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ARTICLE

Assessing the underreporting of deaths among people living with HIV in Rio de Janeiro, Brazil, from 2014 to 2019

Avaliação da subnotificação de óbitos em pessoas vivendo com HIV no Rio de Janeiro, Brasil, entre 2014 e 2019

Evaluando el subregistro de muertes entre personas que viven con VIH en Río de Janeiro, Brasil, de 2014 a 2019

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Abstract

We assessed the proportions and causes of the underreporting of deaths among people living with HIV (PLHIV) in Rio de Janeiro, Brazil, from 2014 to 2019. Demographic variables, mention of tuberculosis (TB), and CD4 cell counts closest to death were used to compare those who had HIV/AIDS mentioned on their death certificate (HMDC) to those who did not. Out of 10,698 deaths, 2,863 (26.8%) had no HMDC, from which 412 (14.4%) had external underlying cause. After excluding deaths from external causes, we found that 24% still had no HMDC. Age ≥ 40 years (OR = 1.75; 95%CI: 1.52-2.01), non-white race/ethnicity (OR = 1.16; 95%CI: 1.02-1.31), the male gender (OR = 1.25; 95%CI: 1.11-1.42), higher CD4 cell counts closest to death (OR = 1.14; 95%CI: 1.12-1.16), absence of TB (OR = 4.86; 95%CI: 3.76-6.29) and not dying within a hospital (OR = 2.61; 95%CI: 2.31-2.95) were associated with increased probabilities of not having HMDC. The proportion of deaths with no HMDC increased from 18.7% to 35.1% between 2014 and 2019. The high proportion of underreported deaths in Rio de Janeiro indicates that HIV/AIDS mortality coefficients in the state may be underestimated. With the changing patterns of mortality of PLHIV, physicians are advised to consider the broader clinical spectrum of HIV infection, and surveillance officers should improve death monitoring.

HIV; Acquired Immunodeficiency Syndrome; Mortality; Surveillance

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Introduction

After combined antiretroviral therapy (cART) became widely available in the mid-1990s, mortality among people living with HIV (PLHIV) greatly decreased. However, evidence showed that the decline in death rates was paralleled with a change from AIDS-related causes of death to deathes from conditions initially unrelated to the clinical spectrum of HIV infection [1,2,3,4,5].

In 1996, Brazil became the first middle-income country to offer free access to both HIV diagnosis and cART to all eligible patients. Although the trends conceal important regional variations, cART substantially mitigated death rates among PLHIV in Brazil as a whole [6]. Accordingly, the mortality profile of PLHIV shifted towards conditions usually unrelated to HIV/AIDS, which has been described locally [7,8], regionally [9], and nationwide [10,11].

Besides these undisputable initial achievements, AIDS death rates in Brazil have been virtually stable since 1999 [6,10]. While the scrutiny of this downfall of the Brazilian response to the HIV/AIDS epidemic is beyond the scope of this work, AIDS death rates for the whole country [10,12] and for at least some of its states [10,13,14] seem to be greater than officially depicted, considering the underreporting of cases [15,16,17] and deaths [18] among PLHIV.

A study conducted a descriptive analysis to find the major causes of AIDS deaths misclassification and to redistribute ill-defined causes of death. The authors found that, from 1985 to 2009, 27% of cases were underreported due to misclassification of AIDS-related causes in Brazil [12]. In a recent study, the official mortality system of Santa Catarina State had an estimated 21% of underreported HIV/AIDS deaths; with other obstacles in the surveillance structure, a 37.1% underestimation was found from 2008 to 2017 [14].

Pacheco et al. [13] have merged data from two large urban cohorts of PLHIV in Rio de Janeiro to the official state mortality database to recover vital status information from patients lost to follow-up; the authors described that 23.9% of deaths did not have mention of HIV/AIDS codes on the death certificate (HMDC). Moreover, about one out of four deaths of PLHIV in Rio de Janeiro had no HMDC even after the exclusion of registers having external causes as the underlying causes of death [19]. Together, these findings emphasize how underreported deaths affect the quality of information on PLHIV mortality and hence the HIV/AIDS surveillance and control.

From 2014 to 2019, we assessed the proportions of underreported deaths among PLHIV in Rio de Janeiro and their associated factors after cross-referencing public HIV/AIDS surveillance databases to the official death registry.

