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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. In this episode, we're discussing endometriosis. Endometriosis is when tissues similar to that that lines the womb grows outside of it. It largely affects the reproductive system and can cause severe and debilitating pain. It can also affect fertility. Typically, women experienced lengthy delays in getting a diagnosis here in the UK woman's first port of call is to see their GP and GPs are often blamed for the diagnostic delays and criticized for not being sufficiently informed about the condition. But some recent research studies have shown that this oversimplifies the problem. And in fact, the issue is more complicated than that. I recently wrote an article for the conversation about how the gender pain gap and the attitudes to women's pain may be to blame for delays in diagnosing endometriosis, and had the pleasure of working with Dr. Annalise Weckesser and Dr. Sharon Dixon on this both have researched endometriosis from the perspective of GPs, and also of women as patients and I interviewed them both to learn more about their work and to try to unpack the complexity around diagnosis. Dr. Annalise worker Sarah is a senior researcher at Birmingham City University and a medical anthropologist specializing in women's health and gendered experiences of sexual reproductive and menstrual health inequalities. She's conducted several studies on endometriosis and other issues that affect women's health. I started by asking her what the main learning points from her body of work to do where my role I do research around gender and health and especially around menstrual health, reproductive health, and sexual health as well. With a real focus on gender gaps in health.

Unknown Speaker 2:02

The main findings across all of my research on gender and health, and it's primarily done with women, is the way in which health issues women face come to be internalized and blamed on themselves and something that they're battling and that there's something internally wrong with them. And there's a lot of individualization and a lot of guilt that comes with that. And that's from across all my studies on endometriosis around STIs around C sections around having epilepsy and giving birth. There's just a lot of guilt and internalization of health issues that women face. So that's across all of my research. And then when it comes to endometriosis, main thing that comes across is what other qualitative researchers find around endometriosis is the long arduous journey of getting a diagnosis which can take up to a decade, and how that has not changed over the past 20 years. And this now what we can start calling as medical gaslighting would be a more well known term for what women describe experiencing, of not having their accounts of their bodies and their accounts of pain and their accounts of their symptoms believed that would be the main theme. So Professor Elaine Denny, she is the one who's done the most research, qualitative research on endometriosis in the UK, and she did numerous studies in the early aughts. And then her and I work together more recently, around 2018 on a study of women's experiences of endometriosis treatment, and what was most startling that came out of that research is Elaine saying that women's narratives of being disbelieved and the inadequate treatment of medical treatment that they were receiving and relief from their pain, how that's not changed, or how not much had changed within 20 years across those studies. From the early aughts to the more recent one, what we weren't finding were people telling us that health practitioners would dismiss their pain, often their menstrual pain and their period pain as typical as just normal period pain, but periods are supposed to hurt. So that was a major one why things haven't shifted much and two decades where the diagnosis times haven't improved. And also there hasn't been any breakthroughs in treatment and 20 years. So the main reasons for that is one endometriosis. Just it's not a priority condition. It's not a priority condition for GPs to explore or for there to be research on. And that's indicative of how women's reproductive health research isn't generally a

high priority when it comes to research monies and, and breakthroughs. And then endometriosis remains really poorly understood because of that, because we haven't had much progress and research remains a disease that is really there's so many unknowns - endometriosis is a really complex disease that doesn't follow typical biomedical models of health, where a woman could have a lot of endo tissue and very little symptoms or the reverse, you could have extreme symptoms, and then surgery reveals that she has very little tissue. So it remains a poorly understood disease. But then, like I said that primary first one is that women's own accounts of their suffering of their pain are still just dismissed.

Unknown Speaker 5:35

Dr. Sharon Dixon is a GP and NIH or doctoral research fellow, whose research also focuses on women's health, including things like female genital mutilation and menopause, she conducted an important study with GPs across England to learn what considerations they take into account when a diagnosis of endometriosis is suspected. First, she told me about what led her to do this research and also how she conducted it.

