

GP Link Lunches | Rashmi Pithavadian, vaginismus research

Dr Kenneth McCroary, Chair of Sydney South West GP Link, hosts a series of meetings with clinical/political/regional individuals or organisations to discuss issues and solutions for GPs working in South Western Sydney.



Rashmi Pithavadian Dr Ken McCroary

Sydney Southwest GP Link is often working with other representation organisations in our region on behalf of General Practitioners. A fellow PHN member organisation Western Sydney University is one such organisation. Recently I caught up with Rashmi Pithavadian, a qualitative research consultant sessional academic at the School of Health Science and School of Medicine at Western Sydney University. Rashmi is a PhD candidate and health sociologist working as a sessional academic and researcher at Western Sydney University. As part of her research she has interviewed people who have vaginismus and health professionals who understand how help seeking for the condition can affect sense of self and health behaviours. Her current PhD work is focused on developing health care resources to support women with vaginismus. While her special area of interest is painful sex in women she also undertakes research, teaches and publishes chapters and journal articles on sexual and reproductive health and broader public health issues. Her award nominated research and teaching centres on the perspective of people who are marginalised to improve their experience of health, treatment and wellbeing. She is also an experienced qualitative researcher who has provided extensive consultancy to support the qualitative component of health-based projects. These projects have been with local health districts, Colgate, Australian Research Council grants, University of Sydney and Western Sydney Universities. Following contributing to Rashmi's research project I thought it would be a good idea to spend some time more formally discussing these often neglected or poorly understood health conditions affecting a significant proportion of the population. In that regard I am really pleased to welcome Rashmi and thank you for taking the time to talk with me today.

Ken McCroary: Rashmi you call yourself a health sociologist. Can you explain what that actually is?

Rashmi Pithavadian: Being a health sociologist is using a sociological lens to approach health issues. My area of interest is sexual and reproductive health so what I do is look at how certain social factors, social interactions within the health care system, for example, or other aspects of health then impact people's experiences of the condition that they may have. My specific research is focused on vaginismus, which is a female sexual dysfunction, but in general I have used health sociology to research and understand how different aspects of society, social interactions and other sorts of social elements impact health for people with sexual and reproductive health issues. This includes social determinants like class, gender, sexual orientation, disability, socioeconomic status for example and how that will affect the way people can seek help for health conditions or how they can access health care resources, how it might impact them in terms of general awareness or lack of awareness in society about sexual and reproductive health issues as well.

Ken McCroary: Great. Thank you. Now you mentioned earlier you are interested in sexual health, reproductive health and particularly the PhD you are working on supporting women with vaginismus and we were initially in contact with your project. For those that aren't familiar can you talk a bit about explaining vaginismus for those that aren't as confident with the topic?

Rashmi Pithavadian: For my Masters research I looked at how women were seeking help for vaginismus and how it affected their sense of self. For my PhD I am looking at how to create a health care resource for health professionals to use alongside people who have vaginismus. Vaginismus is a female sexual pain disorder and while it is defined like that it can affect anyone with the genital anatomy for it regardless of their gender identity. It does tend to affect people that identify as women more often, largely because the population has more people that identify as women. When you have vaginismus, when any type of vaginal penetration is attempted, whether that be a gynaecological examination, tampon insertion or sexual intercourse, that will then trigger a response where the vaginal entry will contract or close and this can make any type of vaginal penetration painful, difficult and/or impossible. Naturally that can cause a lot of mental, social, emotional and physical impacts on people's lives who have the condition. Apart from making sexual intimacy quite difficult because of pain, it can affect relationships and mental health. It can make a lot of people feel anxious, increase the risk of depression, suicidal ideation, self-esteem issues as well. In saying that, it can be quite difficult to seek help for the condition because a lot of people don't understand so that's where that sociological lens can be helpful to understand what are the societal perceptions and understanding of vaginismus and how does that then shape women's experiences to actually seek help for the condition and how does that potentially complicate having the condition and how can it be useful or helpful for them to relieve their symptoms and improve their quality of life.

Ken McCroary: Quality of life certainly is a significant issue with this syndrome and other chronic pain syndromes isn't it?