Methods

Study site

Located in the Southeastern Brazil, the state of Rio de Janeiro is the third most populous Brazilian Federative Unit, with around 17.3 million inhabitants in 2020. Rio de Janeiro also has the second largest economy of the country, contributing to 9.2% of the Brazilian GDP. The state's latest official Human Development Index (HDI) was calculated in 0.761 [20].

According to the Brazilian Ministry of Health [21], in 2019, the state of Rio de Janeiro ranked third in the national ranking of AIDS standardized mortality rates with 7.1 deaths per 100,000 inhabitants, largely outnumbering the country average, estimated in 4.1 deaths per 100,000 inhabitants.

Data sources and study population

Data from four official electronic databases were used: (i) Information System for Notifiable Diseases (SINAN) is the HIV/AIDS case reporting and investigation system; (ii) Laboratory Test Control System (SISCEL) monitors information on CD4 cells count and viral load determination tests; (iii) System for Logistic Control of Drugs (SICLOM) provides strategic support regarding cART dispensation; and (iv) Mortality Information System (SIM) gathers and stores information from death certificates.

Although SISCEL and SICLOM are independent systems, they share common fields regarding patient identification and sociodemographic information.

The study population included PLHIV in the state of Rio de Janeiro who either (i) were diagnosed with HIV/AIDS or (ii) had a CD4/viral load determination or (iii) received cART or (iv) died, at any point between 2014 and 2019. Only individuals aged 13 years or older at any endpoint were included in the analysis.

Data linkage strategy

Data deduplication and linkage were performed with a previously validated fully-automated deterministic algorithm, developed to retrieve vital status from patients lost to follow-up in a HIV/AIDS cohort [13]. The algorithm was also validated to cross-reference PLHIV public databases [22], linking these data to tuberculosis [23,24] and to HIV cohorts [7]. Patient's name, date of birth, and mother's name were used as matching fields.

Records from SINAN and SISCEL/SICLOM were linked to the SIM database to determine the patients' vital status. To maximize linkage accuracy, we cross-referenced registers from SINAN to SIM and from SISCEL/SICLOM to SIM; then, resulting databases were linked, replaced by the final one. SINAN data were deduplicated according to the hierarchical structure and tiebreakers adopted by the Brazilian Ministry of Health, which are based on both AIDS case notification criteria and HIV diagnosis date, as detailed elsewhere [21].

Labels (of residence and death) for municipalities and codes of different types of health institutions were obtained from the Brazilian Institute of Geography and Statistics (IBGE; https://www.ibge.gov.br/) and the Brazilian National Registry of Healthcare Establishment (CNES; http://cnes.datasus.gov.br/) websites, respectively.

Variables of interest

Demographic variables included age, gender, ethnicity, schooling, marital status, municipality of residence/death, and type of institution where death occurred. If demographic data in more than one database diverged, information was chosen preferentially from SIM, SISCEL/SICLOM, and lastly from SINAN. Laboratorial variables included CD4 cell counts and viral load (both closest to the date of death).

Causes of death mentioned in any field of the death certificate were retrieved and classified regarding presence or absence of HIV/AIDS codes (B20-B24), according to the International Classification of Diseases, 10th revision (ICD-10) [25]. We considered two different datasets regarding the inclusion or not of deaths from external underlying causes.

ICD-10 codes of interest included A15-A19 and B200 for tuberculosis and V01-Y98 for external causes. Garbage codes included R00-R99, A40, A411, C26, C55, C76, C78-C80, I10, I26, I50, I51, I64, I674, I679, I694, I698, J159, J18, J96, J98, N17, N19, V89, X59, Y09, Y1, Y2 and Y30-Y34, as described elsewhere [26].

Statistical analysis

Pearson's chi-squared test compared categorical data (proportions of gender, race/ethnicity, schooling level, place of death, and mention of tuberculosis and garbage codes), whereas Wilcoxon rank-sum test compared count data (age and CD4 cell count) mean ranks. Logistic regression models [27] were fitted to estimate the odds ratios for no HMDC. To find the best-fit model, an automated procedure was implemented via a genetic algorithm including first-order interactions [28]. Residual analysis was used to inspect the model's goodness of fit. Mann-Kendall trend test was used to check whether the proportion of deaths with no HMDC consistently varied overtime. All analyses were performed in the R computing environment version 4.0.2 (http://www.r-project.org).

