



## Life Expectancy and Life Years Lost After HIV or AIDS Diagnosis: A Retrospective Cohort Study

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**ABSTRACT:** The AIDS pandemic on average took a life every minute in 2021 despite effective HIV treatment and tools to prevent, detect, and treat opportunistic infections. The objective of this study was to estimate the average life expectancy and life years lost (LYL) in people diagnosed with HIV or AIDS in Puerto Rico from 2000-2020. The epidemiological design was a retrospective cohort study of 24,143 people diagnosed with HIV or AIDS and received services under the Eligible Metropolitan Area (EMA) of San Juan, Puerto Rico. The population with a diagnosis of HIV or AIDS was described using socioeconomic characteristics with frequencies and proportions by category. We estimated the LYL by matching the expected residual lifetime for someone diagnosed with the disease with the life expectancy of the general population at that specific age as the null model. Average years of life lost (LYL) is a measure that reflects expected earlier death as a result of a condition. The number of LYL is dependent on the year of onset of the condition. In general, the earlier the onset of HIV or AIDS results in a larger impact of LYL. For individuals diagnosed at the age of 30 with AIDS the LYL is approximately 35.5 years, whereas for an individual where the onset is at age 70 years, being diagnosed with HIV or AIDS results in approximately 2.7 years lost. In our study, we found a greater number of LYL in patients diagnosed with AIDS in this population compared to those diagnosed with HIV. This study confirms the dramatic impact of HIV and AIDS on the lifespan of individuals and how the age of onset of the conditions impacts LYL.

**KEYWORDS:** HIV/AIDS, Life Years Lost, Life Expectancy, Puerto Rico.

**LIST OF ABBREVIATIONS:** AIDS, Acquired Immunodeficiency Syndrome; ART, Antiretroviral Therapy; AYLL, Average Years of Life Lost; EMA, Eligible Metropolitan Area; HIV, Human Immunodeficiency Virus; LGB, Lesbian, Gay and Bisexual; LYL, Life Years Lost; PR, Puerto Rico.

### INTRODUCTION

HIV/AIDS has become one of the most serious public health problems we face today, with approximately 38 million people living with HIV/AIDS globally as of 2021 [1]. The Immunodeficiency Virus (HIV) has been considered a chronic disease [2]. Since the introduction of antiretroviral therapy (ART), the prognosis of people living with HIV has improved. Still, there is no cure for HIV infection, despite the diagnosis and multiple alternatives for treatment. One method of evaluating a condition's impact on the health of individuals is to assess whether it results in a reduced lifespan. However, calculating the life expectancy of individuals who acquire the condition at different times in their lives is not straightforward. Recently researchers described a method of estimating the impact of a disease considering the age of onset of the condition ([3], [4]), and others implemented these algorithms in an R package for easy use [5]. A few recent examples of how this method has been used to evaluate the life years lost (LYL) can be found in cancer [6], epilepsy [7], and mental illness [8]. Average years of life lost (AYLL) estimates the average time an individual would be expected to live if the individual did not die prematurely compared to a base population without the condition or the general population [9], [10].

LYL has been infrequently estimated for HIV/AIDS, as noted in one study [11], which measured LYL among a population in Iran and found HIV/AIDS patients had 46 fewer years of life expectancy at age 20 than the general population. Another study [12] used the USA population-based National HIV Surveillance System data to estimate life expectancy and average years of life lost (LYL) among persons aged 13 years or older from all 50 states and Washington, D.C., diagnosed with HIV infection during 2008-2011. These analyses did not include survey of the HIV/AIDS diagnosed population of Puerto Rico. Life expectancy after HIV diagnosis was determined using the life table method, and estimates were compared with life expectancy in the general population in the same



