**Research webinar -recording underrepresented groups-20231115\_155005-Meeting Recording**

November 15, 2023, 3:50PM

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So hello everyone and thank you for inviting me to speak.
And my name's Kirsten Simmons and I am an HIV and sexual health doctor in Brighton and I've just started a PhD in February, so I'm in my first year and looking at improving access to sexual health and sexual well being services for midlife women.
So that's women age 40 to 65 years in underresourced coastal communities and me, Sussex.
So, and I'm gonna talk a little bit about why I chose this and topic and give a few highlights about what I found so far.
And then discuss the future work and also and you know why I why I didn't courage other people to be involved in in research like this especially looking at underserved communities.
So the reason I chose this topic was I was working as a physician in sexual health and I was seeing lots of and midlife women and carrying, you know, the carrying heavy responsibilities, working, looking after kids looking after parents looking after other people in their communities.
And some of these women had very unstable housing.
They didn't know where their money would come from.
They were living with chronic illness and English wasn't the first language, and some of them were one of the three women in the UK who were survivors of sexual assault were one of the three women in the UK who are survivors of domestic abuse and and superimposed on everything that these women had been carrying were symptoms of brain flog, silly deprivation, emotional dysregulation, which are all very, very common symptoms of the menopause.
And say there was 7,000,000 middle aged women in the UK and there are 143,000 middle aged women.
The women, age 40 to 65 living in East Sussex and Brighton, Hove and and midlife women are especially underserved population in our in our in our community.
So, and as a clinician, as I was saying, I was seeing a significant minority of underserved middle aged women, some with opportunistic infections associated with advanced HIV leading to disabling consequences which would have been reversed by a simple HIV test that you know that would have happened if they would have, if they're GP, would have thought to test them or they would have thought to go for an HIV test.
Also presenting with Volvo Visions, which and they just were too embarrassed to go and seek helpful until they became full blown malignancies coming with secondary syphilis because they thought middle aged people didn't get syphilis or coming very late for smear tests even though you know cervical smear should be a routine part of care because they couldn't access somewhere to put their children to in order to get to the 8:30 appointment that practice nurse was offering or they just couldn't prioritize their own health due to that other responsibilities.
So I I was really.
I was really feeling for these women and then I realized that in the NIHR Sussex portfolio, only 12% of studies are done on women.
And and that's despite the fact that women have a declining healthy life expectancy and compared to men who have a stable, healthy life expectancy.
And women are often misdiagnosed.
They wait for much longer for diagnosis than men.
They even wait for much longer for pain relief than men in many studies.
And this is also coupled with the fact that there's a big disparity within the population of women.
So not only are women very underserved by research and underserved by healthcare, but within women there's strong differences between who can and who cannot access care.
And so.
I am so why they've spoken about why I chose women?
Why haven't I've chosen middle aged women?
You know, this is a time of significant hormonal and psychological changes, also within a very rapidly shifting cultural landscape that women are having to adjust to.
And why did I choose underresourced coastal communities?
So it's not very well known, but coastal communities have some of the worst health outcomes in the UK with the worst with the worst life expectancy and very high rates of major diseases.
And the chief medical officer?
Professor Whities 2021 report really highlighted the need for more research and more healthcare resources in coastal communities.
Anisa states itself there's a 19.2 year, healthy life expectancy gap between a woman living in central St.
Leonards and a woman living in Groombridge and sexual health and sexual well being are my bread and butter.
There are things that I'm very interested in and they obviously have significant impacts on people's mental health and physical health, but also one that relationships and on community cohesion.
So that's a bit of why I chose this specific project and just a few pointers from the work that I've done so far.
So most PhD start off with what's called a systematic review, where you look at all of the available literature and try and work out and what's not there.
Wanting still needs to be reset, ached and what has been researched, but what quality that research has.
So whether you can actually draw conclusions from that research, so say the systematic review I did looked at the barriers and enablers to access thing, health, sexual health and sexual well being services for middle aged women in high income countries.
So I found lots and lots of studies, but many of them were not focused on looking at middle age women, but because there wasn't.
The research focused on looking at middle aged women and had to kind of extrapolate the findings from them.
