Is Being Undetectable Enough?

You've heard about the 90-90-90 HIV targets. But what about measuring quality of life—maybe we need a fourth 90.

October 8, 2020 By Bob Leahy

In recent years we have seen a huge push toward being undetectable. But is it the gold standard, the true measure of the health and happiness of people living with HIV? Some are saying no. I'm one of them.

Don't get me wrong. This comes from someone who has been a huge and early advocate for Undetectable Equals Untransmittable (U=U) and, before that, Treatment as Prevention (TasP). Since 2013, I'm on record as supporting early treatment, not just for its health benefits but also as a means of preventing HIV transmission. It was not a popular cause back then. Funders, colleagues who work in sexual health, our national organizations all told me I was wrong. When the U=U campaign came along I was elated. I joined forces in the summer of 2016 and with the help of other committed advocates, Canada gradually came on side. I still am committed to U=U, of course. But I've come to believe we need a much wider view of what people living with HIV can and maybe should aspire to, besides a low viral load. That factor is a good quality of life.

Why do we need to look beyond undetectable? The value of being undetectable is diminished when physical, mental, spiritual and sexual health are not optimal, or close to it. Marginalized people in particular may experiences inequities in basic health care, access to services and affordable housing, even support of a caring community. There is in fact a long list of factors that contribute to quality of life. If you are lonely, feel sick, unsupported, hampered by mobility issues or the impact of ageing, then having an undetectable viral load may no longer seem material.

The official emphasis on treatment, treatment, treatment with patient undetectability as its pinnacle couldn't be better illustrated by 90-90-90. These HIV targets set by the United Nations AIDS group encourage cities and governments to aim for 90% of people living with HIV to know their status, 90% of people diagnosed with HIV are on treatment, and 90% of people on treatment are undetectable. True, targets are really important—they help to ensure accountability—but the absence of a measure of quality of life is becoming increasingly more glaring. That is why some have set their sights on a "fourth 90."

The concept of a fourth 90 isn't entirely new. Do a google search, and you will find a variety of approaches. Some see it as applicable in particular to ageing, the rationale I suppose being that quality of life inevitably diminishes with age. Others see it not as something that applies as step four, once undetectability has been achieved but something that applies to all three 90s. In other

words, the notion is that quality of life should be considered at all stages of a person's care cycle, whether they are on successful treatment or not. That's the version of quality of life I support. Let's not leave anybody behind here.

We must go further, though, than just verbally supporting good quality of life for people living with HIV. We must be able to measure it. That's where the work gets tricky. What factors might contribute to a good quality of life? How is data collected and tracked over time, and how is it compared to data from other countries? Few countries are equipped to handle that task, Canada included.

Not that there aren't outposts, jurisdictions which have in fact collected patient data that goes beyond traditional clinical measurements. In Ontario, for instance, the OHTN Cohort Study maintains comprehensive data on 3,700 people living with HIV, not only clinical but psychosocial and behavioral data, collected through a standardized questionnaire that includes numerous quality of life factors. That's the kind of rich data we need to support a formalized approach to quality of life measurement that will be helpful to construct a fourth 90. But importantly, people living with HIV must have their say and in fact lead the drive for a fourth 90 if it is to adequately addresses their realities.

In Canada, it's encouraging that Realize, a national organization charged with fostering positive change for people living with HIV, has recently entered the field of those seeking to make a fourth 90 a reality. It's important but challenging work that I'll be throwing my support behind in the months and years to come.

For now, though, whenever you hear 90-90-90 being discussed—and you will hear this a lot around World AIDS Day as nations boast about their progress—let's also recognize its limitations. Being undetectable is hugely important, but it isn't everything.

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