calendar year. Life expectancy and LYL were also estimated for subgroups by age, sex, and race/ethnicity. The overall life expectancy after HIV diagnosis in the United States increased by 3.43 years from 25.4 in 2008 to 28.9 in 2011. As noted by the authors, this was likely related to advancements in treatment and the potential impact on life expectancy following HIV diagnosis. Improvements were observed irrespective of sex, race/ethnicity, transmission category, and stage of disease at diagnosis, though the extent of improvement varied by different characteristics. Based on the life expectancy of the general population, in 2010, the LYL for individuals diagnosed with HIV was 12.8 years for males and 16.5 years for females across all ages. Per this study, at ages 20, 40, 60, and 80 years, males diagnosed with an HIV infection in 2010 had AYLL of 17.6, 14.1, 10.4, and 6.2 years respectively. Females diagnosed with HIV infection in 2010 at ages 20, 40, 60, and 80 years had AYLL of 24.5, 18.3, 12.1, and 7.3 years, respectively. Despite these improvements in life expectancy among people diagnosed with an HIV infection during 2008–2011, disparities by sex and race/ethnicity persisted in this study. The average LYL across all ages by race/ethnicity are still present, with blacks having 13.3 average life years lost and whites 13.4 average life years lost compared with 14.7 average life years lost for Hispanics/Latinos.

LYL has also been used to evaluate effects on life span in other conditions besides HIV/AIDS. For example, one study [13] estimated the total years of potential life lost in United States veterans to demonstrate greater loss to alcohol-attributable deaths in veterans with minoritized (non-heterosexual, e.g., lesbian, gay, bisexual, queer; LGBTQ+) sexual orientations compared to those without. It also demonstrated the same greater loss to alcohol-attributable deaths in veterans for acute versus chronic causes and for women versus men regardless of sexual orientation status. A similar analysis in 2022 found more years of potential life lost to alcohol-attributable deaths in lesbian, gay, and bisexual (LGB) men compared to non-LGB men. [14]. Another study in 2012 [10] found that patients with metastatic melanoma had an AYLL of over 20 years, which did not improve over three decades of the survey between 1970 and 1999.

The measurement of life years lost has the important advantage of allowing the breakdown of excess mortality into specific causes of death considering the age of diagnosis, which is critical in examining the magnitude of each cause and implementing focused public health programs. Life years lost have rarely been estimated for HIV in general, and we found no published studies of this type for the Puerto Rico population. The objective of this study was to estimate life years lost in people diagnosed with HIV/AIDS in Puerto Rico from 2000-2020. We evaluated if patients with HIV or AIDS have a reduced lifespan by calculating the life expectancy and life years lost (LYL).

## MATERIALS AND METHODS

### A. Study Design and Participants

The epidemiological design used in this study was a retrospective cohort study. The population under study consists of all the people who were diagnosed with HIV or AIDS and who received services under the Eligible Metropolitan Area (EMA) of San Juan, Puerto Rico, during the period from 2000 to 2020. The first part of the study is based on sociodemographic characteristics such as age, gender, income, poverty level (%), HIV/AIDS risk factors, family composition, immunological classification, type of health insurance, age of HIV/AIDS diagnosis, and vital status. Posterior to describing the population, we estimated the probability of survival in people diagnosed with HIV or AIDS, comparing with the general survivorship curves for Puerto Rico to estimate the LYL. The information on the patients for this research was obtained from the electronic medical records of people diagnosed with HIV/AIDS belonging to the eligible metropolitan area (EMA) of San Juan, Puerto Rico from 2000 to 2020. All information and data were kept strictly confidential, encoded with identification numbers, and stored only with those identification numbers. Access to coded or encrypted storage was physically limited to authorized personnel only via an access code. The San Juan Bautista School of Medicine IRB (EMSJBIRB-17-2022) approved the study.

### B. Data analysis

The population with HIV or AIDS was described using frequencies and proportions by category. Although the survey size was 24,143 patients, information for some of the variables was missing, and consequently, the sample size by analysis varies. In each case, the sample size is noted.

We estimated the relative impact of HIV or AIDS on individuals' mean estimated life expectancy as a consequence of being diagnosed at a given age and the expected number of years to live, if current age-specific mortality rates remain the same. Our null model for life expectancy is the survivorship curve of the 1999-2001 demographic survey for Puerto Rico [19]. Evaluation of other survivorship curves shows only small differences and generally has minimal impact on the primary interpretation of the results. For



analysis of the impact of the number of "Life Years Lost: LYL" as a consequence of a disorder, we applied a method proposed by Andersen (2017) [3, 4] and Erlangsen et al. (2017) [20].