Ethics

This project was approved by the Research Ethics Committee of the Sergio Arouca National School of Public Health, Oswaldo Cruz Foundation (ENSP/Fiocruz; number 1.172.797).

Results

According to the eligibility criteria, 109,636 individuals were included in our study, from which 36,429 (33.2%) were reported to SINAN, 101,496 (92.6%) were registered in SISCEL/SICLOM and 10,698 (9.7%) were found in the mortality database. Of those registered in SINAN and SISCEL/SICLOM, respectively 5,601 (15.4%) and 7,709 (7.6%) were found in SIM.

Around 2,863 (26.8%) of the PLHIV found in the mortality database had no HMDC, from which 412 (14.4%) had external causes and 1,074 (37.5%) had garbage codes as the underlying cause of death. After we excluded deaths from external causes, 24% of the registers still had no HMDC.

Individuals with no HMDC were older, had higher CD4 cell counts closest to death and were more likely to be male ($p < 0.001$ for all). On the other hand, they were less likely to have tuberculosis as the underlying or contributing causes of death ($p < 0.001$). Among those who had HMDC, 81.4% died within hospitals, whereas 58.9% did not ($p < 0.001$; Table 1). Overall, quite similar findings were seen after registers of external underlying causes of death were excluded (Table 2). Multiple logistic regression outputs are shown in Table 3.

Being older (OR = 1.40; 95%CI: 1.24-1.58; $p < 0.001$), non-white (OR = 1.19; 95%CI: 1.06-1.34; $p = 0.004$), male (OR = 1.42; 95%CI: 1.26-1.59; $p < 0.001$), having higher CD4 cell count closest to death (OR = 1.16; 95%CI: 1.14-1.18; $p < 0.001$), not having tuberculosis (OR = 5.80; 95%CI: 4.50-7.49; $p < 0.001$) and not dying within a hospital (OR = 2.91; 95%CI: 2.59-3.27; $p < 0.001$) were associated to increased probability of no HMDC.

Table 1

General features of deceased people living with HIV (PLHIV) from Rio de Janeiro, Brazil, retrieved by linkage of the official HIV/AIDS databases to the mortality system. Complete dataset considered.

Variables	Total	HIV/AIDS *		p-value **
		Yes	No	
	n (%)	n (%)	n (%)	
Total	10,698 (100.0)	7,835 (73.2)	2,863 (26.8)	
Age (IQR)	45.1 (35.4-55.5)	43.5 (34.5-53.5)	50.3 (38.9-60.5)	< 0.001
Male	6,894 (64.5)	4,892 (62.4)	2,002 (70.0)	< 0.001
White ethnicity	3,614 (33.8)	2,650 (33.8)	964 (33.7)	0.34
At least 1 year of schooling	9,572 (89.5)	7,018 (89.6)	2,554 (89.2)	0.457
CD4 count closest to death *** (IQR)	214 (62-496)	149 (44-392)	404 (175-666)	< 0.001
Tuberculosis *	1,468 (13.7)	1,361 (17.4)	107 (3.7)	< 0.001
Garbage codes #	1,155 (10.8)	81 (1.0)	1,074 (37.5)	< 0.001
Death within a hospital ##	8,052 (75.4)	6,375 (81.4)	1,677 (58.9)	< 0.001

IQR: interquartile range.

* Mentioned in any field of the death certificate;

** p-values for Wilcoxon rank-sum test for continuous variables and Pearson's chi-squared test for categorical variables;

*** Complete dataset had 3,551 cases with unknown CD4 count closest to the death;

As the underlying cause of death;

16 individuals had unknown place of death.

Table 2

General features of deceased people living with HIV (PLHIV) from Rio de Janeiro, Brazil, retrieved by linkage of the official HIV/AIDS databases to the mortality system. Dataset with no external causes.

Variables	Total	HIV/AIDS *		p-value **
		Yes	No	
	n (%)	n (%)	n (%)	
Total	10,234 (100.0)	7,783 (76.1)	2,451 (23.9)	
Age (IQR)	45.3 (35.6-55.7)	43.5 (34.5-53.5)	52 (41.0-61.4)	< 0.001
Male	6,518 (63.7)	4,861 (62.5)	1,657 (67.7)	< 0.001
White ethnicity	3,467 (33.9)	2,628 (33.8)	839 (34.2)	0.161
At least 1 year of schooling	9,150 (89.4)	6,971 (89.6)	2,179 (88.9)	0.302
CD4 count closest to death *** (IQR)	198 (58-476)	147 (43-389)	376 (157-646)	< 0.001
Tuberculosis *	1,463 (14.3)	1,357 (17.4)	106 (4.3)	< 0.001
Garbage codes #	971 (9.5)	72 (0.9)	899 (36.7)	< 0.001
Death within a hospital ##	7,837 (76.7)	6,332 (81.4)	1,505 (61.8)	< 0.001

IQR: interquartile range.