Unknown Speaker 5:58

There's really important evidence about the difficulty significant and well documented delays that women can face between presenting to a GP with symptoms and then being able to receive or achieve a diagnosis of endometriosis. What we didn't know from looking at the quantified data around the delays in diagnosis and the journey through consultations and symptoms is how that is the deliberative processes or the reflections or the things that might underpin or maintain or create those journeys and how those arise. And there will be multiple such journeys. GPs are often identified as being an important area to consider. In these delays in diagnosis, it's certainly been suggested, in conclusion by some of this work that GP awareness and knowledge when needed to address these documented delays. What we wanted to understand was GP perspectives on how they approach supporting somebody who presents to them with undifferentiated symptoms, because that's what we do in primary care. By the time somebody gets a referral to secondary care, there's been a series of filters and analytic steps and initial diagnostic tests. We weren't asking what people knew or didn't know or understood or didn't understand, what we were really trying to explore was how GPs understood using the knowledge that they had and how they navigated their way. Through that journey. We used a neutral vignette, which was co developed with people with lived experience of endometriosis seeking care, and which was very much a starting point. We weren't constrained by it. We weren't confined by it. But we just used it as a launchpad for what are the things that you might think about, if somebody came to your room saying, I've got terrible period pain, I've had it for a long time, I've come off the call, it's really got worse. So we gave them that scenario. And then through the interview, we could develop the scenario a little bit, but that was the core idea was that we weren't asking them to give accounts of what they had or wouldn't do in difficult scenarios, we were asking them to think about how they would approach the thinking to solve this problem. We were able to speak to a wide range of GPs across five Clinical Research Network regions across the UK. So I'm very grateful to the CRN for their help with that. And that meant we spoke to people working in urban areas where there were tertiary specialist centers, but also more rural areas where there wasn't a local specialist center. And we also actively didn't recruit through Women's Health Network. So we didn't proactively seek out GPs with a kind of special interest in women's health care, or working in specialty centers, we were trying to get as much of a real world experience as possible. Next, I asked Sharon, what she found in the course of her study, and she told me about the complexity GPs face and diagnosing endometriosis. And interestingly, even those who were very well informed about endometriosis find diagnosis difficult. And this relates to the huge range of symptoms associated with endometriosis that could also be attributable to other conditions. One of the really central and key findings was how complicated and complex this navigation can be. When what you have is someone presenting to you with relatively unfiltered or on assessed news symptomatology or developing symptomatology and concerns. And even with good awareness of endometriosis. There were steps and there were processes and there

were complexities to navigate. And that took thinking and it took collaboration and it took time to GPS reflected that, you know, they're supporting women throughout the life course. So they would be seeing teenagers with very painful periods. They'd be seeing women throughout their whole reproductive life and and through into the menopause. And at each stage of that presentation, there were potential complexities, you know, certainly as women got older, if they had very heavy painful periods, then needing to consider gynecological malignancy, but actually that was a pervasive concern throughout. So it was difficult. And the approach that GPS told us that they took was about trying to work with the woman understand what her concerns and her priorities were. And if what they wanted was pain relief. And if first line treatment worked, then that was very helpful. But that actually unearthed a really important uncertainty, which was actually also reflected in guidance. So the guidance is offer first line treatment. And if symptoms are not well controlled, then consider referral for further investigations or assessment. What primary care withholding was a really complex, difficult uncertainty about what you do and having how you might navigate the situation where you put somebody on first line treatment, and actually, their symptoms are very well controlled. And actually, what we reflected was that if the symptoms remained well controlled on something like menstrual suppression with the combined contraceptive pill, or with hormonal contraception for five or six years, and then they were stopped, and then the period pain came back, but perhaps also there was difficulty in conceiving. And then we're referred, when we look at those original retrospective studies we talked about that would look like a seven year delay in diagnosis. And arguably, it is, but how we understand representing that and how we navigate it and how we might mitigate against it or improve it is not as simple as saying they didn't know, I think there is some reflection about the communication and the collaboration and the shared decision making and what information needs to support that. So I guess that journey is different if both the women and the GP know that there might be something else underlying it. But they have decided that while things are well controlled, that it's not the woman's priority to pursue it. And actually, that was also very clear GPS were very clear that if women wanted diagnosis they would refer on but they also had a lot of lived experience that when symptoms were very well controlled. With first line treatment, even if you did refer on you would still achieve a probable diagnosis and may not be referred for further investigations. And I think it is important to reflect that one of the difficulties with endometriosis diagnosis, although I recognize that this is evolving, but at the time of the study, the understanding was that it would usually respond to require a laparoscopy. And that's a procedure with risks and GPS also talked about their concern of supporting people who had pain arising from the diagnostic test itself, particularly if these had been perhaps repeated over the years or how even a laparoscopy could have a false negative and that that was very difficult. So the whole process could be really complicated. And you are holding all these uncertainties for the here and now but also into into the future to knowing how to personalize or tailor conversations or interventions or advice about tests or interventions or care was also something that was lumbar, the GPS reflected on. And I think what that showed was that some of these complexities weren't about what GPS didn't know actually, a lot of it represented how much they did know and including what they knew about what perhaps isn't known.

