

MariJo Vázquez Podcast

March 2019

Podcast in [Spanish](#)

For rough translation into English, please see below

La Ola. Mujeres con VIH: sus voces, empoderamiento y activismo.

En este pódcast, MariJo Vázquez, de Barcelona, nos habla de cómo utiliza su propia experiencia para explicar a los alumnos de enfermería cómo llevar los conceptos éticos de la confidencialidad y la autonomía a la práctica clínica. Habla de la importancia de apreciar el poder, la sabiduría y la expertitud de los 'pacientes' en la formación de futuros profesionales de la salud, y de la falta de integración de los derechos sexuales y reproductivos de las mujeres viviendo con VIH en la atención clínica.

MariJo lleva 23 años como activista, primero haciendo activismo político, y últimamente participando en la formación de profesionales de la salud.

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Pódcast 4
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Introducida por L'Orangelis Thomas

Introducción:

En este pódcast, nos habla MariJo Vázquez de Barcelona. MariJo lleva 23 años como activista, primero haciendo activismo político, y últimamente participando en la formación de profesionales de la salud.

En este episodio, MariJo explica cómo utiliza su propia experiencia como mujer viviendo con VIH y otras condiciones más, para explicar a estudiantes de enfermería cómo llevar conceptos éticos como confidencialidad y autonomía a la práctica clínica. Habla de la importancia de apreciar el poder, la sabiduría y la expertitud de los 'pacientes' en la formación de futuros profesionales de salud. Además, nos habla de la escasa integración de los derechos sexuales y reproductivos de las mujeres viviendo con VIH en la atención clínica.

Rough translation into English

I'm MariJo Vázquez, I live in Barcelona, and I love to say my age. I'm 63, and I love to say it because 23 years ago I didn't think I'd get here. Every year is a triumph.

I was diagnosed with HIV 23 years ago, and since then I have spent my time trying to improve my personal life, which has a great impact on who I am and how I live my life, and those around me.

I have been involved during that time in support groups of women living with HIV.

In 2009 I had the opportunity to do some work with women living with HIV in Spain. The idea was to bring the story of HIV from the perspective of women. We learnt about the power of narrative, the curative power of telling our stories, and the success of this project, *Sanar a traves de nuestras historias*, for the women, as they expressed it themselves, was to be able to hear their own voices in a book they had not written, with an immediate benefit of seeing themselves through others' eyes. The benefit for me was to get to know people who I did know, but I didn't know their deepest motivations.

I started doing political advocacy, thinking that if policy makers heard normal people, they would change their attitude. But after a few years, I realised that wasn't the case.

So I changed my focus and started doing more personal and direct work. I started giving a module for masters students where I talked about the importance of research that is not extractive, participatory, and recognition of the wisdom and expertise of people.

I started doing a little narrative as an expert patient, about my relationship with HIV and the health system, to transmit to them through my experience the things that might be missing for them.

I spent two or three years doing this narrative format. And last year, we made a leap and did a workshop with 5 sessions that was evaluable, voluntary (but half the course attended), divided into diagnosis, preparation for chronic disease, treatment, side-effects, gender and violence within health centres. We explained within the context of each session, we spoke about our experiences, eg of diagnosis, what did patients need from the professional giving the diagnosis? We talked about stigma, and prejudices – I always say there is no-one without bias, but you have to be aware of your bias and get over it.

So it was a training on different aspects of illness and clinical attention.

This year we are doing something similar, though not the same because there is not the funding. But we have been able to take things forward a bit. For example, I give a talk on SRHR, using the work that Salamander Trust did with the WHO. I use this, saying, women have their ideas and they can inform guidelines.

We ask them to extract pearls of knowledge, not to stay in the theoretical, but to derive a principle for action based on what they have heard, and support it with what they are basing it on, which part of the experiences I have shared with them?

Confidentiality – this is a problem. They know the ethical principles perfectly, but don't know how to translate them into practice. For example, what would happen if a woman with HIV goes to the doctor, and doesn't want to tell her husband? Their immediate reaction is, she has to tell her husband. But you don't know what is going on at home. So I say, Who should tell him? Well, in principle she should, but if she doesn't want to, I should. And I say, but who is your patient? The husband, or the woman?

If you give them an example where ethical principles could clash, they are lost, they don't have the perception and get lost when there is not a clear division between principles. I try to say, it's an ethics of care, and you need to see the context. You need to analyse the situation, and that challenges them.

Another very important aspect is empathy. The teachers explain to them that they have to be empathetic, it's an aspect of care, but what does it mean? How do you put it in practice? One student says, it means putting yourself in the place of the other. I ask, what does that mean? How do you do it? What are my needs? They say, I might hold someone's hand when I give them news. I say, I don't like people holding my hand. And so they don't know what to do. And I say, exactly. And what can you do to find out? And they are stuck. I say, do you think I could tell you what I need? Of course. So if you listen, I can tell you. This is empathy.

But they don't know how to put it into practice. And when they go to the workplace and deal with patients, they don't realise that patients know things. And if they don't have this awareness, the professionals think they have to tell us what to do, instead of listening to us and deciding together what to do. They see themselves as professionals and the patient as someone who knows nothing. They don't value patients as equals.

They only value autonomy in a physical sense, not a moral sense. And also respect for autonomy can convert into an abandonment. It's not about saying, this is the situation, away you go.

I break it down for them. One of the aspects is this, of saying, don't worry. You can't say that to someone who is going through something – you can say other things, but not 'don't worry'. I'll be there for you – great, you'll be there, but will I?

Now, the trend in the nursing school is person-centred care. You could say, good! Not so good – what has to change is the attitude to the power of the patient. The patient is deprived of power. As soon as you are a patient, you are powerless.

They want to tell you what to do. They do it with the best of intentions. I give them a very clear example, something that happened to me. One time I was in hospital, and I'd gone for a walk in the corridor. When I came back, there was a Dr and 6 students around my bed, talking about my case, but I wasn't there!

I say to them, patient-centred means knowing, who is the patient? Who is in charge? The patient has all the power over their life. All of it.

I always talk about forming a team. I want a doctor or nurse who knows a lot – but they should not eliminate me or sideline me while they decide for me.

The last year's students knew me as the 'impatient patient'.

If you need clinical attention, we have a good system. But other integrated aspects of SRHR are not taken into account. I go to the hospital for HIV but to the walk-in for SRHR, so there is a bit of me in each place. No-one talked to me about menopause – not the HIV clinic or the gynaecologist. It is addressed, but only from a purely clinical perspective, not the emotional or social aspects. I don't think gynaecologists know much about HIV and HIV specialists don't talk about menopause.

Young adolescents with HIV since birth – of whom I knew several – are not well accompanied. It is more the civil society organisations who support them.

The response of these students makes us hope that gradually the training of health professionals will bring in this other concept, this understanding that they are not the only ones who have knowledge, that the patient knows about their own life. This is the only way to make sure that care becomes more effective.