Unknown Speaker 0:05
Welcome to this podcast series on evidence in women's health brought to you by the Center for evidence based medicine and the postgraduate program in evidence based health care. My name is Dr. Anne Marie Boylan, and I'm a senior researcher and lecturer in the program, and together with Associate Professor Jamie Hartmann-Boyce, we'll be interviewing relevant experts discussing the strengths and limitations of different sources of evidence as they relate to women's health and considering their implications for future research. This episode focuses on intrauterine contraception commonly known as the coil. In June 2021, two high profile women in the UK, TV presenter Naga Munchetty and journalist and author Caitlin Morin, shared their severely painful experiences of coil fitting. In an article in the Times Caitlin Morin called for pain relief to be offered to all during coil fitting, she wrote, why is it presumed that women will be fine with having their cervix artificially dilated? We know that opening the cervix is infamously painful. It's legendary that when it happens naturally during birth, it tends to chauf a bit. This prompted Naga Munchetty to give a visceral account of her coil fitting done by her GP without any sedation or pain relief. She described screaming in agony so much so that her husband in the waiting room tried to find the room she was in to demand and enter the procedure. The nurse assistant had tears in her eyes, Naga fainted several times. She described her GP as great unprofessional, and afterwards, her GP told her that she also felt terrible about it. Naga concluded this wasn't about the coil, but about how seriously we take women's pain. In response to this doctors were quoted in the media sympathizing with stories of coil fitting pain. But caveat Agnes with the statement that severe pain is rare that the coil is a highly effective form of contraception, and that women shouldn't be put off getting hit by these types of stories. Given the uncertainty around who feels pain, I spoke to Dr NEDA tag Hannah jadie, a sexual and reproductive health doctor and academic clinical fellow who specializes in fitting coils for those who have had problems having them fitted by their GP or who have experienced trauma and require a highly trained specialist. First, I asked her to tell me about coils and about pain during fitting

Unknown Speaker 2:14
Intrauterine contraception is the very medical term for what is often called a coil in UK language. So it's a method of contraception, which sits inside the uterus. And there are, broadly speaking two different types, types that release hormones. Those are called hormonal coils, or types that don't have any hormones but work through the use of copper. And that's called a copper coil. They can be used for contraception, and they're both very effective methods of contraception. But there are lots of other reasons that people might use them. And that includes for things like heavy menstrual bleeding for menopause. So lots of different reasons why someone might choose to use in to try and contraception, they are really safe, really effective methods. So the using intrauterine contraception in terms of avoiding pregnancy is as effective as as sterilization actually. But as with any method of contraception, there are downsides to them to thinking first about the copper call. So the non hormonal method of contraception, one of the main downsides is that it can make your periods heavier and more painful. And so obviously, that makes it really unsuitable as a method for lots of people who already have heavy painful periods thinking a little bit about the hormonal coil, for example, what often we call the Mirena or the Jade s, there are different hormonal side effects that people might experience with those methods. And those include things like mood changes, abnormal bleeding patterns, breast tenderness, and other hormonal side effects. So the procedure to have an interview, train contraception, or a coil fitted, most often on awake people, although you can have it done with a general anesthetic, or with sedation as well is exactly the same whether it's a copper call, or whether it's a hormone or coil. And although as I said, it's the safe and common method, and it is a safe and very commonly done procedure, there are some risks. So common risks include experiencing pain to the possibility of experiencing pain during the procedure, there's a small chance of infection, there's a small, very small chance so around one and 1000 risk of what we call perforation, so accidentally making a hole in the room when we fit the coil. And after the procedure, there's also a risk of the coil actually falling out.