Rashmi Pithavadian: Absolutely. Quality of life has such a big impact with things like vaginismus and other sorts of sexual pain disorders and I think sometimes that's overlooked. A lot of the time when people hear about it they think the person has difficulty with penetration and that's it but it has a lot of implications and ramifications on people's lives. If you are having trouble with vaginal penetration, first of all in terms of sexual intimacy that's going to affect the relationship you are going to have. Vaginismus is one of the leading causes of unconsummated relationships and marriages in women's lives and it can affect the quality of relationships. It can make it very difficult to start a family for people who are interested in doing that. Research has also shown that people who have vaginismus, their partners also have a higher risk of developing sexual dysfunction as well. It is something that has quite migrating effects on others too. Having vaginismus, any sort of sexual pain disorder really, that's going to affect mental health especially when you're a woman and you're comparing yourself to your friends or even in the media or in society when people are always talking about things like their sex lives, how good their relationships are. It will affect how you view yourself, your relationship, your self-esteem. In my research I found a lot of women said they stopped seeking out relationships, they stopped dating because they felt like they weren't enough if they couldn't have sex the way they wanted to. It affects their relationships in that way which is a very big part of quality of life if someone is seeking out a relationship.

It can exacerbate pre-existing mental health predispositions or conditions like anxiety. It makes a lot of people feel anxious that they are not going to get better and that anxiety can spill over into other things. In my research I found that some women pointed out that it was affecting their sleep because they were worrying about how they were going to get better. Not many health professionals understood or were able to help them, they felt like their partners were withdrawing. It was taking a big toll not only on their sexual intimacy but on their own personal mental health. Even moving aside from the sexual and relationship aspects and looking at the person's own experience, if people with vaginismus have difficulty having a gynaecological examination that can make it very difficult to have pap smears. It leads to a lot of them avoiding getting pap smears done because they are afraid it will cause a lot of pain and it's something they can't endure so that's something to consider as well. In terms of quality of life that can have a big impact if you are unable to do the health checks you need to do.

Some women, depending on their line of work, some of them had said they were unable to use tampons which they actually needed to use. This was for women who had developed vaginismus as a secondary condition where they had a normal period where they didn't have problems with vaginal penetration and suddenly got vaginismus, they found that it had changed the way that they were able to do things and that impacted the quality of life. Even with other conditions like vulvodynia, with vulvodynia the genital pain you experience is not restricted to just vaginal penetration. A lot of people with vulvodynia have vaginal and genital pain constantly and that can make it very difficult to even move around depending on the severity. There are some women that have both – they have vaginismus and on top of that they've got out vulvodynia or they might have endometriosis or something like that. There are a lot of comorbidities that need to be considered in management and that can then make quality of life even harder and exacerbate that when they have vaginismus.

Ken McCroary: It is certainly a challenge for the women and other people that have this syndrome. We talked about the way sometimes their interaction with their healthcare professional had not always a positive and, sometimes a very negative impact, on their quality of life and their long term therapeutic options and their long term willingness to seek future help. I thought that might be a lead in to getting some insight into the clinicians' perspective, the health professionals, and the impact they have on the women with the condition.

Rashmi Pithavadian: I'll start off sharing what the women I have interviewed have said about their experiences and link that to what healthcare professionals have said as well. With the women I've interviewed, I interviewed 20 women that had vaginismus and one that identified as agender. What was interesting about the people I interviewed pointed out it sometimes took a long time to actually gain a diagnosis of vaginismus. This was because the health care professionals they were consulting didn't know about it or they gave them advice that wasn't helpful. Some of them had gone to healthcare professionals and GPs saying they tried attempting sex and it was very painful and they're not too sure what to do, they've never been able to use tampons and they didn't connect the two together but now they are starting to wonder if there is something wrong. They were getting responses from some health professionals saying "no, you probably aren't relaxing enough, maybe have a bath". There were occasionally comments like "maybe have a glass of wine and relax a bit more" but what these women had noticed was that it wasn't really helping. Sometimes they weren't being taken seriously enough.