So say the main positive action points that I found were and that where where a service is concentrated.
So there's a big disadvantage of being a middle aged women woman, but there's also, as I alluded to at the beginning of very big disadvantage of being a middle aged woman who belongs to an underserved group in terms of accessing services.
So if you're older within that group of middle aged women, if you belong to a sexuality minority, an ethnicity minority, if you're poor, if you've had poor access to education and and lots of different of those, and of those underserved groups have much poorer access to sexual health and sexual well being care.
Another endpoint was a huge impact of mental health provision on sexual on access to services.
So if you have poor mental health, it makes it much more difficult to access sexual health and sexual well things services.
Another point was how poorly we educate midlife women and also their providers about sexual health and sexual well being needs.
So and the study showed that women use really inadequate indicators to assess, and the STI status of their partners.
And they didn't know how to differentiate between good and bad information and and and they really wanted much better education.
For example, better websites and in order to to to work out how to access the care they needed.
This was also unfortunately very similar for providers, so providers were ages sexist, heterosexist, racist and unable to ask the right questions even when women were presenting with clear and symptoms or clear conditions that would affect their sexual health, they didn't.
They were very reticent to ask about sexual health, but but really encouraging me.
The study showed that providers had a good appetite for learning more.
Other findings were about culture, so about how women, especially middle aged women, are socialized to minimize discomfort and how that really reduces their access to services, but also on a positive in a positive way.
How they learn from younger relatives?
How to negotiate the new sexual landscape that's here, for example, on 9 dating and and you know, accessing credit exposure prophylaxis, things like that.
And other important things that came out with the public health messages.
So although sexuality is much more in our public health sphere and much more in our media, and there's not much positive midlife representation, and other things were about and important thing and enable us to accessing systems were were how to change healthcare systems.
So to make one stop local and services which had INTEGRATED care that were much more and easily accessible to women had much better locations for women.
And so that's a bit about what I found in the systematic review.
But of course I wanted to make it much more practical to how we can improve services here in East Sussex.
And there's also an ongoing at the moment really interesting and work policy work going on, improving Women's Health services in, in the form of the Women's Health strategy for the UK.
The UK so as part of that I've been involved in the woman's health strategy for Sussex and and emptying a quantitative study.
Study.
So that's and focus groups and interviews really trying to hear women's voices about what they want and sexual health and sexual well being services to look like and and then a quantitative study where I'm identifying what helps you to access services.
And along the way, they've been many challenges like there are in many PhD in research projects in terms of getting ethical approval in terms of and I've really enjoyed networking, but obviously you have to work out how to balance your time in terms of and how much you can give to other to charitable organizations and how much you can balance that with what work you need to get on with.
And I've set up a women's healthcare research network for and cancer and Sussex, which is already really formed some really useful collaborations between clinicians and academics.
And I'm also in the process of setting up a national community healthcare network for coastal community researchers and clinicians.
And I suppose my aim is to really and and in bed research into policy, because I think often clinicians and researchers are very a living and very separate worlds.
And you know, seeing in my clinical work how this group of women have really been marginalized, I I really wanted to influence policy change.
And the only way you can do that is really and giving the evidence for that.
And so, and I suppose I and niece is, you know, the people who have helped along the way.
I've got three young sons who, and you know, to you can really balance research with having a family with Dean, clinical work.
It is difficult, but you know it's it's almost more important for me having three young sons to to make sure we're we're addressing the inequalities that women face and making them aware of that.
And these are some of the key references and I suppose and some final remarks would be about how how enjoyable research is and how it gives you such different skills from clinical work, but also how being able to combine both really and helps you to to reach a larger number of patients and you know you have first you have insight into what patients need and and and then you can have those skills to really work with Commissioners and policymakers to address those and say thanks very much for listening.
And and I would really welcome and emails if you have any questions or if you'd like to get involved in any of those, the Women's Health network or the Coastal Communities Network.
Many thanks.

 **HOLTER, Fiona (EAST SUSSEX HEALTHCARE NHS TRUST)** stopped transcription