Unknown Speaker 12:58

Annalise also talked about the complexity of diagnosing endometriosis, and about GPS role as gatekeepers in terms of women's access to care. She shared a really interesting study she did with linguist Dr. Stella Buelow about the metaphors women use when describing their symptoms of endometriosis., and how familiar GPs who were well informed about endometriosis were with them.

Unknown Speaker 13:17

After working with Elaine and hearing that after 20 years, not much has shifted, I wanted to do a research project focused on GPS focused on people that we could consider the gatekeepers to being referred on to specialist care and the Lane had told me that that won't be possible GPs are so hard to get, they have no time and also GPS because of the power dynamics. They're used to being

the ones doing the investigating, rather than being investigated, or they're the ones used to doing the research rather than being researched. So that's when I partnered up with Stella Buelow, a linguist at Manchester, Matt and Stella had collected over the years all these metaphors of people with endo use to describe their pain. And what we did is we did telephone interviews with GPs and some gynecologist as well. And we presented these metaphors that people use to describe their pain to see if doctors how they recognize them if they were useful to helping them diagnose Endo, and also the study was more about doctors perspectives on treating people with perceived endometriosis. So some of the really interesting findings that came from that study was one as found elsewhere. GPs and gynecologist find diagnosing endometriosis incredibly challenging and incredibly complex. And this was even for the GPs who were actively seeking not to miss it. So these weren't GPs that didn't know much about endo or there was a knowledge gap they felt they had themselves gone and taught themselves more about endometriosis and they felt really committed not to missing such diagnoses because they know how much they've been missed. And they know about the delays. And so they take it really, really seriously because of that. And so even for these GPs, they found it really, really challenging because the symptoms around endo can present a so many different possible conditions. The other one was how that pain score that typically gets us of asking someone to rate their pain from a scale of one to 10 how both women and doctors reported that wasn't very useful because they just found it very subjective and didn't get to the quality of the pain. And so doctors talked about they really preferred using measures of asking how pain or symptoms impacted someone's life, their day to day life, they found that much more useful, like can you get out of bed? Can you go to work? Are you able to do social things? how is this impacting your relationship, but then, when we presented those metaphors that women typically use to describe their endo pain, these metaphors that could be quite violent, they're often about like poker, a hot poker in my stomach dabbing pains. And when we presented these to doctors, they did say they recognize them. But a minority just a few did not recognize the metaphors and they said if women to use those, they would suspect a different condition. And these are often around bowel pain, which endo can present. And so that does speak to a need for more understanding about the various ways endo can present. Endometriosis wrongly, still often gets considered as a solely gynecological condition or a menstrual health condition. So people doctors will think that that means it's in in the pelvis region only, but you can have urinary pain, bowel pain, pain in your knee, running the international endometriosis Social Research Network. We were so thrilled to see how endometriosis got highlighted and profiled in the women's strategy, but with a big caveat, we were really disappointed how the women's strategy still has no dedicated funding to it. There's no money specifically going into more research or how to improve existing care. And 10 years ago, there were 63 endometriosis specialist clinics introduced across the UK. And despite the introduction of those clinics, diagnosis delays have not decreased in fact, they've only increased with COVID and the backlog of referrals they've only dramatically increased. The other main criticism of the women's strategy was it really presented that the way we're going to improve things around endometriosis was to address the knowledge gap.

