U=U advocates face challenges in Nepal

U=U is backed by science but not by the Nepalese medical fraternity.

July 15, 2018 By Undetectable = Untransmittable

This is a guest blog by Mr. Sanjeev Raj Neupane, HIV Technical Specialist at Save the Children Nepal and Mr. Anjay Kumar KC, President of CDUN (Coalition of Drug Users in Nepal)

Approximately two months ago, the expectant spouse of a colleague of ours went into labour and was admitted to one of the most distinguished private hospitals in Kathmandu, specializing in preventing perinatal HIV transmission, for delivery. This married couple has been living with HIV for some time now and had been planning for the baby in consultation with their Doctor, right from inception. Having been on ART for almost 10 years, both of them have had an undetectable viral load since 2012. What this means that in the context of the Human Immunodeficiency Virus, both partners are unable to transmit the HIV virus, or in other words, pass on the virus to others.

The biggest risk for vertical transmission is the mother's viral load – a measure of how much HIV is in the blood. HIV is present in breast milk just like the viral load in blood. The risk of infection is there because the virus in the milk could pass through the lining of the baby's stomach. Anti-retro viral therapy (ART) is taken to reduce the viral load to 'undetectable', giving a risk factor of zero. [1]

The delivery was normal, without the need for assistance, and nature just took over. However, as with many pregnancies, lactation was a bit of a problem for both mother and child, but there was milk in the breasts and the child was feeding. Suddenly, into the third week after delivery/birth of the baby, the milk duct obstruction suddenly turned seriously into multiple breast abscesses that would require surgical intervention under general anesthesia.

During the pre-surgical assessment, the doctors in the hospital made them buy medical paraphernalia not required even for extremely complicated and infectious surgical procedures, making the procedure three times more expensive.

Without reading too much into this, would it be safe to assume that the doctors were simply being over protective? On one hand, there is nothing wrong with being cautious of course, and there must be precautionary measures in place as per the principles of universal precautions. However, being overly protective, (such as using a bio hazard suite while performing a surgical procedure on an HIV positive patient with undetectable viral load), I think goes against the basics of science.

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The uncomfortable truth is that, here in Nepal, we still have a number of weird and wacky beliefs and attitudes of our own in the medical community about HIV positive patients. Some of these practices the doctors like to hold on to, even in the face of overwhelming proven scientific evidence to the contrary. While some of these strange beliefs about HIV are harmless and downright amusing, some blow up into full scale violations of medical ethics, whose adherents refuse to consider any evidence to the contrary despite overwhelming scientific evidence that is most up-to-date or recent.

U=U

The United States Center for Disease Control and Prevention (CDC) has also officially recognized the science of U=U or Undetectable = Untransmittable, which means suppressing HIV viral load through Anti-Retroviral Therapy prevents sexual transmission of HIV. CDC officials have said “people who take ART daily as prescribed and achieve and maintain an undetectable viral load have effectively no risk of sexually transmitting the virus to an HIV-negative partner." [2]

The influential British medical journal The Lancet HIV endorsed the idea in an editorial in November of 2017. All told, close to 700 organizations in 100 countries now agree, according to Bruce Richman, who is leading the “Undetectable = Untransmittable” (U=U) campaign credited with beginning to change public perception of HIV transmissibility [3].

U=U is a simple but hugely important global campaign based on a solid foundation of scientific evidence. It has already been successful in influencing public opinion, causing more people with HIV (and their friends and families) to comprehend that they can live long, healthy lives, have children, and never have to worry about passing on their infection to others. The CDC officially backing the science behind the campaign is another key step towards U=U being the most important message of 2017 in the fight against HIV.[4]

The science behind the campaign is clear. Between September 2010 and May 2014 the PARTNER study prospectively enrolled 1166 sero-different couples at 75 clinical sites in 14 European countries. Entry criteria included the positive partner having an undetectable viral load on ART and that the couples were not always using condoms when they had sex. These results are simple to understand – zero transmissions from over 58,000 individual times that people had sex without condoms. They are also notable for the complexity of the analysis that was needed to prove that none of the new diagnoses were linked transmissions from within the couple.

