Mortality trends among persons with perinatally-acquired HIV (PHIV) in United States and 6 territories and freely associated states, 1978-2022

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Preetam A Cholli[1], Xueyuan Dong[2], Margaret Lampe[1], Yang Liu[1], Jessica Fridge[1], Athena P. Kourtis[1], **Alexandra Balaji[1]**, Kate Buchacz[1]
[1]Centers for Disease Control and Prevention, Atlanta, GA, USA, [2] DLH Corporation, Atlanta, GA, USA

BACKGROUND

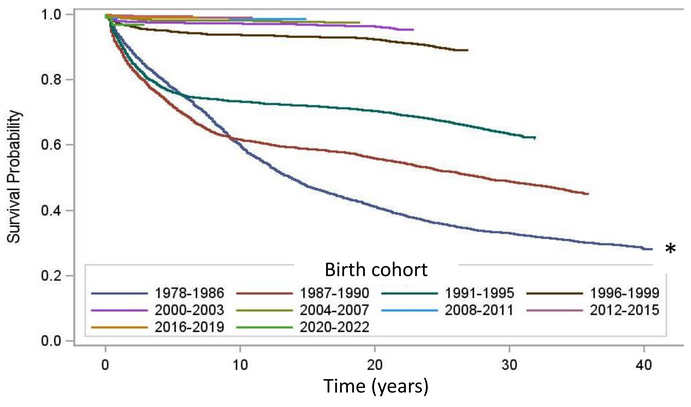
- Recent U.S. mortality trends among people aging with perinatally-acquired HIV (PHIV, "lifetime survivors") are poorly characterized.
- Using CDC's National HIV Surveillance System (NHSS) data, we (1) analyzed survival trends and all-cause mortality among PHIV cases since the first were identified, and (2) described characteristics of decedent PHIV cases between 2020-2022.

METHODS

- We categorized PHIV cases born between 1978 and 2022 (as reported to NHSS through December 2023) into cohorts based on year of birth:
  - No ART era[a] (1978-1986)
  - Early-ART era[b] (1-2 drug regimens) (1987-1995); divided into 4-5 year cohorts (with 1987-1990 as referent group)
  - Combination ART (cART) era[c] (1996-2022); divided into 4-5 year cohorts through end of observation
- A Kaplan-Meier survival analysis was conducted to estimate the probability of survival across different birth cohorts
- Population-level demographic characteristics were calculated for each cohort
- All-cause mortality rates (MR; deaths per 1000 person-years) were calculated by age for each calendar year.
- An extended Cox model was used to assess associations of PHIV case mortality across different birth cohorts and demographic characteristics

RESULTS

Fig 1: Survival probability among PHIV cases, by birth cohort*



*Deaths among PHIV cases in the 'No ART era' cohort (1978-1986) are from AIDS case-reporting and should be interpreted with caution.

Despite great progress, lifetime survivors born in the earlier periods of HIV in the U.S. continue to face high mortality as they age into adulthood.

Understanding their care needs, comorbidities, quality of life, and causes of death is essential to improving their health, well-being, and survival.

Table 1: Characteristics of diagnosed and decedent PHIV cases in the U.S., by treatment era and most recent period (2020-2022)[d]