That speaks to other research that there is an androcentric inclination within the healthcare system and what a lot of these people I interviewed had pointed out was that it sometimes took them years to get a diagnosis, to get treatment, to gain the appropriate support from health care professionals. They had to do their own research seeking out other health care professionals. Some women unfortunately had taken breaks, as in they had a couple of years where they thought that they can't be helped, they've got something that's very wrong with them that no one else has and that's why the doctors couldn't diagnose them and so it took them having a life changing event or starting a new relationship to make them actually want to seek help again. And then they realise that "it is a diagnosable condition, I just need to find the health professionals that can offer that support for me". Health professionals, so far I've done 23 interviews with health care professionals that treat vaginismus or had patients or clients who have had vaginismus. I've spoken to an array of GPs, psychologists, gynaecologists, urogynaecologists and pelvic floor physiotherapists. The majority of them have pointed out they think vaginismus is not very well known in medical spheres. It was aligning a lot with what the people with vaginismus I interviewed have said as well – that there is a lack of awareness. There is a lack of awareness about vaginismus in society, in the public spheres as well, but there also tends to be a lack of awareness in medical spheres too. That's very interesting because the healthcare professionals had pointed out when you look at social media, TV shows, movies, things like that you might have certain comments about male dysfunction like erectile dysfunction, premature ejaculation, and it's not that it's in a positive light and the presentation of those conditions is not positive either, but as a result of that there is a bit more social awareness about those conditions. With vaginismus and other sexual pain disorders, it's not really talked about and it's not presented or portrayed in media. Some have mentioned that it's only the recent TV show, Sex Education, that for the first time had presented vaginismus very briefly and even shown the vaginal trainers as well that you use to treat the condition.

There was a consensus amongst health professionals that there could be more medical awareness, training and focus on vaginismus. Obviously when you're a GP, you have a limited time to see a patient, you can't fix the problem there but to know this isn't just a case of the person can't relax and needs to have a bath or have a glass of wine, maybe this is a bit more serious. Maybe it's out of my scope but I recognise it's a problem and these are the appropriate referrals I'm making so the person can then seek the help that they need. A lot of the time that's what women are looking for – to be taken seriously that something is going on and they just want answers. A lot of the women I interviewed had said that sometimes healthcare professionals had questioned them are you sure that you were lubricated? Were you aroused enough? And they felt like that wasn't really the issue and maybe what they were saying wasn't being taken seriously. It was great to hear so many health care professionals' perspective on that. A lot of them had reiterated that point that it's really important to listen to patients and clients and what they are saying because if you don't, it can lead to them having negative health seeking experiences. Having those negative health seeking experiences of not feeling heard, not being taken seriously to get the appropriate diagnosis, not being heard and not being referred onto the appropriate professionals to receive the appropriate treatment can have that domino spiral effect that impacts women's mental health. They start feeling negatively towards themselves like everything is hopeless, nothing is going to work, I'm stuck like this, and it turns into quite a negative isolated mentality of I'm the only one that has this problem. That was definitely something health care professionals noted as well as the people that had vaginismus that I interviewed.

Ken McCroary: It's challenging the fact there are lots of conditions that aren't taught well in undergraduate medical school but it's a kind of disappointing excuse to be downplaying and invalidating people's presenting symptoms and signs. Any thoughts you are having so far in ways we can improve that?

Rashmi Pithavadian: I think the important thing is not to be invalidating. I teach at Western Sydney University as well and I do teach health sociology units to year 1 to year 3 medical students and something they would sometimes say is that in other topics they had undertaken, they were taught you shouldn't trust the patient. I found that quite a few students were saying that if the patient says something don't just assume that it's true, it may not be what you think, maybe they are hiding something, and I think it's about not always having that mentality. There might be situations where patients might say something and if you have reason not to believe it that's one thing but if you've got a patient coming in and saying it's so painful to insert a tampon, every time I try to have sex with my partner I just feel like it's not working, it's too painful. I feel like sometimes not having that mentality that you automatically distrust the patient, that distrust can almost lead to the invalidation. Certainly not all healthcare professionals do that but I think there might be a link between being taught this attitude of don't trust what patients say and that leading to the invalidating advice. I think it's just important when someone comes to see you and is telling you, especially when they are talking about pain and how bad they are feeling, I think it's good to take them seriously.