* Mentioned in any field of the death certificate;

** p-values for Wilcoxon rank-sum test for continuous variables and Pearson's chi-squared test for categorical variables;

*** Dataset with no external causes had 3,473 cases with unknown CD4 count closest to death;

As the underlying cause of death;

16 individuals had unknown place of death.

Table 3

Odds ratios (OR) for no HIV/AIDS codes mentioned in the death certificate of people living with HIV (PLHIV) from Rio de Janeiro, Brazil, retrieved by linkage of the official HIV/AIDS databases to the mortality system.

Variables	Complete dataset		External causes removed	
	OR (95%CI)	p-value	OR (95%CI)	p-value
Age group (years)		< 0.001		< 0.001
< 40	-		-	
≥ 40	1.40 (1.24-1.58)		1.75 (1.52-2.01)	
Race/Ethnicity		0.004		0.019
White	-		-	
Non-white	1.19 (1.06-1.34)		1.16 (1.02-1.31)	
Gender		< 0.001		< 0.001
Female	-		-	
Male	1.42 (1.26-1.59)		1.25 (1.11-1.42)	
CD4 cell count closest to death *	1.16 (1.14-1.18)	< 0.001	1.14 (1.12-1.16)	< 0.001
Tuberculosis **		< 0.001		< 0.001
Yes	-		-	
No	5.80 (4.50-7.49)		4.86 (3.76-6.29)	
Death within a hospital		< 0.001		< 0.001
Yes	-		-	
No	2.91 (2.59-3.27)		2.61 (2.31-2.95)	

95%CI: 95% confidence interval.

* For 100 cells increase;

** Mentioned in any field of the death certificate.

After we excluded deaths from external causes, the association with male gender (OR = 1.25; 95%CI: 1.11-1.42; p < 0.001), not having tuberculosis (OR = 4.86; 95%CI: 3.76-6.29; p < 0.001) and not dying within a hospital (OR = 2.61; 95%CI: 2.31-2.95; p < 0.001) on HMDC likelihood weakened, whereas the association with older ages (OR = 1.75; 95%CI: 1.52-2.01; p < 0.001) strengthened. Odds ratios for both race/ethnicity (OR = 1.16; 95%CI: 1.02-1.31; p = 0.019) and CD4 cell counts closest to death (OR = 1.14; 95%CI: 1.12-1.16; p < 0.001) did not change. Proportions of deaths with no HMDC increased over time, ranging from 18.7% in 2014 to 35.1% in 2019 (p < 0.001). Garbage codes were not modelled since they represent a *post hoc* event and do not truly predict a patients' death.

Discussion

Our main result is that, after deaths from external causes were ruled out, we found that 23.9% of PLHIV who died between January 1, 2014, and December 31, 2019, in Rio de Janeiro, had no HMDC. Those people were, therefore, out of the state mortality system's scope, indicating that state HIV/AIDS mortality coefficients, which are based solely on state-level death information, may be biased towards lower estimates.

According to the World Health Organization's guideline for death certification, in case of accidents, injuries, or poisonings, the external cause should be reported as the underlying causes of death instead of HIV/AIDS codes [29]. When such deaths were excluded of the analyses, proportions of no HMDC increased to 26.4%. This corroborates our previous work assessing the proportions of underreported deaths in cohorts of PLHIV in Rio de Janeiro [13,30].

We emphasize the conflict between proportions of deaths occurred in hospitals for those with HMDC (81.4%) and for those without such codes (58.9%). As previously reported, patients in the city of Rio de Janeiro are becoming increasingly aware of their HIV serostatus in emergency care systems, with a worrying proportion already presenting pronounced immunodeficiency signs and evolving to death with no prior testing [31].

Male gender and younger ages are associated with violent deaths; therefore, after deaths from external underlying causes were excluded, no HMDC became less associated to male gender and more associated to older ages. Excluding younger patients may also have weakened the association of no HMDC with tuberculosis and with death outside hospitals.