The results provide a dataset to question whether transmission with an undetectable viral load is actually possible. The results should help normalize HIV and challenge stigma and discrimination.

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U=U challenges criminalization laws that, in many countries, including the US, continue to imprison hundreds of people based on assumptions of risk that these results disprove, even when condoms are used and viral load is undetectable.

Hundreds of people living with HIV (PLHIV) in the US have been charged with criminal offences for the perceived or potential risk of HIV exposure or transmission. Some are serving or have served long prison sentences for spitting, scratching or biting and others for not being able to prove they had disclosed their HIV positive status before having sexual contact (even in the absence of any risk of HIV transmission). HIV criminalization has created a viral underclass in the law, further burdening a disenfranchised community, putting a disproportionate share of the shared responsibility for preventing sexually-transmitted infections on one party, and discouraging people at risk from getting tested for HIV.

The results will also have a positive impact on quality of life of both HIV positive and HIV negative individuals who are in sero-discordant relationships, irrespective of their choice to use condoms.

This research is wonderful but many people are not aware that U=U. We need more education and we need to deal with the social stigma of HIV before the positive impacts of U=U can be widely felt. Despite all the research, the stigma is still there—not just in sero-discordant relationships but also in society.

U=U is not just a slogan. It’s a formula for eliminating HIV from the world. So if all people living with HIV in the world are identified, kept on Antiretroviral therapy and their viral load is suppressed, there will be no more transmission of HIV from one person to another and virtually the virus is eliminated from world.

But it is not as easy as it looks like.

First of all identifying all the people living with HIV itself is not an easy task. Many people living with HIV who are mostly from the key population don’t know that they are living with HIV. The 90-90-90 bandwagon and the lofty slogans like “Know your status, Get Tested” are helping many

countries in increasing the diagnosis many countries are still failing to diagnose people living with HIV. Another problem is enrollment of diagnosed HIV positive patients in ART. “Test, Treat and Retain (TTR)” and same day ART initiation has helped increase the number of PLHIV on ART but still there are some missing links. PLHIV are either missing or lost to follow up from the state they are diagnosed positive and enrolled in ART

Many of the PLHIV who are on ART don’t know their viral load status. Though the viral load monitoring around the world is being expanded; many PLHIVs taking ART for long time don’t know their viral load status because they don’t have access to the viral load testing facilities. Increasing the access of People on ARV to viral load testing is key to know whether they have undetectable viral load or not but a lot still need to be done to increase access of many PLHIVs to access viral load testing services.

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Many health workers and medical practitioners are still not aware of the science of U=U. Like many developments in the four-decade history of HIV, this one has been slow to gain acceptance among mainstream health-care providers. Many are not aware of it or must unlearn the habit of drilling outdated safe-sex lessons into patients, as they have been doing almost since the AIDS epidemic began. HIV-positive people also must alter deeply ingrained beliefs that nothing good can come of revealing their status.

The public-health challenge now is moving from theory to implementation. Many questions arise following the information that when a person with HIV has an undetectable viral load, he has effectively no risk of transmitting the virus.

Now the challenge is to get the message out to HIV-positive people, caregivers and the public. And that process has been slow. This is a radical challenge to the status quo and to 35 years of HIV science vs the irrational fear of people living with HIV, and the fear still wins, over the science every time.

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People with HIV deserve and have a right to know that “You can’t transmit the virus if you’re undetectable!”

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Then, finally, overcome with relief, the reality still takes time to kick in. Especially, after 35 years of stigmatization, to be able to say “I don’t feel like I’m a threat anymore, I don’t feel like I’m dirty and I don’t feel like I’m a dangerous person or carry the guilt and shame of being HIV Positive."

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