormones was one of the best things I've ever done for my body and MH [mental health] and I'd go through the hideousness again NOBODY SHOULD *HAVE TO*. They should offer pain relief 100"*

Missing or misleading information about pain

Twitter users shared accounts of receiving incomplete information about pain from providers. Some commented that the risk of pain was minimised, or that the full spectrum of possible pain experiences was not adequately reflected in the counselling they received pre-procedure, leading to a mismatch between the level of pain they expected and their actual experiences:

“...The coil is the best contraceptive that’s worked for me but I was completely unprepared for the pain when it was fitted, I was in tears during the procedure and got no forewarning other than “make sure you eat and maybe take a painkiller” from my doctor.”

Some commented on a disparity in the quality of information they received from providers versus through their social networks. In addition, we identified descriptions of Twitter users receiving misleading information about their risk of pain based on their history. Advice from providers that a patient would experience little or no pain on account of their parity was one such example:

“Me, getting my first IUD inserted 7 months after giving birth. Medic: “Oh, you’ve had a baby, so you’ll be fine getting this without anaesthetic” Reader, I was not fine.”

Twitter users also reported that they had not been given any information about pain relief prior to insertion. There was evidence that omission of information about pain or pain management eroded trust in providers and in professional practice:

“My new doctor is pushing me pretty hard to get an IUD and my biggest concern is that she said it was quick and easy and they do them in office and didn’t mention pain at all. Feels like a trap”

Dismissal of pain

Tweets included reports of pain being ignored or not taken seriously by providers during IUD procedures. The term *gaslighting* was used to describe the minimisation or dismissal of pain by the healthcare profession. Some expressed that their experiences, or the experiences of others who had undergone IUD procedures, were not recorded. Linked to this were concerns that the lived experiences of IUD users were not valued as evidence by the medical community or used to inform clinical practice:

[Responding to a news article] *““For most women, it’s a little bit uncomfortable. It’s a bit like period pain.” Working hypothesis nobody has actually asked ‘most women’. I’ve had 2 babies. Coil fitting is ‘take the rest of the day off’ horrible, ‘a little bit’ is not the phrase.”*

Comparisons were drawn with the management of men’s pain during medical procedures, with Twitter users expressing the view that men’s pain and women’s pain were not acknowledged or treated equally.

Contraception use was framed as a gendered issue, with some sharing the perspective that *things would be different* if men were to use same methods as women:

“...Men get more pain relief for having a catheter inserted than women do for getting a coil fitted. Treat womens health and womens pain equally to mens”

IUD procedures were related to other gynaecological procedures including cervical screening, hysteroscopies and surgeries involving mesh. Some commented that the management of pain for IUD procedures was part of a broader legacy of sexism and misogyny within gynaecology:

“There’s a genuine streak of misogyny in gynaecology and I’m glad to see it finally being exposed with not only mesh but IUD fitting, hysteroscopy, endometriosis, Essure, etc.”

Validation through collective experience

For some, their experiences of pain and how that pain was managed during IUD procedures were linked to feelings of embarrassment, shame and disempowerment:

“I have no words for how angry and powerless these experiences left me feeling. As someone with endometriosis I know I have many more procedures ahead...”

By contrast, the activity of sharing, relating and compassionately responding to one another’s testimonials created a sense of collective experience and community:

“I can relate to this, IUD fitting is the most painful procedure I’ve ever had done – even compared to my recent spinal surgery – women deserve properly controlled pain relief #IUD”

Connecting to this community was a way for some to have their pain legitimised and to make sense of their experiences – a process which was described as validating:

“I finally feel validated with my own horror story of an IUD fitting. As the pain ramped up past 10 and I was screaming the house down I was told scar tissue was to blame. Surely someone should have noticed that before the point of no return?...”

This community was a way to access information and guidance from those with lived experience. Peers shared requests for information, offered advice and encouraged self-advocacy during IUD procedures:

“Also, any ladies reading this who are now crapping themselves at the thought of getting an IUD inserted – it’s still worth it. You might feel okay. You can always ask them to stop, or use a smaller speculum (ignore those who say you can’t; I do). Just don’t put up with any shite.”

This community was also viewed as a springboard for collective action, with the power to generate new evidence, challenge societal norms around the management of pain during gynaecological procedures and advocate for improvements in clinical practice:

“I would also encourage women who had bad reactions to the IUD itself to report it via the Yellow Card Scheme as their doctor probably won't. You can report any drug or device...”

“Well, I didn't expect to become the spokesperson for uteruses this year, but it'll be a title I'm proud to hold... Speak up. Sign the petition...”

While the tweets in our sample overwhelmingly contained messages that supported those who shared testimonials, we also identified tweets containing misogynistic and racist content.