Characteristics associated with HIV/AIDS mortality underestimation, including being older, having higher CD4 cell counts closest to death, and not having tuberculosis, suggest that the mortality profile of PLHIV is getting closer to that of the general population [32,33,34]. This is likely a consequence of large-scale and early use of cART, which tends to gradually shift the morbidity profile among PLHIV from AIDS-related diseases to manageable chronic conditions [8,11,32]. Moreover, occurrences of no HMDC have increased over time.

Our results point to a high proportion of garbage codes as the underlying cause of death among those not having HMDC, irrespective of whether external causes were considered or not. Notwithstanding, those numbers are very akin to the proportions of garbage codes verified for the overall state's population [26]. It seems, therefore, that upon scale up use of cART PLHIV are progressively resembling the general population in clinical and epidemiological aspects, both beneficial and detrimental.

There are several reasons for HIV/AIDS underreporting on death certificates. Physicians may not be familiar with proper documentation of causes of death on the certificates; either the physician or the deceased relatives may be averse to the presence of HIV/AIDS codes on the death certificate due to stigmatization and the unawareness of the HIV status among patients who pass away in emergency rooms [35], to name just a few.

The major strength of our study is that retrospectively followed nearly 110,000 PLHIV found in official HIV/AIDS surveillance databases for a 6-year time frame so as to assign their vital status through linkage to the official mortality system. Such strategy yielded a considerable number of events (10,698 deaths) thus endowing the analyses with great statistical power.

Our study also has limitations worth acknowledging. As is frequent in population-based studies, especially those involving solely death certificates information, the influence of unmeasured con-

founders cannot be assured to be kept at bay. Also, the linkage algorithm employed, though proven to be accurate enough [22], may have introduced some amount of false-positive and/or false-negative pairings, which we consider to be insufficient to impact on our findings.

The changing pattern of mortality of PLHIV challenges not only physicians to consider the broader clinical spectrum of HIV infection but also surveillance officers to improve death monitoring. Cross-referencing HIV/AIDS databases to the all-cause mortality system on a regular basis is expected to mitigate the underreporting issue in order to produce bona fide mortality estimates.

While the Brazilian official HIV/AIDS death estimates can be in some measure biased, an alternative approach to circumvent this issue would be using ancillary sources of information, such as the Global Burden of Disease initiative, which combines crude data (as those from SIM) to statistical models to account for potential sources of errors, e.g, misclassification of underlying cause of death and underreporting [10].

The evidence presented here supports the suboptimal accuracy of death certificates to classify HIV/AIDS-related deaths. As an example, when ICD-10 was compared to a standardized algorithm developed specifically to classify causes of deaths among PLHIV, the proportion of HIV/AIDS-related conditions was overestimated while liver-related conditions, infections and ill-defined causes of death were downsized, as cirrhosis deaths due to viral or unknown aetiologies are likely to be assigned to HIV/AIDS-related causes [36].

Efforts to gauge and to mitigate the underreporting of deaths among PLHIV are needed in order to improve the estimates of mortality, which are instrumental in monitoring the burden of HIV infection and, ultimately, to guide public policies to hold the epidemic back.

Further analyses are needed to guide programmatic interventions among PLHIV in regions with widespread use of cART, by directing special efforts to the evolving morbimortality spectrum of HIV if curbing the HIV/AIDS epidemic is the goal.

The underreporting of both cases and deaths, along with the late diagnosis and entry into care are the main stumbling blocks to the cost-effectiveness of the HIV/AIDS control program in Brazil. These are enduring obstacles the country needs to be cleared of in order to accelerate the HIV response, with new agendas such as the "test and treat" and "treatment as prevention" programs and the implementation of services for key and priority populations, including sex workers, men who have sex with men and imprisoned individuals.

Conclusion

We found a high proportion of underreported deaths among people living with HIV in the state of Rio de Janeiro, indicating that local HIV/AIDS mortality coefficients could be underestimated. The changing patterns of mortality of PLHIV challenges both physicians to consider the broader clinical spectrum of HIV infection and surveillance officers to improve death monitoring.