This method has the advantage of considering some of the challenges of evaluating life span for age-specific mortality rates (for details, see Andersen 2013 [4]; Andersen 2017 [3]; Plana-Ripoll et al. 2020 [5]). Consequently, this approach has the advantage of measuring the LYL at the "onset" of a specific disorder and comparing the average of these individuals with the general population (null model). For our study, the onset is the year a patient is diagnosed with HIV or AIDS. Consequently, the LYL is an estimate of the average number of years patients with the specific age of onset will lose. To see how the method has been used in other research, see reference [5].

All analyses were done in R (version 4.2.2, R Core Team 2020); the "lilies" R package was used to estimate LYL, and our null distribution of life span is the general population [21]. Data wrangling and basic demographic and visualization were done using the set of packages in "tidyverse" [22].

**RESULTS**

**A. Population characteristics**

The data set used for the current study contains information on 24,737 patients with HIV or AIDS belonging to the eligible metropolitan area (EMA) of San Juan, Puerto Rico, from 2000 to 2020. We excluded 594 (2%) patients with incomplete information from the study. Thus, the analyses were based on the data from 24,143 (98.0%) patients. Of the people evaluated in the study period, 64% had an immunological classification of HIV, 36% had AIDS, and 81% had a vital status of alive. On the other hand, 64% of the population diagnosed with HIV or AIDS for the period of 2000-2020 were men. The average age for men with HIV was 36.8 years, while for women, it was 35.4 years. However, the average age for men with AIDS was 42.8 years, while for women, it was 41.6 years. In this study, 75% of the individuals lived below the poverty level, with an average annual income of \$5,510. With regard to family composition, defined in this study as the number of individuals living in the same household, whether by blood, legal, or affective relationship, most of these people lived with one person or more in the home. In addition, 66% had Medicare as health insurance. People with HIV/AIDS for the period of 2000-2020 in Puerto Rico reported being infected through the following modes: 40.6% through heterosexual contact, 26.1% through the use of intravenous drugs, and 20.6% through homosexual contact. Table 1 presents the demographic information of the patients.

**Table I.** Demographic characteristics of HIV/AIDS patients who received services under the Eligible Metropolitan Area (EMA) of San Juan, Puerto Rico, from 2000 to 2020

Characteristic	N	Percent
Total	24,143	100
<i>Immunological classification</i>	24,143	100
HIV	15,547	64
AIDS	8596	36
<i>Gender</i>	24,143	100
Male	15,472	64
Female	8590	36
Transgender	81	0.003
<i>Average age (years) of diagnosis</i>	24,062	99.6
HIV		
Female	35.4 ± 13.0 yrs	
Male	36.8 ± 12.0 yrs	
AIDS		
Female	41.6 ± 11.2 yrs	
Male	42.8 ± 11.0 yrs	



<i>Family Composition</i>	19956	83
1	125	0
2	14680	74
≥ 3	5,171	26
<i>Average annual income</i> \$5,510 ± 10,635	24,143	100
<i>%Poverty Level</i>	24,143	100
≤ 100	18, 107	75
> 100	6,036	25
<i>Type of Medical Insurance</i>	20,893	87
Medicare	13864	66
Public	2873	13
Medicare Part A and B	949	5
Private Employee	657	3
Medicaid	606	3
Uninsured	561	3
Private Single	512	3
Others	871	4
<i>Vital Status</i>	24,143	100
Alive	19,793	81
Dead	2,290	10
Unknown	2,060	9
<i>Risk factors for transmission</i>	24,062	99.6
Heterosexual	9772	40.6
Intravenous Drug Use (IDU)	6278	26.1
Men Sex Men (MSM)	4952	20.6
Not specific	1813	7.5
Perinatal	668	2.8
IDU & MSM	245	1
Blood transfusion	202	0.83
Others	113	0.5
Hemophilia	19	0.1