That's what we call expulsion. And that risk with any type of coil is around 5%. There is a huge range of normal experiences. Most people do not have severe pain. But equally I wouldn't describe having severe pain as a rare event. So just to go into some of the research around this. So to explain that in more detail. There are some different studies that have looked at this question. So in the UK, there was one study where over 100 women who had cause inserted, were asked to rate their pain on a scale of zero to 10. And in that study 16% describe their pain as being between seven and 10 16%, experiencing more severe pain. In another paper based in Brazil, they found that 33% of women had pain between the level of seven and 10. And it's really hard to compare different studies because there are differences in the medical and obstetric histories of these different populations. And researchers ask women about their pain in different ways. But overall, what we can say is there's a real range of normal experiences. It looks as though most women do not have severe pain. But equally, like I said, having severe pain is not a rare event, it's actually not possible to predict who will experience more severe pain or who will experience less pain. And just to add to that uncertainty as well, it's important to highlight that different parts of the core procedure are painful for different people. So there are a few different stages to a coil procedure, we insert a speculum into the vagina to see the cervix, then we put a clip on the cervix, and then we measure the womb and fit the column those last bits, those last stages are in the uterus inside the womb. And there's a huge range of in the experiences of pain for each of those different stages,

Unknown Speaker 6:14
given the uncertainty about pain during coil fitting. I then asked her about the types of pain relief that can be offered and invited her to discuss some of the key evidence around them.

Unknown Speaker 6:23
There are a few different methods of pain relief that are available and that have been studied to look into how they help with those different stages. And those options include pain medicines, like non steroidal anti inflammatories, and other medication that's been researched as misoprostol, which is a medication that's used to soften the cervix. And also there's been some research around local anesthetic and that can come in multiple forms a gel or spray or as an injection. And there's a useful Cochrane Systematic review from 2015 which summarizes a lot of the evidence around these different methods. And just to highlight a few different points from that review, so there's no evidence that my as Apostel the medication that I mentioned that softens the cervix reduces pain. And also most non steroidal anti inflammatory medications do not seem to reduce pain, stronger medications like Tramadol and approx in have some effect on reducing pain. And some local anesthetics do so that includes cream on the cervix, a 4% lidocaine gel, so that's a gel with a slightly higher percentage of anesthetic in it. And a lidocaine injection, that's a local anesthetic injection have some effect on reducing pain. But it's important to note as well that some forms of anesthetic was specifically the Lidocaine injection that goes into the cervix can also cause pain themselves in terms of national guidance. So the faculty of sexual and reproductive health, they're the organization that governs what we do as contraceptive providers. They issued a statement last year saying that all people should be offered pain relief during core procedures. But the guidance doesn't specify which type of pain relief so it doesn't say whether that should be tablets, anesthetic, gel cream or injection, it just says that all people should be offered pain relief. And hopefully some of the discussion we've highlighted already kind of raises some of the issues around selecting an anesthetic option. And beyond going for sedation, or a general anesthetic, which, of course, are valid options. For people who are awake during a core procedure, it's not really possible to predict which parts of the procedure that find painful, what level of pain they'll feel, or which anesthetic option they benefit from. So that's why each and every time we felt like, well, it's so important that we counsel, the person in front of us about that uncertainty, and about the options that are available and make a plan together to pick a tailored pain relief strategy for that individual did a UK paper which looked at levels of pain, these researchers asked the clinicians fitting the coil to estimate the

level of pain that their patient experienced. And what that showed is actually, as clinicians, we underestimate patient's pain levels. Again, I think that is such a powerful reminder that we are not well placed to make decisions about pain relief for our patients in isolation. Actually, we need to be making them in partnership,

Unknown Speaker 9:17
it's clear that there are significant problems with coil fitting, including a lack of guidance around what pain relief to offer and about who might feel pain. So I asked her to tell me more about the research. She's currently leading on coil filling, and about what other gaps need to be filled.

