

Airing Pain Programme 87: Vulvodynia

From diagnosis difficulties to defining gender: the effects of vulvodynia on women today.

Paul Evans: This is *Airing Pain*, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for healthcare professionals. I'm Paul Evans, and this is the first of two editions funded by the Women's Fund for Scotland.

Winston de Mello: I would reckon one in seven women will suffer vulval pain some time in their lives, and it's a disease that is frustrating to suffer from because there's nothing to see usually.

Rebekah Shallcross: A lot of women used the phrase 'I feel like am I going mad? - is this all in my head?' just because they were repeatedly told 'I can't see anything so therefore there's nothing wrong'.

David Nunns: Some of the women I see are quite disempowered by the whole process. They have tried to access healthcare, but often the problem has been belittled or they've been given an inappropriate treatment and that's been a barrier.

Paul Evans: The vulva is the female external genitalia, the sexual organs, and vulvodynia is a condition where there is no skin disease, no infection, but the patient complains of burning, rawness or soreness in the vulval area. Dr Winston de Mello is a consultant in pain medicine at the University of South Manchester.

Winston de Mello: When you have vulvodynia which is essentially a nerve based pain it's very different from the classical pain, like when you break a leg; the leg gets fixed and your pain goes away. With vulvodynia, the nervous system is involved and consequently the nerve misfires. So patients with vulvodynia will complain of burning or soreness down below, they cannot tolerate clothing or [their symptoms] might be provoked by clothing, exercise, insertions of tampons or even sexual intercourse. And you can see that the impact on their quality of life is huge, and also on their partners' and families'.



The trouble is you see what you want to see. So for the general practitioner who's got less than five minutes to make a consultation, if they're lucky they may be sent to a specialist – and this could be a gynaecologist, it could be in genitourinary medicine, it could be a vulval dermatologist, or even a pain physician if there's somebody interested in that area – so I think it's a bit of a postal code lottery as to where they go. And this is what starts that long process of making the diagnosis.

Paul Evans: Dr Winston de Mello. Dr Rebekah Shallcross is a trainee clinical psychologist and research associate at the University of Manchester. She presented a paper on women's experiences of having vulvodynia at the British Pain Society's Annual Scientific Meeting in 2015.

Rebekah Shallcross: My research is split into two different parts really. The first part is a review of the literature that's already out there. A lot of that literature is around women's experiences with the sexual nature of vulvodynia and the impact upon relationships. But also, that research comes from a discourse analysis perspective, which basically means that it's looking at how women talk about their experiences, and it analyses how they speak about it and infers meaning. So they talked about the journey towards a diagnosis as actually being quite harmful, quite long, quite difficult, quite emotionally draining.

Paul Evans: That was Dr Rebekah Shallcross. Dr David Nunns is a gynaecology consultant at Nottingham City Hospital. He is a trustee of the Vulval Pain Society.

David Nunns: It's actually very easy to diagnose, it's a bedside diagnosis. So we'd expect a health professional to take a history, carry out a proper examination of the vulva using a good light, excluding skin disease and infection. And then based on the history and the examination a health professional should be able to diagnose it at the first visit. So it is an easy diagnosis: there's no need for any biopsies or additional MRI scans etc which have been done in the past, so it is an easy diagnosis to make based on the proper assessment.

Paul Evans: Well, if that is so, why do some women report the journey to diagnosis, as Rebekah Shallcross was saying earlier, as harmful, difficult and emotionally draining? Winston de Mello again.

Winston de Mello: It's a disease that is often confused with other problems; common things are candida or fungal infections, urinary tract infections or sexually transmitted diseases, or sadly sometimes even the premalignant states. So it's a diagnosis by exclusion, like most chronic pain conditions. The first thing you must be absolutely sure is that you have no red flags, i.e. no other explanation for this disease. So you've got to exclude the skin problems, the premalignant states, the malignancies and other differential diagnoses, and that is why it's important, to a certain extent, the journey that a patient has to go [on]. So quite often these patients will doctor shop, will see so many specialists before the diagnosis is made.

Rebekah Shallcross: They experienced a lack of awareness of vulvodynia within the healthcare system. They encountered attitudes from healthcare professionals that were particularly unhelpful, feeling that some of the attitudes were simply because they were women. So for example they felt that they were labelled as neurotic or as frigid, or that they just simply needed to relax. 'Get in the bath and have a glass of wine' was something that a lot of women had been told, which is obviously particularly unhelpful when you're in constant pain.