**B. LYL results**

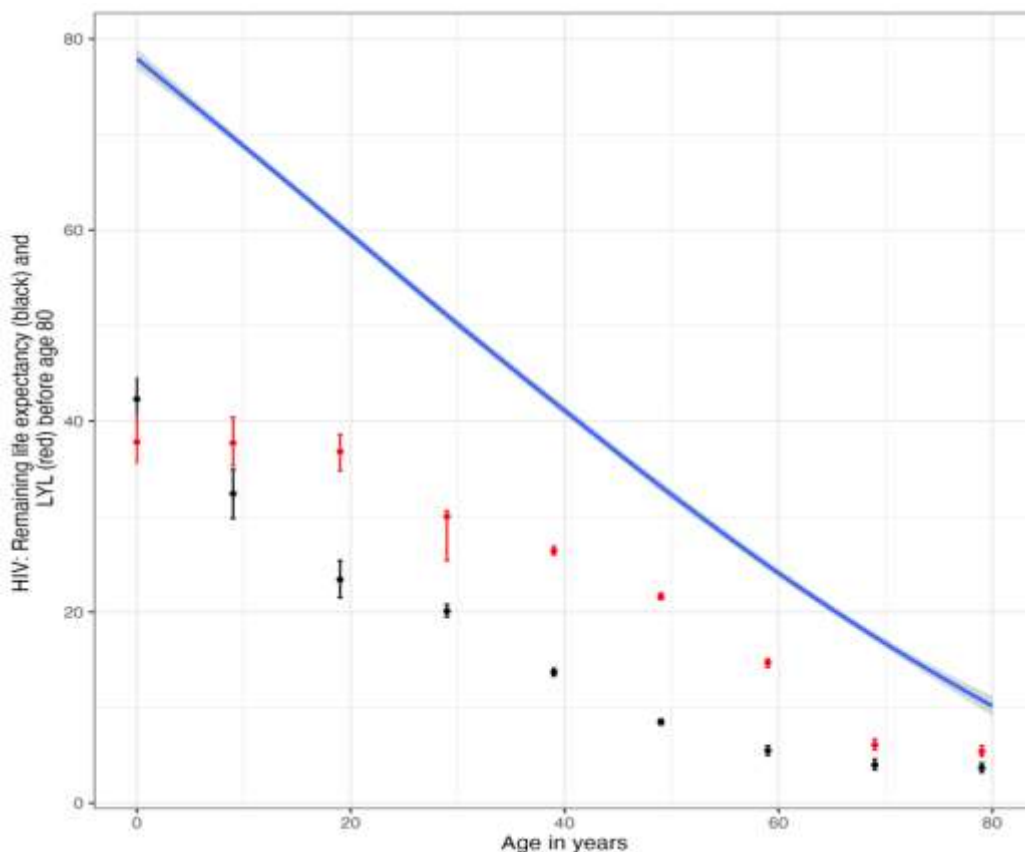
The model assumes that the mean life expectancy of the general population of Puerto Ricans is 80.15 yrs old, which is the mean life expectancy for males (76.7 yrs old) and females (83.6 yrs old). The model also requires a maximum age, for which we used a tau of 80.2 years old which is the mean of life expectancy of males and females. We evaluated varying the maximum tau (80-99), and the changes in the results were insignificant.

*Impact on HIV patients*

For very young patients with HIV, the expected LYL is ± 37 years, while for the age of onset of HIV in patients at age 30 the LYL is ± 30 yrs, and at age 60 LYL is ± 14.6 yrs. Consequently, the average life expectancy across all ages (years to be alive after the onset) of an HIV-diagnosed individual is approximately ±15.0 more years. The life expectancy of individuals irrespective of the age of onset is many years less than the normal population. An individual who is diagnosed with HIV at the age of 20, 30 and 50 is