Unknown Speaker 17:39

After listening to Annalise and Sharon talk about their studies and their broader body of work. I think several things are clear, lengthy delays in diagnosis aren't simply attributable to a lack of GP knowledge and calls for more education for GPs deflect from the range of other issues at play. Endometriosis is a complex condition that can mirror others and sinister life threatening conditions also need to be ruled out equally. Treatment and Research and endometriosis need to be improved. Historically, there's been a gender health gap in health care. With women's suffering inequalities, their pain is often dismissed and treated less aggressively than men's treatments trailed on men have been routinely prescribed to women without adequate understanding of the effect on their bodies and women often suffer poorer outcomes when treated by male doctors and the gender health gap is even more marked for women from racially minoritized groups in the UK, black women are less likely to be

diagnosed with endometriosis than white women. And this could be attributable to poor access to health care. Nonetheless, research is desperately needed to understand and rectify these injustices. One of the questions I had is when we think about qualitative research and when I hear people talk about the different study designs they're using and the different theoretical angles they might be taking. I don't know how to tell if it's a good study or not. Or even if there is such a way to categorize qualitative research, what should I be looking out for when I'm reading a qualitative study in qualitative research, we tend to look at the hows and whys rather than the frequency of something with a prevalence. And to do that we use methods like interviewing and observation and focus groups. So we ask people about their perceptions and views and experiences. And there are lots of ways of approaching this where methodological approaches grounded in various philosophies, like phenomenology, and there are a whole range of sort of philosophies that we draw on in order to do this work. So it's always systematic and rigorous, or we should always aim for it to be systematic and rigorous. I think if you're not well versed in qualitative research, it can seem messy, and it can seem unscientific and anecdotal. But really what we do is prioritize the voices, experiences and perspectives of the people who are mostly affected by the topic we're researching. And in terms of what makes a good qualitative study, you might instinctively think that bigger numbers means more data, and therefore better understandings of something. And that's not necessarily true. It's probably much more important that we speak to the right people, so sampling the people who are affected by a topic. And a range of ways might be one of the more important things and thinking about it from whose perspective and another really important aspect of what we do is acknowledge that we as researchers, and anybody else who's involved in the research from the collecting data point of view or interpreting a prospective need to be able to reflect on what they bring to the data and their understandings of it also to the sampling and recruitment, to setting the topic to every aspect of the study and thinking about that in a way that ensures that we can take a step back and try not to influence the data themselves. And like in quantitative research, there are various sorts of checklists that can be used or have been developed for use in qualitative research. And they are not without their problems. And, in fact, in a couple of papers that I've written with Veronica Williams and David Noonan, we've been quite critical of these checklists, because they don't necessarily focus on issues of importance that that may affect quality. And so in addition to the checklists, there are also frameworks which are difficult for people new to qualitative research to use, because they require quite a bit of existing knowledge. One of them, for example, was written by Lucy Yardley in 2000, and is still very commonly used, and I think is one of the more broadly all encompassing types of frameworks. And she talks about sensitivity to context, which means thinking about the context of the research and ensuring that you have taken into account all the relevant literature and the theories about the different topics that you're researching, and so on commitment, and rigor is the next one. And this is about sort of in depth engagement with the data and with the topic. So it's nothing surface level, we're really going deep and trying to understand the nuance of the the research, transparency and coherence which means essentially being transparent, and ensuring your research can be seen as trustworthy. And a lot of that is down to reporting and having a clear audit trail. And interestingly, she's also added one about impact and importance. So doing work that has value and will have an impact for the people that affects rather they suppose, than blue sky thinking, which is also very important. But I suppose in health research, what we want is actionable insight, and results as quickly as possible.

Unknown Speaker 22:13

Thank you so much. I will definitely become talking to you. If I do more qualitative research. I think it segways into the next big point that I wanted to bring out from what I listened to in those interviews, which was about research that adds value research with impact, so much of that seems dependent on political and cultural contexts. And what really became clear during some of your wonderful interviews were the fact that these areas are often not considered particularly impactful are often under researched. I know there's a new women's health strategy from the government in here in England, which is

maybe trying to help fix that. Could you tell us a little bit?