Attitudes around women and sex, again, so ideas that perhaps if they didn't have a male partner that there wasn't really anything to be worried about. All of these things – the attitudes of some healthcare professionals, I have to say not all, and the longevity and the need to be very very persistent, to keep going back to your GP, to keep asking for referrals, the need to do research yourself and look on the internet and see what clinics are available and ask for referrals, and a sense of having to do all the work themselves – all of those things had an impact on women's levels of distress and their levels of pain as well.

Winston de Mello: Most doctors are trained to treat disease first. So in primary care the GP is trying to exclude a potential malignancy or some other disease process like inflammation or infection. There has to be a triage process by which the patient has got to have these diseases because obviously if you've got a disease that results in vulval pain then you've got to treat the disease first, and then the pain that coexists.

But if you've excluded all the red flags, i.e. all the diseases, then you're left with this cohort of patients where there's nothing to find. When I was in my youth these would be labelled as psychosomatic or psychosexual. Then it turned out that maybe it's a dermatological problem so a lot of dermatologists got involved, and then the neurologists got involved, so it's a very



complex interaction [between] lots of factors which is why sometimes patients can fall in between the different clinicians.

Paul Evans: Is there a particular age when women might get this?

Winston de Mello: Twenty or thirty years ago I would say this was a young woman's disease, late teens/early twenties. Now we're finding [cases of vulvodynia in] children even younger, in the early teens, and even in the post-menopausal level, so it's quite a big spectrum with a big peak in the late teens early twenties.

Paul Evans: And you have no idea what causes it?

Winston de Mello: We have some suggestions of why it might occur. It may be chronic infection – previous exposure to infections – it may be a virus; it may be drug induced; it may be trauma from repetitive stress injuries, so it's a constellation of several things and the fashion changes as we get more information.

Paul Evans: Pain consultant, Dr Winston de Mello. Dr David Nunns again.

David Nunns: When I did my initial research nearly twenty years ago we found that the average length of time from the onset of symptoms to getting a diagnosis was around two years, because of lack of awareness. I think that's probably come down in time in recent days because of better awareness amongst health professionals and women, but also the internet as well and people accessing information.

But there still seems to be a delay in accessing the right people. So people almost get stuck at a level of healthcare and can't get beyond that level, and that's what we really need to address: get the right patients to the right health professional.

Paul Evans: So how do you address that?

David Nunns: The awareness of vulvodynia at a health professional level is very important; that's at the level of a GP, a gynaecology service, dermatology, genitourinary medicine service, and also a chronic pain management service as well. So all levels of health professional dealing with women's health probably need to be aware of vulvodynia, and I



think we've made some progress there. But also enabling health professionals to know when to refer on. Because if they're not confident in management then they need to send on, and not all health professionals are confident or happy examining the vulva and taking quite a personal history of some of the women.

I think the other issue is the awareness of vulvodynia in the public as well. Despite being in this very sexualised society – much more so than twenty years ago – we have more awareness of vulvodynia but we still have a great difficulty for some women to come forward; to actually see their GPs and to then get a referral onwards. So there's that empowerment that some of our women need to make that first step. That again is difficult because it's a very isolating, private condition: often many of our patients feel they can't talk to anyone about it, they can't share their problems.

Rebekah Shallcross: Women often talk about things like believing for instance that in order to be a woman you have to have penetrative sex, and so obviously for women with vulvodynia that can be quite problematic. Now we might call that a kind of social construction: you know, to be a woman you don't have to have penetrative sex and there's lots of examples out there of, for example celibate women or lesbian women or women who simply don't like to have sex, and who still identify themselves as women.

So there's lots of these social narratives and discourses that women sort of subscribe to and believe in that can actually be challenged, and [it] can be helpful for women to challenge those social discourses because those things can cause psychological distress to women. So it's not all about the experience of pain, it's about what the experience of pain means to women.

Paul Evans: Do you mean women who choose to be celibate as opposed to women who can't have penetrative sex, they do not choose to be celibate, so there are bigger issues in their minds?