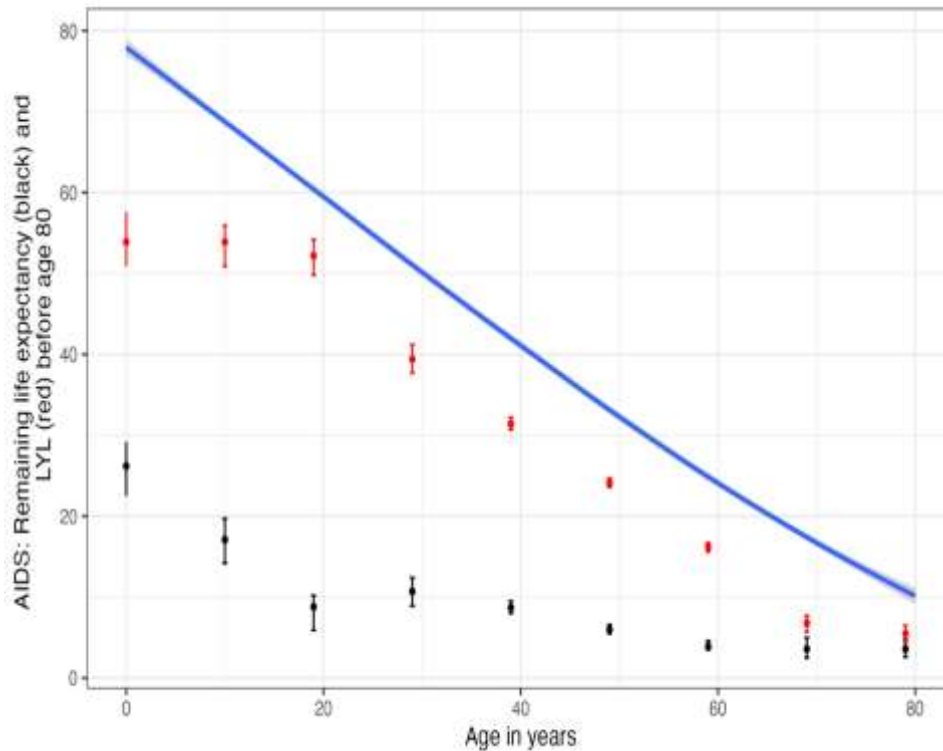
expected mean lifespan is another  $\pm 24$ ,  $\pm 22$  and  $\pm 9$  years respectively (Figure 1, black dots). Considering the whole population across all ages the average life expectancy is  $\pm 44$  years to live (Figure 1, blue line).



**Figure 1:** HIV: LYL and life expectancy of individuals diagnosed with HIV at a specific age. The blue line represents the mean life expectancy of individuals at a specific age for the general population of Puerto Rico. The black dots and confidence intervals represent the mean life expectancy of individuals who are diagnosed with HIV with onset at age X. The red dots and confidence intervals represent the mean LYL of an individual diagnosed with HIV with onset at age X.

*Impact on AIDS patients*

Individuals diagnosed with AIDS (Figure 2) had greater LYL than those diagnosed with HIV (Figure 1). In general, across all years of onset of diagnosis of AIDS, an individual has a mean loss of 27.8 years and a remaining life expectancy of 7.2 years. A 20-year-old diagnosed with AIDS is expected to lose approximately 48.3 years of life (Figure 2, red dots), living approximately 8 years more after the onset of the condition (Figure 2, black dots). Individuals diagnosed with AIDS in their 30's will lose between 27 and 36 years of life and have between 9 and 11 years on average to live. This compares to the general population, which has, on average, between 40 and 48 years more of life for that same age group (Figure 2, blue line).



**Figure 2:** AIDS: LYL and life expectancy of individuals diagnosed with AIDS at a specific age. The blue line represents the mean life expectancy of individuals at a specific age. The black dots and confidence intervals represent the mean life expectancy of individuals diagnosed with AIDS with onset at age X. The red dots and confidence intervals represent the mean LYL of an individual diagnosed with AIDS with an onset at age X.