Unknown Speaker 22:52

The women's health strategy for England was released in August this year 2022. It outlines key priorities for improving women's health. Nearly 100,000 people in England responded to the call for evidence for it in the form of a survey. Over 93,000 of these were women who shared their personal experience, in addition to over 5000 other respondents including health professionals, partners, family and friends. And the strategy does a couple of things. It outlines a areas identified as priorities to women about their health, and these include menstrual health and gynecological conditions including endometriosis, fertility, pregnancy, pregnancy loss, menopause, mental health and well being cancer, healthy aging, and long term conditions and the health implications of violence against women and girls. It also presents a set of ambitions about improving women's health for each of these areas, including a call to ensure their voices are heard. But all recent public inquiries and scandals that have affected women, including the issue of trans vaginal mesh and the ockenden report repeatedly call for women to be listened to. So this is one stark area where there's quite a shocking wide scale failure. And the women's health strategy also highlights how women have been neglected from research and how research has neglected women and how they've been let down by research treatment and clinical practice. And it calls for this to be improved.

Unknown Speaker 24:09

That's really interesting. It's actually something that I do a little bit of teaching around, is thinking about representation in research. And though it's great, the strategy is asking for that reporting. I think history might suggest it's not quite enough. So an example that I often use is when we think about women's participation in cardiovascular research, we know that women are less likely than men to be diagnosed with cardiovascular disease early and to receive appropriate and timely intervention, which is really critical when it comes to outcomes with cardiovascular disease. And that I think, is widely acknowledged to be in certainly there was a Lancet Commission on Women and cardiovascular disease back in 2019. That concluded that the structural gender bias in cardiology stems from a historical failure to ensure gender balance in cardiology research, but one of the things I found really interesting about that is that this isn't a new finding, right? We've known this from at least, you know, the 1980s. And by the mid 1980s, the US Public Health Service Task Force drew attention to this issue with a dearth of data on women. And the US National Institutes of Health began requiring the reporting of women's participation in clinical research. So exactly as our women's health strategy is doing here. However, two decades later, women remain underrepresented in these clinical trials. And that's a real issue. They The Lancet Commission concluded that a few reasons for this are higher prevalence of comorbidities in general older age and women's compared with men's having cardiovascular disease. So we often kind of think of heart attacks as occurring in men, but they occur is commonly in women, it's just like they commonly occur a bit later. Additionally, of course, and one of my particular, it's a really complex area, but perhaps a bugbear is exclusion, often of women of childbearing potential, or people of childbearing potential in clinical trials, which prevents young women from enrollment and a lot of studies. So it'll be interesting to see this monitored, but at least it'll be more clear and transparent, maybe we'll see more needs to be done. And I suppose the other thing around that is, it's really easy to say, oh, women are underrepresented, or people of color are underrepresented, or older people are underrepresented. But of course, none of those things exist in silos, there are issues of intersectionality, we need to consider. And I wonder if the women's health strategy talks about that at all.

Unknown Speaker 26:33

So that is another really interesting point and a very important one, because women of color typically, as we know, tend to be diagnosed later with certain conditions, and don't maybe get the same treatment as white women do. And, you know, I think the medical perspective is off white male bodies as the predominant focus. But next is probably white female bodies, and not the bodies

of women of color. But yeah, in the strategy in terms of who responded to the call for completion of the survey, there were quite a small number of women of color. And so obviously, this doesn't fully represent their voices. And I think the main overarching stuff that will make a difference from the Women's Health Strategy, is this push for better information for people in general, how that's going to be done. I'm not sure but hopefully through research and better research funding for women's health, although, of course, there's no funding attached to the women's health strategy. So it's quite an ambitious strategy. But without the practicalities needed to underpin it in terms of taking it forward. The other thing I should say is that doctors are cited as people who should be better informed about women's health. And I'm not sure that's always the case. I think as Sharon has explained to us, there's a lot of complexity around certain women's health conditions. And also the research just hasn't moved on in the way that it should have. So as Annalise was saying, the work that Professor Ely and Danny has done has shown this sort of reiteration of the same type of themes coming up in the qualitative work in terms of women's experiences of endometriosis 20 years after her initial studies. So a lot of this research is lagging behind and treatment is lagging behind. So it can't just be on doctors to present best information we understand the complexity of the conditions and how complex diagnosing this type of thing is, rather than just saying they need to be better informed and they need to do a better job. Thanks Jamie for discussing this with me and also thanks to Annalise and Sharon for sharing their incredible expertise. And thank you for listening. For more information about our research teaching and postgraduate courses please visit www.CEBM.ox.ac.uk. Please subscribe to iTunes and stay tuned for our next episode.

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