Contributors

A. A. Paula contributed to the study conceptualization, data curation, original draft, writing, review, and editing. P. Chequer, D. R. F. Pires, K. R. V. Lemos, L. G. Barone, and V. G. Veloso contributed to the study conceptualization, writing, review, and editing. A. G. Pacheco contributed to the study methodology, study conceptualization, data curation, writing, review and editing. All authors approved the final version of the manuscript.

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References

1. Crum NF, Riffenburgh RH, Wegner S, Agan BK, Tasker SA, Spooner KM, et al. Comparisons of causes of death and mortality rates among HIV-infected persons: analysis of the pre-, early, and late HAART (highly active antiretroviral therapy) eras. J Acquir Immune Defic Syndr 2006; 41:194-200.
2. Croxford S, Kitching A, Desai S, Kall M, Edelstein M, Skingsley A, et al. Mortality and causes of death in people diagnosed with HIV in the era of highly active antiretroviral therapy compared with the general population: an analysis of a national observational cohort. Lancet Public Health 2017; 2:e35-e46.
3. Krentz HB, Kliewer G, Gill MJ. Changing mortality rates and causes of death for HIV-infected individuals living in Southern Alberta, Canada from 1984 to 2003. HIV Med 2005; 6:99-106.
4. Martínez E, Milinkovic A, Buira E, de Lazzari E, León A, Larrousse M, et al. Incidence and causes of death in HIV-infected persons receiving highly active antiretroviral therapy compared with estimates for the general population of similar age and from the same geographical area. HIV Med 2007; 8:251-8.
5. Palella Jr. FJ, Baker RK, Moorman AC, Chmiel JS, Wood KC, Brooks JT, et al. Mortality in the highly active antiretroviral therapy era: changing causes of death and disease in the HIV outpatient study. J Acquir Immune Defic Syndr 2006; 43:27-34.
6. Brito AM, Castilho EA, Szwarcwald CL. Regional patterns of the temporal evolution of the AIDS epidemic in Brazil following the introduction of antiretroviral therapy. Braz J Infect Dis 2005; 9:9-19.
7. Pacheco AG, Tuboi SH, May SB, Moreira LF, Ramadas L, Nunes EP, et al. Temporal changes in causes of death among HIV-infected patients in the HAART era in Rio de Janeiro, Brazil. J Acquir Immune Defic Syndr 2009; 51:624-30.
8. Grinsztejn B, Luz PM, Pacheco AG, Santos DV, Velasque L, Moreira RI, et al. Changing mortality profile among HIV-infected patients in Rio de Janeiro, Brazil: shifting from AIDS to non-AIDS related conditions in the HAART era. PLoS One 2013; 8:e59768.
9. de Paula AA, Pires DF, Alves Filho P, Lemos KRV, Veloso VG, Grinsztejn B, et al. Mortality profiles among people living with HIV/AIDS: comparison between Rio de Janeiro and other federative units between 1999 and 2015. Rev Bras Epidemiol 2020; 23:e200017.
10. Guimarães MDC, Carneiro M, Abreu DMX, França EB. HIV/AIDS mortality in Brazil, 2000-2015: are there reasons for concern? Rev Bras Epidemiol 2017; 20 Suppl 1:182-90.