Rebekah Shallcross: It's not necessarily about celibacy, it's about what we constitute as "real sex". What a lot of women talk about is a loss of intimacy, but there are other ways to be intimate with a partner. And you're right it's not to say that that's not difficult for women, but that there might be other ways around that that don't involve penetrative sex but can still involve pleasure for women and also a sense of intimacy with partners as well.



Paul Evans: Rebekah Shallcross. So is there a stigma involved in a woman's decision not to go to her doctor? David Nunns again.

David Nunns: The impact of vulval pain on an individual is so variable. Some of our patients have a chronic pain issue, an unprovoked pain that impacts on their daily function. And, as in any chronic pain condition, that really does impact on the way they lead their life, and I don't see, in that group of patients, that there is a stigma attached in going to a health professional and getting access to care. They need help, basically.

Where there is less of a day to day pain management problem but more of a sexual pain problem – with an unprovoked pain aspect to their problem, that might be the case as well – then I think the impact on the dynamics at home in a relationship within, we call it the biopsychosocial model don't we, where people are at home, living in the living environment and they're functioning in the work environment, that can produce a complex problem that doesn't necessarily lead them to access help. And it's very easy just to forget about the problem in many ways. Whether that comes down to an embarrassment or a sort of legacy of stigma I'm not sure. I think there are a lost group of patients really who never access care because they've not been able, confident enough to come forward in the first place, and whether stigma's attached to that I'm sure it is yes.

Rebekah Shallcross: Guilt and shame are certainly things that women talked about experiencing in relation to their relationship, because they believe that as a woman they are expected to provide sex for men. Relationships that were able to have what they term an egalitarian discourse, which basically is an equal discourse so that one person isn't prioritised over the other, in those instances the communication between the partners was more open. Because of that they were able to have an open discussion about what each other wanted, and that enabled them to both, kind of, come up with creative ways to be intimate as a couple and to be happy as a couple.

And an example of that in a paper that I was reading, one woman talked about completely moving away from her partner in terms of physical contact – so, you know, not even hugging or kissing because of where that might lead – and she was able to talk to her partner about that and he was like 'Oh! You know I don't care about that. If you want to give my bum a squeeze-' I think was the phrase she used, 'then that's absolutely fine, that doesn't mean



we've then, you know, that that's going to lead to something that's going to be painful for you'. So in that sense, because they didn't prioritise the male's need over the female's need they were able to come to an arrangement that worked for them that they were both happy with.

Paul Evans: Is there still a legacy of what I guess was the Victorian idea of sex that the woman's job was just to lie back, suffer and think of England?

Rebekah Shallcross: Well it's interesting you say that because that phrase was also used by some of the women. One of the women that I spoke to used the phrase – and again I have to stress that this was in some instances, generally earlier on in the journey, when women got to specialist services it was a kind of different story – but yes, one of the women used the phrase 'sort of like the Old Boys' Brigade'. So, you know, women are going into these services and they're often seen- it's not necessarily about being a man in the system it's about what kind of beliefs you have. So they encountered difficult attitudes from women as well. But yes, I think women did speak about sort of patriarchal attitudes within the system; that was certainly a phrase that one woman in particular used, and her thoughts really were around, economically, women aren't as important, so we're not contributing as much to the economy as a general statement. And that was her view [of] why this was seen as unimportant.

Another phrase that was used a lot was if this was a man, would I be having the same difficulties accessing help? So a lot of women compared vulvodynia to impotence and were saying that, actually, if this was something that was affecting men would there be more research into it and would I be able to access help more quickly?

Paul Evans: Rebekah Shallcross. Winston de Mello again.

Winston de Mello: I think the most important thing is to reassure these patients that the natural history of the pain is not forever. Up to 70% of women would get better anyway if they didn't even have an intervention by the medical profession. So that's the good news.

But what we can do is help that patient through their journey, and it's using several strategies all at the same time. The most important being coming to terms with a chronic illness, and I think the best sources of information there are things like the website of the



Vulval Pain Society, just getting some basic, everyday standards of care in place. And then you've got all your other strategies: medication and more complex interventions, nerve blocks and in very rare cases surgery.

But probably more important than all that is the psychological support, coping with the disease and knowing that there are other people around. So having patient study days that are run either locally or regionally or nationally are just as important for the woman to realise she's not on her own, and it's not unique.