Unknown Speaker 9:31
Right now I'm leading a project exploring the experiences that people share about coil and sessions on Twitter, actually. So just a bit of background to this past year in June, there were some really high profile stories about the coil, where journalists, Naga Manchetty and Caitlin Moran talked about their own personal experiences of pain during closed session. And the response across multiple platforms were huge. I was coming across hundreds of tweets from people sharing their earnings. periences In response, and that included people who had had cause inserted, but also healthcare professionals sharing their perspectives. And it prompted a real national conversation that had a huge impact on my specialty, and certainly prompted lots of discussion within my own department around how we manage pain, and on a national level that led to a statement in response from our faculty, the faculty of sexual reproductive health. So my feeling really was that it's important for us to use this as an opportunity and understand what are people sharing in these tweets, you know, what is the nature of the strong reaction and the national public conversation? So for this research project, what we're doing is a thematic analysis of tweets that were shared in the days around those testimonials to understand the nature of the tweets and the experiences that were being shared online, ready to see what lessons we can learn from them. And this project has been really eye opening had the real privilege of reading through over 1500 tweets, and we're looking forward to sharing the results and see what lessons we can learn as coil fitters. One of the things that was a really dominant message in this set of tweets is that when people do experience severe pain during closed session, they feel misled and lied to you by that counseling, being told that most people have mild or moderate pain, or that a little discomfort is the normal experience, you then feel totally abnormal. If you have more pain than that, and you feel deceived by your counseling. And a lot of people on Twitter highlighted this contradiction, you know, this mismatch between what their clinician had told them to expect and then what they actually experience, it's impossible not to draw a connection between that sentiment. And the study that I mentioned that I found that as clinicians, we do tend to underestimate women's pain. And another key message that was actually really dominant in the tweets was the sense that women's voices were missing from the evidence that they had not been asked about their experiences. And then when you look at the research, and yes, there are a number of systematic reviews, looking at different types of pain relief. But actually, there's virtually no research exploring what women experience in their counseling, what they experience in the procedure, or what their expectations or wishes are. And that is a real gap that needs to be filled.

Unknown Speaker 12:19
I suppose one of the main things that strikes me is we really don't have enough research here, you know, the things we've heard referred to seem, it's a start, but compared to other areas, we really don't know. And also the kind of misinformation I suppose that is present in people having coil fittings is quite shocking. And just generally, I find pain, a fascinating thing to study, because we have all of these pain scales, which somehow try to just break this down into a quantitative issue. But what also strikes me is the extent to which we need qualitative research as well, you know, I have a very high pain threshold, I'd say. And so it also makes me think my answer on a visual analogue scale would be very different than someone else's going through the exact same thing. So yeah, I am fascinated to hear about this from both a personal and evidence based

perspective.

Unknown Speaker 13:13
And also the fact that pain can be contextual. So pain in some areas might be worse than pain in some other areas. And how do you predict that in advance? Yeah, and as Nick explained, the difficulty with coil fitting is that when a coil fitter meets a woman, there's nothing to help them determine whether this woman will be somebody who experiences severe pain or not. So that makes their job tricky. And it makes pain counseling tricky as well, because they can't say in advance who will feel severe pain.

Unknown Speaker 13:44
Exactly. And I remember like, so I, myself had a C section, two C sections. Both were planned. And then the first one, the anesthesia didn't particularly take, which was fine, because we figured that out. But they're like, You are very relaxed right now. And I was like, Well, I have a lifetime of experience in pain free living with a chronic health condition. So I don't tend to get too wound up about it. Right. But that also made me think about if they're just looking for visual signs on my face, to tell them whether or not something is working, probably I'm not giving away as much as maybe I could be in terms of that experience. But one of the things, especially an area where we clearly don't have enough research and don't have enough research funding, I found it really interesting to hear about use of Twitter in this space, because it seems to me that things like Twitter, or even like online discussion forums could be potentially such a rich way of getting information for studies. It's free for us to access feels really I don't know if easy is the word but accessible for students, for example, who might be doing projects where they don't have fun and they can't get ethics approval. They can't reimburse participants for their time. And I wonder about the strengths and limitations to these approaches. You know, one thing that I always think about when I look at experiences of people online is the The chance that his representative seems low certain voices of the population may be more likely to express experiences via these means. And are there anything that you might say to researchers, particularly maybe Junior researchers who are thinking about making use of something like Twitter or Facebook or online blogs to help inform their research? Is there anything that should be mindful of