11. de Paula AA, Schechter M, Tuboi SH, Faulhaber JC, Luz PM, Veloso VG, et al. Continuous increase of cardiovascular diseases, diabetes, and non-HIV related cancers as causes of death in HIV-infected individuals in Brazil: an analysis of nationwide data. PLoS One 2014; 9:e94636.
12. Fazito E, Cuchi P, Fat DM, Ghys PD, Pereira MG, Vasconcelos AM, et al. Identifying and quantifying misclassified and under-reported AIDS deaths in Brazil: a retrospective analysis from 1985 to 2009. Sex Transm Infect 2012; 88 Suppl 2:i86-94.
13. Pacheco AG, Saraceni V, Tuboi SH, Moulton LH, Chaisson RE, Cavalcante SC, et al. Validation of a hierarchical deterministic record-linkage algorithm using data from 2 different cohorts of human immunodeficiency virus-infected persons and mortality databases in Brazil. Am J Epidemiol 2008; 168:1326-32.
14. Tombini LHT, Kupek E. Size of the adult HIV-infected population adjusted for the unreported AIDS mortality in the Santa Catarina State, Brazil, 2008-2017. Curr HIV Res 2019; 17:277-89.
15. Ferreira VMB, Portela MC. Avaliação da subnotificação de casos de Aids no Município do Rio de Janeiro com base em dados do sistema de informações hospitalares do Sistema Único de Saúde. Cad Saúde Pública 1999; 15:317-24.
16. Ferreira VM, Portela MC, Vasconcellos MT. Variables associated with underreporting of AIDS patients in Rio de Janeiro, Brazil, 1996. Rev Saúde Pública 2000; 34:170-7.
17. Gonçalves VF, Kerr LRFS, Mota RMS, Mota JMA. Estimation of underreporting of AIDS cases in a Brazilian Northeast metropolis. Rev Bras Epidemiol 2008; 11:356-64.
18. Carmo RAD, Policena GM, Alencar GP, França EB, Bierrenbach AL. Underreporting of AIDS deaths in Brazil: linkage of hospital records with death certificate data. Ciênc Saúde Colet 2021; 26:1299-310.
19. Pacheco AG, Tuboi SH, Faulhaber JC, Harrison LH, Schechter M. Increase in non-AIDS related conditions as causes of death among HIV-infected individuals in the HAART era in Brazil. PLoS One 2008; 3:e1531.
20. Instituto Brasileiro de Geografia e Estatística. Cidades e estados. https://www.ibge.gov.br/cidades-e-estados/rj.html (acessado em 18/Jun/2021).
21. Ministério da Saúde. Boletim Epidemiológico HIV/Aids 2020. http://www.aids.gov.br/pt-br/pub/2020/boletim-epidemiologico-hivaids-2020.
22. de Paula AA, Pires DF, Alves Filho P, de Lemos KRV, Barçante E, Pacheco AG. A comparison of accuracy and computational feasibility of two record linkage algorithms in retrieving vital status information from HIV/AIDS patients registered in Brazilian public databases. Int J Med Inform 2018; 114:45-51.
23. Saraceni V, Cohn S, Cavalcante SC, Pacheco AG, Moulton LH, Chaisson RE, et al. Prevalent tuberculosis at HIV diagnosis in Rio de Janeiro, Brazil: the TB/HIV in Rio (THRio) Cohort. J Acquir Immune Defic Syndr 2014; 67:98-101.
24. Pacheco AG, Durovni B, Cavalcante SC, Lauria LM, Moore RD, Moulton LH, et al. AIDS-related tuberculosis in Rio de Janeiro, Brazil. PLoS One 2008; 3:e3132.
25. World Health Organization. International statistical classification of diseases and related health problems. 10th revision. https://icd.who.int/browse10/2019/en (accessed on 10/Nov/2020).
26. Minto CM, Cascão AM, Lima S, Kuyumjian FG, Godoy L, Souza MFM. Evaluation study of the improvement of the quality of death information in hospitals of the states of Rio de Janeiro and São Paulo, Brazil, 2017. Rev Bras Epidemiol 2019; 22 Suppl 3:e19008.supl.3.
27. Hosmer D, Lemeshow S. Applied logistic regression. New York: Wiley; 2000.
28. Calcagno V, Mazancourt C. glmulti: an R package for easy automated model selection with (generalized) linear models. J Stat Softw 2010; 34:1-29.
29. World Health Organization. Guidelines for HIV mortality measurement. Geneva: World Health Organization; 2014.
30. Pacheco AG, Saraceni V, Tuboi SH, Lauria LM, Moulton LH, Faulhaber JC, et al. Estimating the extent of underreporting of mortality among HIV-infected individuals in Rio de Janeiro, Brazil. AIDS Res Hum Retroviruses 2011; 27:25-8.
31. Saraceni V, da Cruz MM, Lauria LM, Durovni B. Trends and characteristics of AIDS mortality in the Rio de Janeiro city after the introduction of highly active antiretroviral therapy. Braz J Infect Dis 2005; 9:209-15.
32. Yang H-Y, Beymer MR, Suen S-C. Chronic disease onset among people living with HIV and AIDS in a large private insurance claims dataset. Sci Rep 2019; 9:18514.
33. Kaplan-Lewis E, Aberg JA, Lee M. Aging with HIV in the ART era. Semin Diagn Pathol 2017; 34:384-97.
34. Cardoso SW, Luz PM, Velasque L, Torres T, Coelho L, Freedberg KA, et al. Effectiveness of first-line antiretroviral therapy in the IPEC cohort, Rio de Janeiro, Brazil. AIDS Res Ther 2014; 11:29.
35. Trepka MJ, Sheehan DM, Fennie KP, Niyonsenga T, Lieb S, Maddox LM. Completeness of HIV reporting on death certificates for Floridians reported with HIV infection, 2000-2011. AIDS Care 2016; 28:98-103.
36. Hernando V, Sobrino-Vegas P, Burriel MC, Berenguer J, Navarro G, Santos I, et al. Differences in the causes of death of HIV-positive patients in a cohort study by data sources and coding algorithms. Aids 2012; 26:1829-34.