**DISCUSSION**

One of the main findings of this study was that the number of Life Years Lost is dependent on the year of onset of the condition; the earlier the onset, the greater the LYL. A newborn diagnosed with HIV is expected to lose approximately  $\pm 38$  years of life, while a 50-year-old is likely to lose about  $\pm 22$  years of life. As the age of onset of HIV increases, the LYL is reduced as expected. Individuals who are older when they are diagnosed with HIV or AIDS tend to have fewer years of life remaining and to come closer to the normal average life expectancy because of the naturally expected life span. This trend is consistent with other studies estimating LYL in the United States ([12], [15].) In addition, there is a greater number of life years lost in patients diagnosed with AIDS in this population compared to those diagnosed with HIV. This finding is also consistent with prior results in 2016 [12] indicating that those with late-stage disease at diagnosis (stage 3 [AIDS]) had a life expectancy that was, on average, 6.6 years lower than that for persons with HIV not classified as stage 3. This finding signals poorer outcomes with late diagnosis and more advanced disease. In 2021, approximately 5.9 million people did not know they were living with HIV, per UNAIDS data. [16] This situation underscores the importance of prevention, and it is important to consider demographic aspects such as gender, age, poverty level, and factors related to lifestyle to develop better prevention strategies.

Our study is currently limited in the ability of our estimated values for LYL to be compared with prior studies. Any such comparisons would need to be interpreted with caution due to discrepancies in time frames, methods, and populations. For example, our results differ from those described in a 2016 U.S. study noted above [12] in finding a generally greater number of life years lost, which may in part be related to our study population being in Puerto Rico. LYL at age 50 in our study was approximately 20 years, versus lower LYL figures observed in that study (12.06 for males, 15.08 for females.) [12]. This difference may represent access to care factors in the mainland United States versus Puerto Rico, and/or other factors that present issues comparing studies, including differences in the time frame, population, and methods. The 2016 study [12] used data from 2008-2011, which is subsumed in but



not identical to our population. Finally, their method involved subtracting from life table data from 2010, which will yield different estimates from ours.

Likewise, while our estimate of approximately 20 years lost for a 50-year-old diagnosed with AIDS is similar to results obtained specifically for Hispanic Americans in the United States in a 2010 study, it is higher than the study's estimate for blacks and whites [15]. One could speculate that comparable factors between our population in Puerto Rico and those affecting Hispanic Americans in the mainland United States could come into play, such as socioeconomic status and access to care and economic resources. However, the United States mainland may also have different outcomes compared with Puerto Rico as a whole. Additionally, the data were from the timeframe between 1996-2005, which overlaps with but is different from our timeframe; one may expect more recent estimates to be improved due to developments in treatment [12], which can help improve life expectancy, though still with co-morbidities [17,18]. When comparing the burden of disease on life expectancy across studies, caution is needed as methods may estimate different quantities; researchers should consider such differences concerning the purpose of the research and the type of available data when deciding among different methods to estimate YLL. [9] Future studies may also be performed that employ designs that minimize such discrepancies to allow accurate inter-study comparisons, including with our study results.

Another limitation of the analysis is that the sample sizes are unequal among ages. For example, few newborns and youth were diagnosed with HIV or AIDS. Likewise, the number of individuals with onset of diagnosis of HIV or AIDS at age 60 or above was small. In addition, the deaths reported during the study period by the San Juan Eligible Metropolitan Area (EMA) were not matched with the Puerto Rico Demographic Registry. Furthermore, the data for the San Juan Eligible Metropolitan Area (EMA) does not include people who have been tested anonymously or people infected with HIV/AIDS who have not been tested. Our sample population only includes individuals who requested services through EMA.

In conclusion, the number of life years lost (LYL) depends on the year of onset of the condition. As the age of onset of HIV increases, the LYL is reduced. There is a greater number of life years lost in patients diagnosed with AIDS in this population compared to those diagnosed with HIV. Average years of life lost (AYLL) is a measure that reflects early death as a result of a condition. It reflects how many years earlier than anticipated a person dies. Average years of life lost, in addition to survival and life expectancy, is an important measure of disease impact, which has been infrequently used to measure the impact of the HIV/AIDS epidemic, particularly in Puerto Rico. The large differences between in life span of individuals with HIV/AIDS and the control population in Puerto Rico is dramatic and should be a call for action to improve the general health of this affected population.

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