Moving away from trust or distrust and taking it seriously and thinking okay this sounds like a problem for them, just acknowledging it in that moment as a health care professional. If you can't obtain objectively how much of a problem it is, still recognising they are talking about a quite sensitive issue, a lot of people are not comfortable to talk about painful sex and things to do with your genitalia, acknowledging and appreciating they have come and are talking about this complaint. Even if you don't know and you can't gauge what the problem is or how severe the problem is, trusting that 'okay they feel like they have a problem so I need to take that seriously' and making an appropriate referral. If you can't make the appropriate referral in the moment or you're lacking that knowledge in the moment it might be worth even in the consultation itself quickly looking something up so you can see these are the symptoms, it could be this and I might not diagnose it but I can look up and see that it's usually treated this way and I can refer them onto a pelvic floor physiotherapist. For GPs they are always very time poor so that's something to keep in mind, but I think moving away from that attitude of you can't always trust what patients are saying and viewing it as they are talking about things like pain and sensitive issues we have to trust that.

If they are bringing it up, it is a problem for them so taking that seriously and making the referral or if you are unsure how to make the referral quickly looking through your sources in that consultation so you can at least tell them what the next step is because that's where a lot of people get stuck – invalidating advice and they don't know where to go from there. Hopefully health care professionals can move away from making comments like that and instead think about what's the next step I can direct the person to. I think having that approach would be really helpful and can give the patient a sense that there is something else I can do and I don't have to just sit with these symptoms because I'm not being heard.

Ken McCroary: Yeah, supporting people, taking it seriously and acting upon their signs and symptoms not letting them down which is very disappointing. You mentioned more broadly the marginalised health impacts upon certain individuals with marginalization in society and being a sociologist how do you cope with that? What do you see day to day in this region now that you are working in Western Sydney?

Rashmi Pithavadian: Even in my research what came up was people depending on where they were living, so if they were living in the Blue Mountains for example, they pointed out it was very hard to see regular pelvic floor physiotherapist because they were far away from the pelvic floor physio they needed to see. They said they weren't very high income earners which meant they had to take the day off work which also complicated things so what I found and what a lot of them had pointed out as well was that location definitely does make a difference as well as income. If you are in a situation where it was hard for them to take the time off they found they were having to postpone their appointments and they were seeing pelvic floor physios twice a year rather than monthly which is what the pelvic floor physio had ideally recommended. Part of that was also transport. They said having to take the whole day off, drive there and pay for parking and things like that, doing the exercises, waiting to see the health professional and driving back definitely plays a part.

I have also spoken to people who have lived in rural areas, so just outside metropolitan Sydney, and they noted that sometimes they were only able to actually see the healthcare professional they were referred to when they went to the metropolitan areas and a lot of them had been working in rural areas as well so it meant that again it made it very delayed. That is something that may not always be talked about in vaginismus. In vaginismus the treatment and the management of the symptoms you need ongoing support, ongoing health care professional support in terms of psychology sessions and pelvic floor physiotherapy sessions or seeing a gynaecologist if you have pelvic pain comorbidities or multi-morbidities as well. That regular contact with healthcare professionals can make treatment more successful and can result in better management of symptoms and if you have a lower socioeconomic status or have to work a lot more, there are patterns where people are living in areas where they are not very easily able to access the necessary healthcare support to get them regular contact. In comparison, I had some people I interviewed who were lucky enough to be supported by their parents or were living a more centralised Sydney area and they talked about how for them that was something they could access more easily and in interviewing them, they seemed to have achieved the treatment progress they wanted and sooner as well so that's something that in terms of geography needs to really be considered.

Other aspects as well relating to things like ethnicity and culture. I did have some people who I interviewed they talked about when they first came to Australia they didn't really understand the healthcare system and it was very hard for them to figure out who they were meant to be seeing. Since Western Sydney is very multicultural there are other implications to that that can sometimes impact health seeking especially for vaginismus which is already quite a sensitive issue to talk about. If English isn't your first language or you are not very proficient in English or you don't know the health care system very well and you are a recent immigrant to the country it becomes another barrier you have to navigate in order to be able to seek and receive the help you need. If English isn't your first language, that makes it very difficult to be able to even articulate quite specialised and sensitive symptoms you're experiencing to healthcare professionals so I think ethnicity and culture can sometimes be another barrier in the greater western Sydney area. Also sometimes the topic of religion came up.

Some people said they felt pressure, often due to their families, to get better really quickly but it just added more pressure than not and obviously things like gender - not everyone with vaginismus identifies as being a woman so keeping that in mind as well. That's something that if health professionals don't recognise or consider that people can feel like they aren't being understood or supported enough and that can then lead to another negative health seeking experience of feeling misunderstood, not acknowledged and that can lead to a downward spiral. So definitely a lot of factors that are prevalent in the Western Sydney area as well.