Resumo

Os autores avaliaram as proporções de subnotificação de óbitos e fatores associados em pessoas vivendo com HIV (PVHIV) no Rio de Janeiro, Brasil, entre 2014 e 2019. Variáveis demográficas, menção de tuberculose (TB) e contagem de células CD4 mais próxima ao óbito foram utilizadas para comparar indivíduos que tiveram códigos para HIV/aids mencionados na declaração de óbito (HMDO) àqueles que não apresentaram tal menção. Entre 10.698 certidões de óbito, 2.863 (26.8%) não citaram HIV/aids. Entre estes, 412 (14,4%) apresentaram causas externas como a causa subjacente. Depois de excluir as causas externas, 24% das certidões não mencionaram HIV/aids. Idade acima de 40 anos (OR = 1,75; IC95%: 1,52-2,01), raça/etnicidade não branca (OR = 1,16; IC95%: 1,02-1,31), sexo masculino (OR = 1,25; IC95%: 1,11-1,42), contagem de CD4 mais alta próximo ao óbito (OR = 1,14; IC95%: 1,12-1,16), não ter TB (OR = 4,86; IC95%: 3,76-6,29) e morte extra-hospitalar (OR = 2,61; IC95%: 2,31-2,95) mostraram associação com aumento de probabilidade de não apresentar HMDO. A proporção de certidões de óbito que não citavam HIV/aids aumentou de 18,7% para 35,1% entre 2014 e 2019. A alta proporção de óbitos subnotificados no Rio de Janeiro indica a possível subestimação dos coeficientes de mortalidade por HIV/aids no estado. A mudança nos padrões de mortalidade em PVHIV desafia tanto os médicos, no sentido de considerar o espectro clínico mais amplo na infecção pelo HIV, quanto os especialistas em vigilância, no sentido de aprimorar o monitoramento da mortalidade.

HIV; Síndrome de Imunodeficiência Adquirida; Mortalidade; Vigilância

Resumen

Evaluamos los porcentajes y factores asociados con el subregistro de muertes entre personas afectadas por VIH (PLHIV) en Río de Janeiro, Brasil, desde 2014 a 2019. Se utilizaron variables demográficas, mención de tuberculosis (TB) y recuentos de células CD4 más cercanos al fallecimiento, para comparar a quienes tenían VIH/SIDA reflejado en el certificado de defunción (HMDC), con quienes no lo tenían. De las 10.698 muertes, 2.863 (26,8%) no tuvieron HMDC. De entre ellos, 412 (14,4%) tenían causas externas como causa subyacente. Tras excluir las causas externas, un 24% no tuvieron HMDC. Edad ≥ 40 años (OR = 1,75; IC95%: 1,52-2,01), raza no blanca raza/etnicidad (OR = 1,16; IC95%: 1,02-1,31), género masculino (OR = 1,25; IC95%: 1,11-1,42), recuentos de células CD4 más altos más cercanos a la muerte (OR = 1,14; IC95%: 1,12-1,16), que no tenían TB (OR = 4,86; IC95%: 3,76-6,29), y que no murieron en un hospital (OR = 2,61; IC95%: 2,31-2,95), estuvieron asociados con probabilidades crecientes de no tener HMDC. La proporción de muertes que no tenían HMDC aumentó de un 18,7% a un 35,1% entre 2014 y 2019. La alta proporción de muertes subregistradas en Río de Janeiro indican que los coeficientes de mortalidad VIH/SIDA en el estado quizás estaban subestimados. Los patrones cambiantes de mortalidad suponen un desafío para las PLHIV, así como para los médicos, a la hora de considerar infección por VIH dentro de un espectro clínico más amplio, al igual que para los agentes de supervisión, con el fin de mejorar el monitoreo de muertes.

VIH: Síndrome de Inmunodeficiencia Adquirida; Mortalidad; Vigilancia

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