

“How Much Time Do I Have Doc?” Reflections on the Lifespan of People with HIV

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Scientists love to quantify; it is in our nature, if not in our training, to measure everything around us. Imagine my interest and disgust that there is even a scoring rubric for quantifying the liquidity and/or solidness of stool called the Bristol Stool Scale [1]. Yuk!!! But I find the area of predicting lifespans, especially for those with a particular disease, interesting and at times baffling. Predicting the lifespan of a mayfly is one thing (by the way, it is just a day), but predicting the lifespan of people with HIV is entirely different. Despite excellent prognosis, thanks to the advances of combination Antiretroviral Therapy (cART), many adults with HIV have experienced Lazarus Syndrome; once they were expecting to die but now they are expecting to live and even retire. But is that to say everyone with HIV will retire? In fact, can that be said of any of us? Yet, insurance companies, actuaries, and yes, scientists, pursue these passionately and derive predictions that at times are perceived as gospel. But is it? Well it depends on who you ask.

According to computer models generated by Nakagawa and colleagues [2], a 30 year-old person who is diagnosed early before HIV has had a chance to compromise his immune system can expect to live 75 years; but the same person if diagnosed with AIDS can expect to live to 71.5 years. Altogether, these researchers estimate that 10.5 years of life are lost due to HIV. Helleberg and colleagues [3] constructed a computer model of a 35-year-old patient with HIV; if he smokes, his life expectancy is 62.6 years (12.3 life years lost due to HIV/smoking) and if he does not smoke, his life expectancy is 78.4 years (5.1 life years lost due to HIV). Based on a large sample of ~23,000 adults in Canada and the United States, Samji and colleagues [4] found the mid-point life expectancy for men who have sex with men was 69 years, while for intravenous drug users it was ~30 years; yet, initial CD4+ lymphocyte count was indicative of greater life expectancy than those with a more compromised immune system (lower CD4 lymphocyte nadir) which was predictive of a reduced lifespan. Yet, comparing adults with and without HIV in Denmark from 1995-2005, approximately 12 life years are lost due to this disease [5]. Yet, other studies have found that those with HIV experience similar rates of mortality compared to the normal population [6-9].

So how can there be so many differences in the literature? Clearly, it depends on a host of issues such as access to care, medication compliance, the presence of comorbidities (e.g., heart disease, diabetes, and hepatitis C), health habits such as smoking, excessive drinking, substance use, physical

exercise, stress and depression, and the list goes on. It is important to keep in mind that many of these studies do not factor in these essential health data. Perhaps personality plays a role as well. In fact, some studies in the gerontological literature even suggest that those individuals who are more optimistic, hopeful, and basically "hardy", experience better health outcomes and longer life [10].

The bottom line is that much of this depends on the individual. Whether someone adheres to their HIV medications and keeps the virus from replicating and proliferating in the body is obviously important. Likewise, not smoking, working out, and having a purpose to live for are unquestionably important for health and longevity. Unfortunately, such studies that report that adults with HIV have "automatically" reduced their life span, although statistically accurate, may not be clinically meaningful. In fact, such information could actually be detrimental, discouraging, and even dangerous. When someone is first diagnosed with HIV, suicidal ideation is quite common [11]. During this time, people are often confused, scared, and unprepared with how to cope with such a complex and frightening disease. Yet, if someone dealing with the initial diagnosis of HIV is also told that they by default lose a third of their lifespan or a decade of their life due to the disease, this may shift such suicidal ideation into overdrive. Or for someone trying to live and age with this disease, such messaging about compromised lifespans should also be tempered with, "What can be done to improve successful aging?" versus more draconian statements about subtracted life years. In fact, to this day, adults with HIV have trouble acquiring life insurance because of their risk status of dying [12], which may further reinforce the stigma and fear many already feel and internalize [13]. Although the study of lifespans is important, instead of communicating how much time people "have" with their disease, I think we have to be mindful that with all of the advances in treatment, we need to empower patients with tools for healthy living and emphasize that when it comes to how long a person with HIV will live, nothing is written in stone.

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