Ken McCroary: You certainly come across with much passion and commitment to marginalised people and individuals in need. Where does that come from? How does that develop?

Rashmi Pithavadian: I've grown up and lived in Western Sydney my whole life. There are all these different pockets. There are pockets in Western Sydney where there are a lot of issues in terms of things like access, lack of resources and health care and things like that and there are other parts of Western Sydney where as time has passed on it has been getting more urbanised. I think having seen the different walks of life and challenges people have in Western Sydney I think that's something I feel like I have lived in parts of Western Sydney so I can definitely see how it can be so challenging for others and I can definitely empathise with that. I, myself, sought help in the health system and I can see how challenging it's been. There have been points in my life where I haven't had much money and that has made it a lot more difficult to seek help. As someone who has sought help for healthcare conditions in Western Sydney and knowing what a big difference various aspects like economic status, income, finance, culture, ethnicity can have on the success of your health seeking I think seeing it on both sides, like being in a position where I didn't have much and seeing how that changed as I got more, has also made me feel like that is really not fair. If I can do something that can raise awareness or seek information that is going to close that disparity that's something I just feel I'm passionate to contribute to seeing as I've seen and experienced those different challenges as well.

Ken McCroary: Great. Thank you. I guess last question about vaginismus and sexual health disorders is about the management of these conditions will develop or are you feeling a little bit treading water in the fact that has there been change? I know we've got endometriosis clinics being developed and menopausal centres in South Western Sydney being developed. But do you see the repetitively of that less gendered focused health system you mentioned earlier happening or should we really be doing much better?

Rashmi Pithavadian: I do think there has been improvement broadly speaking in terms of women's health issues and I guess trying to move away from that androcentric inclination, but I still think a lot more needs to be done. It's great that endometriosis is getting a bit more of a spotlight, which is so important to improve people's quality of life, but I still think conditions like vaginismus, sexual pain disorders where with endometriosis you have complications where you are bleeding and there are other impacts from that as well you know you've got uterine lining growing outside of where it's supposed to be growing and that can then have other medical implications and that can then have other domino effect of affecting your iron and things like that.

I think because conditions like vaginismus and even conditions like vulvodynia to a lesser extent as sexual pain disorders I think they sometimes fall to the wayside because people think oh well no one's bleeding, no one's got complications that are very biomedical and clinical. A lot of the ways that vaginismus and other sexual pain disorders affect people's lives is following that holistic model of health where it is affecting their mental health, their social health, their emotional health and I think as a result of that that causes vaginismus to fall to the wayside. I think people forget about it or think it is not as important as other sorts of conditions that cause more critical clinical observable and measurable symptoms like bleeding and anaemia and things like that. I do think there needs to be more focus on vaginismus. I'm hoping things can get better. I think things have improved. I think even with the internet I feel like at least some people, with the people I interviewed some of them had said what helped them persevere with health seeking after healthcare professionals had told them I don't think there's a big issue was that they started searching the internet to figure out could this be something else.

The internet is not the same as seeing a health professional but it still helped them to look up their symptoms and know that it could be a thing and think, 'I don't know if that's my diagnosis but it's not just me.' I think that helped on a grander scale of people thinking 'I don't know if I can totally trust the advice on the internet for treatment but at least I know other people are having the same problem.' And there has been an increase in people using Facebook support groups and other online support groups like some Reddit groups and things like that for support for vaginismus so I think in that regard it has been improving but I think in terms of like a governmental focus and a medical or a healthcare focus I think a lot more should be done for vaginismus. I think the fact that even in the diagnostic phase vaginismus has been merged with dyspareunia into genito-pelvic pain/penetration disorder and the fact that again, dyspareunia which means painful sex, the fact that painful sex and vaginismus have just sort of been bashed together and said this is what it is again speaks to the fact the nuanced experiences are being even more overlooked in that merging and as a result it can sometimes have implications on making diagnosis of specific experiences and symptoms of vaginismus. It makes it harder being clumped together with other conditions that cause painful sex so I think that even that change speaks to the fact that while there is improvement in some areas of women's health, I think there is still needs to be more generalised focus and interest on other aspects of women's health that do have less clinically observable impacts on quality of life like mental, social and emotional health as well apart from physical health symptoms.