Unknown Speaker 15:19
Absolutely. And qualitative research using forums and online resources like that isn't new. So researchers have been doing it for a very, very long time. So there is a precedent for this type of stuff. Twitter, obviously, is one of the relatively newer social media platforms in terms of the internet, it's not new at all. Exactly. And yeah, so it's, it's an interesting place. Obviously, the main difficulties are around the amount of contextual information you can get, because you can't really find out who has tweeted the thing that they've tweeted. So that's a bit of a problem, because in qualitative research context is key. And we need to know intricacies about this particular person before we can fully understand that in saying that, what we can do is produce descriptive research to explain the types of things that people present on social media in relation to a phenomenon and this research that Neda, is leading which I have had the pleasure of working with her on along with a number of other colleagues scraped the tweets about coil fitting around the time that several high profile figures in the media here in the UK talked about their own horrible experiences of coin fitting, so it was all based on that. And what we've ended up with is a good number of tweets, so several 1000 of them that we have looked at and analyzed in quite a rigorous way. So we developed a structured codebook and analyze the data in light of that, and then have developed some themes around the experiences of pain and what needs to be done. So I think what you could say about Twitter or other types of social media platforms, is they provide a quick way of accessing data about something but not comprehensive data. And of course, we'll acknowledge that as a limitation within this study, there are ethical issues. So students who are approaching this type of research should gain ethical approval, because even though these things are publicly available, people aren't posting them with a view to them being used in research. So in the

Twitter study, what Netta has been doing is contacting women who have tweeted that we would like to quote in the paper and asking their explicit permission to quote them interesting. So we've, and we have ethical approval for yesterday as well. So I think that's important, okay. And ethics committees are familiar with this type of research. So it's not difficult to get the permission for it, so long as you've thought through all the issues that may affect your participants.

Unknown Speaker 17:35
Absolutely. And I suppose it just whatever wants doing things like this, I always try and be mindful the digital divide right in terms of who and does and does not have access to the internet and various technologies. And this is not at all related to the topic of coil fitting. But we recently published a meta analysis led by a colleague at Leicester looking at essentially what lockdown appeared to do to blood glucose levels and people living with diabetes. And the vast majority of studies found that if anything, blood glucose improved during that period, but there were a couple of clear outliers. And what we realized was the majority of the data we were getting were from people with continuous blood glucose monitors, who had them hooked up to their clinic records via the internet, and were uploading their information. And that is not necessarily a representative sample of the population. And in the one really clear outlier, they were collecting information in a different way. And there you saw people who were struggling to access medical care, and things got notably worse. So it's always been really mindful, I suppose we get things off the internet, or that rely on certain technologies that we are probably looking at, on average more privileged population,

Unknown Speaker 18:40
and very definitely a subset of the population. As you say, there is no doubt that intrauterine contraception is beneficial. And historically, all forms of contraception have been one of the key factors in liberating women through offering them reproductive choice and also a means of alleviating painful periods or menopausal symptoms. But the fact that women can experience extreme pain as a result of coil fitting definitely requires further research as Netta explained the research and guidance around pain and who might feel it and at what stage of the procedure it might be felt is lacking. She also highlighted research led by Hannat Akintomide from 2015, showing that doctors can't effectively assess coil fitting pain by observing women this may be due to socially ingrained norms about women's high pain tolerance and implicit social rules around how and when women should express pain. Having spoken to NEDA about all this several things are clear to me. Doctors can't rely on their observations to determine how painful the procedure is and women need to be made to feel comfortable in expressing their pain. More research is definitely needed into both patients and doctors experiences of coil fitting and better evidence about who might experience pain and how to medicate. It is also needed. Thanks to Jamie for discussing this with me and to NEDA for sharing her incredible clinical and academic expertise and thank you for listening

Unknown Speaker 19:58
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Unknown Speaker 20:08
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