DISCUSSION

Our study findings highlight important experiences and expectations around how providers counsel patients about pain and analgesia prior to IUD insertion. Twitter users shared reports that they were not counselled about the full spectrum of possible pain experiences prior to IUD procedures or about available pain relief options. While it is not possible to predict any individual's experience of pain,¹⁹ some users shared accounts of their risk of pain being minimised on account of characteristics such as parity, resulting in a mismatch between their expectations and experiences. These accounts align with other qualitative research demonstrating that some users of long-acting reversible contraception (LARC) report receiving incomplete information about associated risks, and that this limits their ability to make an informed choice.¹⁴ Our findings support guidance from the Faculty of Sexual & Reproductive Health (FSRH) that all potential IUD users should be advised that insertion pain can range from none to severe, and that analgesia should be discussed and offered.¹⁹ Further research is needed to evaluate counselling practices and uptake of this guidance in current clinical practice.

A second key finding relates to role of lived experience in this public discourse about pain during IUD procedures. While Twitter users expressed a sense of validation and community through sharing and relating to one another's testimonials, they raised concerns that lived experience of IUD procedures is not valued as evidence or used to inform clinical guidelines and practice. Prior qualitative research has explored patient experiences of LARC removal requests,^{14 20 21} LARC self-removal^{22 23} and IUD insertion for postpartum patients specifically.²⁴ However, there is a dearth of qualitative medical research exploring patient's experiences of the fitting procedure once they choose this method, or of the removal procedure in medical settings.

IUDs are a safe and effective method of reversible contraception, with high levels of satisfaction reported among users.^{25 26} Echoing this, tweets in our sample described the benefits of IUDs and shared support for its use. However, our study also reveals accounts of substantial negative consequences in cases where patients reported pain that they were not adequately prepared for, or that was not appropriately acknowledged or responded to. These included avoidance of future gynaecological examinations and procedures, a sense of disempowerment, embarrassment, and erosion of trust in professional practice. These accounts attest to the need for strategies to evaluate and improve the patient experience for those opting to use IUDs as a clinical priority.

Strengths and limitations

The major limitation of this study is sampling bias, since IUD users who experienced substantial pain may have been more inclined to share tweets in response to pain testimonials. Hence this study cannot inform questions about the incidence of pain in IUD procedures (nor did we set out to answer that question). The nature of the sample was such that we did not know the geographic origins or any demographic data of Twitter users whose posts we analysed. There is evidence that demographic characteristics including race may influence how providers counsel patients about IUDs²⁷ and how clinicians assess and manage pain in general,²⁸ and there is a need to explore this in future research. A limitation of using Twitter data to gain in-depth insights is that tweets are short by nature and may lack important additional context. Unlike with interview studies, for example, it is not possible to make further enquiries to gain additional information which may be relevant to interpretation of the data. Our search was limited to tweets shared across a 2-day period; we therefore may have missed other important narratives that are relevant to this public discourse.

A strength of this study is that multiple coders (NT, FIA, A-MB, H-MvdW) collaboratively performed the analysis, each with different backgrounds in terms of discipline and experience. NT is a community sexual and reproductive health doctor; A-MB is a qualitative health services researcher; H-MvdW is a medical doctor and social science researcher, and FIA is a public health doctor. Some members of the research team have varied personal and professional experiences of IUDs as users and as providers. Given that in reflexive thematic analysis, researchers are active in the research process and interpret data through their individual lenses, we consider this multidisciplinary approach to be a strength of the study. Although all coders read the entire dataset of tweets for familiarity with the data, tweets were not formally 'double-coded' (though such an approach is not universally recommended in qualitative research).^{29 30}

CONCLUSIONS

In this study we set out to understand the nature of public conversation on Twitter about pain and ‘the coil’ following media coverage of high-profile testimonials. Notwithstanding the limitations of our sample, we address a gap in medical qualitative research and report important findings about public perspectives and experiences of pain during IUD procedures. Our findings support the need for strategies to improve the patient experience as highlighted in the recent Women’s Health Strategy for England.⁵ Central to the accounts and perspectives shared on Twitter is the need for patients to be well-informed about the full range of possible pain experiences and available analgesia options, and for pain to be appropriately acknowledged and responded to. We call for more research which places the experiences, expectations and wishes of those with lived experience of IUD procedures at its centre.

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Contributors NT conceived and designed the study, performed data screening, led thematic analysis and drafted the manuscript. WA performed the data collection and contributed to the manuscript. H-MvdW and FIA contributed to the study design, thematic analysis and manuscript. TG contributed to the study design and manuscript and provided supervision. A-MB contributed to the study design, thematic analysis and provided supervision. All authors have read and approved the final manuscript. NT is the guarantor.

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Competing interests None declared.

Patient and public involvement We formed a patient and public involvement (PPI) group including people with lived experience of IUD procedures, some of whom have shared testimonials on social media platforms. This group reviewed and gave their input on the study methodology and recruitment materials. The details of this publication have been shared with Twitter users contacted via the study Twitter account; this account is now private to protect the privacy of users contacted.

Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants and the authors obtained ethical approval for this study from the University of Oxford Medical Sciences Interdivisional Research Ethics Committee (Ref: R77414/RE001). Participants gave informed consent to participate in the study before taking part.

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