Ken McCroary: Well said, thank you. And just to finish up we are an organisation that does value wellbeing and I'm wondering if you have any advice for our GP colleagues in South Western Sydney and our wider GP allied health and supportive admin staff about wellbeing?

Rashmi Pithavadian: I think especially GPs because they are the first point of call, the first point of contact its really tricky because GPs are time poor a lot of the time and it can be hard but I think just being willing to listen, being willing to think okay if I don't know this maybe it's something I need to go and do research on. Healthcare professionals being open to they don't have all the answers, and that's fine, no one is expecting them to have all the answers but in those situations being a little bit proactive and speaking to a senior colleague or doing your own research, doing training courses and things like that. It would be great if GP practices could have even some guidelines on if you have patients presenting with these sorts of symptoms of pain or issues with penetration, if you don't have the answers follow these steps so at least there is a guideline for them to know what to do in those situations. I think sometimes health professionals may not realise people with the condition, it takes them a lot to open up to them and to bring up such a sensitive issue and they view health care professionals as these authoritative bodies so I think sometimes being aware what health professionals say, even like a little thing, can have a big impact.

I interviewed someone who said they saw healthcare professionals who had diagnosed them with vaginismus and then proceeded to say "Okay when someone has sex with you they probably feel like they are hitting a brick wall" and this person said to me that even though it seems like a small sentence to the health professional that said it in passing, this person I interviewed said it caused them to shut down, they didn't want to put themselves out there and date people which is something they wanted to do but they just felt like 'if being with me is like hitting a brick wall, then there's no point.' I think even just little things like being cognisant and cautious of the language that's being used, trying to always use positive reinforcement – being realistic but using positively reinforcing language. So in that situation I asked her what would you have preferred the health professional to say and she said she understands conditions like this can be tricky to treat but she would have preferred the health professional to say vaginismus can make things difficult in terms of relationships but there is management, there is treatment and you can improve your symptoms. It can sometimes be a different road for each person, it doesn't mean you have to feel the same way the rest of your life. That is what that person wanted instead of the health professional saying if you are dating the person you are with, they will feel like they are hitting a brick wall. It's just throw away comments. There were so many instances where the women I interviewed had noted these little comments healthcare professionals had said and that had completely demoralised them.

It just sounded like very little statements health professionals didn't mean anything by it but I think it's important for health professionals to realise what they say actually has a lot of power in how their patients perceive themselves. It might not seem as apparent at first but just being cognisant and sensitive to that as well. I think also some health professionals may come from a privileged background and being aware not everyone is going to come from the same background as you and just because something might be easy for you it doesn't mean it's going to be easy for your patient. I had a patient tell me when she first came to Australia she wasn't that proficient with English and she had a doctor from a white Anglo background and he had given her these forms to fill out and he said go fill them out and she was trying to explain she didn't know how to fill them out. He just repeated to her that she needed to go and fill them out and come back with it and she said that was something again that meant that she ended up just not being able to figure out how to do it and then got super flustered and de-motivated and didn't end up going back – it deterred her. I think things like that – it might seem obvious go fill out your forms – but it is different for everybody, not everyone has the same skills, the same abilities to do things considering social factors as well. I think health professionals sometimes just being a bit aware of what is my privilege, what is my background, how is that potentially leading me to have expectations and is that potentially fair to all the patients I see? They need to reflect and have that reflective thinking and listening and response where they are able to amend their approach and be flexible so they can better support people with vaginismus or sexual pain disorders they have consulting them.

Ken McCroary: I really appreciate your time today. It's been quite enlightening and I'm really encouraged by the effort you are putting into these areas that are sadly neglected for many complicated and in-depth reasons which we can't solve in one hit but if we keep working together hopefully we will make a difference. Thanks again Rashmi so much for joining me – I really appreciate it. Thank you.

Rashmi Pithavadian: That's alright. Thank you for probing me with some really good questions and I'm happy to contribute wherever I can, even if it's small steps, to help raise awareness as it's definitely been something that's been neglected. If we all work together and are able to contribute something I'm sure that in due course there'll be some changes.

Remember if you're not a member of GP Link already or you would like to learn more log onto our website at <https://sswgp.link/>.