4: Women, Medicine and Informed Consent

The fourth of the ten part essay series has been adapted from a presentation by Allan Achesa Maleche at the Global Dialogue on Decriminalisation, Choice and Consent.

In 2012, 22-year-old Ruth Achieng suffered a miscarriage and was rushed to Nairobi's Kenyatta National Hospital. She was barely conscious when she was admitted. A week later, a doctor touring the ward informed her that she had been sterilised. Why? Because they realised that she was HIV positive. Today, Achieng is one of 40 women planning to sue the Kenyan government for forced or coerced sterilisation. But what's being argued in return is that many of the women who claim to have been forcibly sterilised *did* sign consent forms; however, these forms were presented to them *while they were in labour*. Can a woman undergoing huge amounts of pain at the mercy of her doctors do anything *but* sign a form? And it gets more complicated. What if she can't read or write? Or if the form is in a language different to the one she knows? Can this really be called 'informed consent'?

The development of informed consent was triggered by human rights violations faced by research subjects in several mass experiments. Some of these includes the Nuremberg Trials under Hitler, the Tuskegee syphilis experiment in Alabama, and the Thalidomide scandal in the United Kingdom. As a response to these violations, institutions and scientists developed agreements that explained the conditions and risks of their experiments to their subjects – the first 'consent forms' so to speak. More recently, this practice has been adopted by the healthcare sector and is known as informed consent. Though this process began in America, it has now extended itself to various parts of the world. At the heart of informed consent is the idea that medical practitioners should provide patients with information about the benefits and risks of a procedure. The patient is then asked to sign a consent form to indicate that they are aware of the consequences of accepting a particular treatment. This means that the procedure can now be performed. But as Achieng's story shows, it doesn't always play out the way in was originally intended - especially when it comes to sexual or reproductive health.

Take the situation in Kenya - which isn't all that dissimilar to scenarios in several parts of the Global South. Most people who access sexual and reproductive health services (SRHR) in Kenya are women and young girls, and one of the greatest barriers to informed consent is poor literacy. Since not all women are at the same literacy level, explaining the implications of a consent form greatly differ and can take varying amounts of time. With overworked doctors in understaffed hospitals, the time needed to actually explain the purpose of the forms is a rare luxury.

Then comes language. Or rather, the several languages spoken within any single ex-colonised country whose contours were drawn by mapmakers who spoke none of them. When informed consent documents - usually developed in the Global North - are translated, they come up against the reality of several local languages being spoken in one place. Which one do you pick? What happens in areas where the concept of signing a document is in itself alien? Does the consent form then help or hinder access to healthcare? The language problem is not just one of translation though. All across the world, consent forms for healthcare are about risk; however, the language they use is so obtuse, most of us are unable to identify what exactly the risk is. And moreover, most healthcare providers are unable to tell us. These forms present a fictional narrative of 'choice' - one where we as patients can make our 'own' decisions about what happens to our bodies. But in reality, we're presented with language we cannot understand talking about risks that cannot be explained: is this still consent?

Many would argue not. An important parallel can be found in a 2013 Canadian report that explored the ways in which social media contracts and agreements tend to be constructed in obtuse, unreadable language. The report states, 'It is imperative that…when consent is given, such consent be meaningful and appropriate in the circumstance…to achieve this, the language put before individuals should be clear and accessible.' A set of guidelines issued on the basis of this report then goes on to define what counts as 'readable' language. It states that language 'readable to the average person…can be accomplished through clear explanations, a level of language suitable to a diverse audience, and easily readable font size.' Significantly, the report goes on to say that a user's consent is valid *only if* the form they signed actually made sense to them. If we apply this logic to informed consent forms, it's a fairly good starting point, especially insofar as it helps do away with the idea that simply a signature constitutes consent.

Aside from language, one of the biggest barriers to informed consent is the power relation that exists between healthcare workers and patients. The doctor's white coat has been instilled with superiority, which means that we often tend to be in situations where 'the doctor is always right' or that where the doctor knows what is best for our bodies. And because most of us aren't in medical or healing professions ourselves, there isn't much by way of information that could present us with a counter discourse. But if we're meant to be giving *informed* consent, isn't part of that the right to knowledge about the real risks of what a doctor might present as the 'only' option? Isn't it the right to a second opinion? Or even the right to say no to medical treatment?

In most places these options are either unavailable or only available to those who can afford them. Be it in rural Kenya, where doctors see countless patients every day with no

time to explain alternatives, or in the heart of America, where getting *any* medical treatment may likely be the result of a long and tedious battle with insurance companies, information is *not* at the heart of informed consent. Which of course leaves us with the question, how informed is 'informed consent' anyway?

Here's something else to chew on. Because sexual and reproductive services are mainly accessed by women, gender inequality has a big role to play. Doctors often consult with husbands before making decisions on behalf of women, and the more socially stigmatised the woman, the less decision making power she has. Women with mental disabilities, HIV positive women, and women from low socio-economic backgrounds are only a few examples of the countless women who enter healthcare systems only to have decisions about their bodies made by male relatives, doctors and hospital staff. All too often a patriarchal morality and perception of women's bodies also comes into play, and this can often have devastating consequences. Take the example of the 2 finger rape test in India. This now officially outlawed practice (that continues to take place in alarming numbers) involves a doctor 'testing' the elasticity of a rape survivor's vaginal walls to see whether she is 'accustomed to sexual activity'. Why? Because if she's a 'loose woman' who has had sex before, the assumption made is that *all* sex she has is consensual. Seriously, this is a real thing that happens all the time. And because a post-rape examination may often involve checking inside the vagina, most women – if asked – will consent to the process. But what they're *not* consenting to is the use of that examination to determine the credibility of their allegations; however, doctors can well argue that because they *did* give their consent to the examination itself, they're free to use the information as they wish.

So where do we go from here? Well, there are no easy answers, but definitely some immediate areas that need work. Firstly, ensure that informed consent guidelines (medical ethical guidelines as well as legal ones) take into account language and culture and power issues and emphasize meaningful consent. Secondly, boost training for medical providers on obtaining meaningful consent. Thirdly, take all steps to address gender discriminatory practices that interfere with informed consent

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