David Nunns: 'There's no doubt that people get better from this condition' – what does that mean? In our outcomes when we look at what happens to patients we're looking for an improvement in their symptoms, so their pain will go down, they will have fewer flare ups of pain in an average week or month, their function will improve, they might go out the house more, less time off work, doing more things that we often take for granted, sometimes their mood can improve because they're in less pain, and the final outcome we look at is their confidence in self-management. I would say that those are key outcomes for patients really: less symptoms, more function, improvement in mood and confidence in self-management.

And we can see that across the board, I think about 70% of patients, improve and feel happier with the treatment that they get. Now that treatment will vary according to the needs of patient, so some patients on a scale have very minimal symptoms and need simple reassurance in self-management, and some patients are very complex and need to be in pain clinics with a multi-disciplinary team.

But essentially we think of four 'P's': 'P' for patient education and knowledge; second 'P' is the pain modification through our pain modifying drugs, either creams, gels or tablets, or even more advanced pain modification; third 'P' is physiotherapy or physical therapy to the pelvic floor muscles; and the fourth 'P' is the sort of psychosexual, psychological support, CBT type strategies. So we can draw on quite a large evidence base of treatments and pull out lots of themes that work for women, and when we put them all together those four 'P's' – and they all sort of go hand in hand – you get an overall package of care that often works. It's a bit like making a sandwich: you have your base layer and all your ingredients. I sort of say to patients don't use just one thing in isolation, try and add in the different layers of those four 'P's' to the overall package to get the benefit.



Rebekah Shallcross: One of the key things that women said would help was to really do a lot of research yourself. And I'm not saying you should have to, but once women got to services that were set up to help women with vulvodynia then progress was made. I think predominantly because women felt that their pain was taken seriously, getting to specialist services was important, and also multi-disciplinary services were really important.

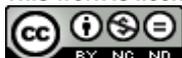
So there was quite a few papers that looked at multi-disciplinary groups that women could attend, so intervention groups, and they looked at things like psychotherapy to address the psychological consequences of having pain and also going through this system repeatedly, things like physiotherapy, things like mindfulness – they were all particularly helpful.

Those are quite individual treatments, they are targeting women. What I would like to see more of is ways of helping women challenge some of those unhelpful narratives that we talked about earlier. Those are some things that can be very distressing for women if they buy into them, but if we can challenge some of those things, move more towards that egalitarian discourse as opposed to 'I'm a woman and therefore I have to provide sex for my male partner' then those challenges might actually be quite helpful in terms of the distress that vulvodynia can cause.

Paul Evans: I mean you say 'egalitarian discourse', discourse would be quite good. Just people speaking to each other.

Dr Rebekah Shallcross: Yeah, opening up communication, absolutely. That is very difficult for women, I think, to talk about, because there's such a taboo around women and sexuality, you know. It does take a lot of bravery, but from the women that I spoke to, their expectations about how people reacted – they thought that people would think that they were weird or that people would not really understand. But actually the women I spoke to who did speak to friends and family found that they were actually very accepting of it, and that in itself, as you say, opening up communication, was helpful.

Paul Evans: Going back to your first 'P', patient education. We talked about getting information off the internet; I've never heard of vulvodynia, I had to go on to Wikipedia last night to find out what it was. How do you increase the information, or the way of finding information?



David Nunns: There's often too much on the internet and it is confusing. And that's why I always go back to those four 'P's because the message is so confusing for a patient. In that patients can know about vulvodynia but what they really want to know is the treatments – where do I go to, and who do I go to? I think that will always be an ongoing battle with the internet and what's available. We would always say through the Vulval Pain Society, because we know that many visitors don't have a diagnosis, 'you need to see a health professional'. We don't want you don't want to self-diagnose vulvodynia and you've got a skin problem.

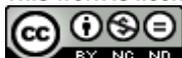
The Vulval Pain Society was set up in '93 as an information support network for women with vulval pain. I set that up with a nurse in Manchester in '93 with the aims of just providing some information because at the time there was nothing at all. Over the years we've increased our web presence and we've tried to be sensible and holistic about the condition, and we've certainly been able to be the group that health professionals refer to.

For the health professionals we've a slightly different tack really. We introduced into the training curricula of gynaecology and dermatology and genitourinary medicine doctors a mandatory teaching on vulval disease, which included vulvodynia. So for our gynaecologists of the future, who are seeing most if not many of these women, the curriculum in the past was quite poorly developed, it was probably one sentence. So we've changed that to include a proper assessment, history and detail on basic treatment for vulvodynia. So they have to do it basically, and when you make something mandatory it suddenly gives it a platform. There's a need for them to learn about vulvodynia, which is a good thing I think.

Paul Evans: What advice would you give to a woman who thinks she has this?

David Nunns: The key thing for women who haven't got a diagnosis who are experiencing vulval pain is they need to access a health professional who's going to listen to them, take a history, examine them. They can go along to their health professional with a mention of vulvodynia and ask the health professional 'do I have vulvodynia?' as a simple question.

If they're happy, if they're satisfied with their care, that's fine. If not then I think there needs to be a next step really. What we might call a clinical pathway, which is the journey for the patient. That service might be gynaecology service, it might be what we call a vulval clinic, which is a clinic that's dedicated to vulval disease.



If a patient's at the beginning of her journey, she's been diagnosed with vulvodynia, then I think she needs to read as much as possible about the condition and look at those four 'P's. And this is difficult for some patients. They have to take self-management and take control of their own care plan, you might call it, because at the moment the current system is quite fragmented and disjointed. And that's quite do-able I think for many patients, not all.

And I think for those women who've got vulvodynia and they've been living with the condition for many years, I think medicine's changing very rapidly. You know I think about where we are now, where we were five years ago, ten years ago, there are a lot more treatment options out there, both medical and non-medical. Just keep reading and keep a look out really for new developments because there are new developments, things generally are getting better.

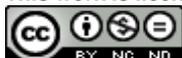
Paul Evans: So what you're saying is 'Something that didn't work for you five or ten years ago, things have changed. Try again'?

David Nunns: Explore things again. The drug that might have been tried in the past, where the quality of life was worse on it than off it, may have changed. So the sister drug might be out now that might be better. That sister drug might be a cream rather than a tablet, so it's less likely to give you side effects.

Sometimes you need to think outside the narrow focus and the medical model. Some of my patients have had tremendous improvement with psychological therapies and psychosexual input. It was never offered perhaps in the past, but the offer may be there now.

Physiotherapy, I think, has been an underused treatment in the past. Probably more or less non-existent ten years ago for this problem, less so five years ago, but now physiotherapists are very interested in this condition. So it's just opening your eyes again and having a refresh really at what things you've tried and what you could try in the future.

Paul Evans: That's Dr David Nunns, gynaecology consultant at Nottingham University Hospital. The address for the Vulval Pain Society is <http://www.vulvalpainsociety.org>. I'll just remind you that whilst we in Pain Concern believe the information and opinions on *Airing Pain* are accurate and sound, based on the best judgements available, you should always



consult your health professional on any matter relating to your health and wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

Don't forget that you can download all editions and transcripts of *Airing Pain* from Pain Concern's website which is <http://painconcern.org.uk/>. There you'll find information and support for those of us living with chronic pain, our families and carers, and for healthcare professionals. There's also information on how to order Pain Concern's magazine, *Pain Matters*.

In the second of these two editions of *Airing Pain* supported by a grant from the Women's Fund for Scotland, we'll be exploring how the conditions of Interstitial cystitis, Painful Bladder Syndrome, impacts on the lives of women who have the condition.

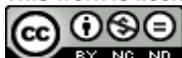
Pat Brown: The symptoms were as if every step I took someone was stabbing me with a knife up my vagina, there's no other way I can explain it.

Jennifer Hayes: All you can really do, because you need to be near a toilet and it's so painful and you feel just generally so unwell, I sit on a hot water bottle and just read or watch telly.

Pat Brown: and then the pain radiated out from there. I couldn't sit all, I was in pain all the time.

Paul Evans: Painful Bladder Syndrome, its effect on women's lives, and how to manage the condition will be in the next edition of *Airing Pain*. That address for the Vulval Pain Society once again, it's <http://www.vulvalpainsociety.org>. Now, to end this edition, a bit of good news for those who think their doctors don't listen to them!

Winston de Mello: I am proud to say that I have learnt more about vulvodynia from my patients than from my clinicians.



Contributors

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