	Total Cases (1978-2022)		No ART era[a] (1978-1986)		Early ART era[b,^] (1987-1995)		Most recent period (2020-2022)	
	Diagnosed	Decedent*	Diagnosed	Decedent*	Diagnosed	Decedent*	Diagnosed	Decedent*
Total, n (row %)	19,146 (100)	6,765 (100)	2,817 (15)	294 (4)	10,176 (53)	3,573 (53)	120 (1)	323 (5)
Median age at death (years)	NA	4	NA	1	NA	2	NA	29
Sex								
Male, n (%)	9,140 (48)	3,341 (49)	1,371 (49)	145 (49)	4,909 (48)	1,756 (49)	60 (50)	177 (55)
Female, n (%)	10,006 (52)	3,424 (51)	1,446 (51)	149 (51)	5,267 (52)	1,817 (51)	60 (50)	146 (45)
Race/ethnicity								
White (non-Hispanic), n (%)	2,188 (11)	877 (13)	353 (13)	38 (13)	1,200 (12)	536 (15)	16 (13)	33 (10)
Black (non-Hispanic), n (%)	10,808 (57)	3,895 (58)	1,440 (51)	178 (61)	5,690 (56)	1,998 (56)	74 (62)	178 (55)
Hispanic/Latino, n (%)	4,770 (25)	1,744 (26)	913 (32)	73 (25)	2,668 (26)	948 (27)	20 (17)	82 (25)
Other, n (%)	1,380 (7)	249 (4)	111 (4)	5 (2)	618 (6)	91 (3)	10 (8)	30 (9)
Region of birth								
Northeast, n (%)	7,120 (37)	3,005 (44)	1,565 (56)	189 (64)	4,270 (42)	1,666 (47)	14 (12)	124 (38)
Midwest, n (%)	1,614 (8)	473 (7)	149 (5)	3 (1)	789 (8)	266 (7)	14 (12)	13 (4)
South, n (%)	6,616 (35)	2,402 (36)	708 (25)	71 (24)	3,681 (36)	1,177 (33)	64 (53)	141 (44)
West, n (%)	1,520 (8)	495 (7)	166 (6)	17 (6)	820 (8)	271 (8)	16 (13)	28 (9)
U.S. territory, n (%)	693 (4)	336 (5)	183 (7)	11 (4)	415 (4)	179 (5)	0 (0)	11 (3)
Foreign-born, n (%)	1,557 (8)	49 (1)	43 (2)	1 (0)	188 (2)	13 (0)	11 (9)	5 (2)

^Data presented is the combined birth cohorts from the early ART era (1987-1990, 1991-1995)
*Decedent cases from each respective birth cohort, which occurred as of 12/31/2022

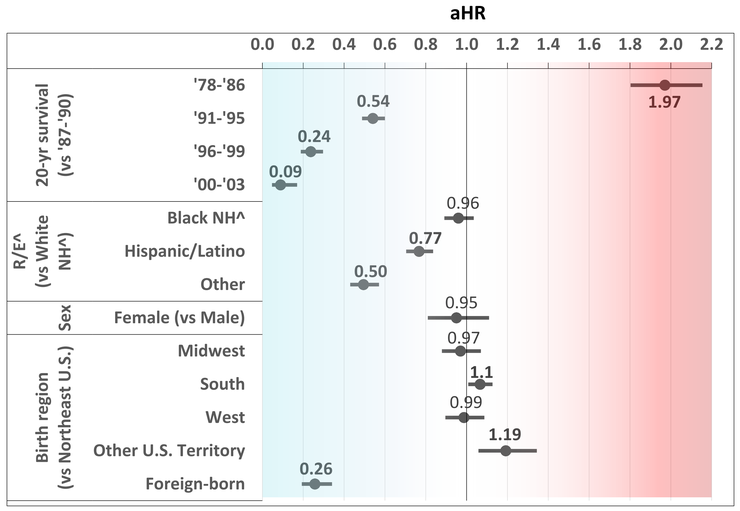
RESULTS (cont'd)

Table 2: Mortality rate* of PHIV by age, calendar year[d]

Age	'78-'86	'87-'95	'96-'99	'00-'03	'04-'07	'08-'11	'12-'15	'16-'19	'20-'22
Overall	0.75	45.70	16.58	6.19	4.47	4.11	4.16	4.60	4.22
<1	0.00	10.30	1.34	0.32	0.11	0.00	0.04	0.00	0.05
1-2	0.60	14.68	2.78	0.32	0.02	0.04	0.02	0.00	0.00
3-5	0.15	10.59	3.99	0.47	0.08	0.02	0.00	0.00	0.00
6 12	0.00	9.33	6.54	2.25	0.53	0.08	0.06	0.04	0.00
13-18	0.00	0.80	1.80	2.06	1.80	0.86	0.22	0.08	0.00
19-24	0.00	0.00	0.13	0.87	1.84	2.57	2.30	1.44	0.61
25+	0.00	0.00	0.00	0.00	0.08	0.54	1.52	3.04	3.55

*Mortality rate: deaths per 1000 person-years

Figure 2: Adjusted hazard ratios (aHRs) for associations between PHIV case mortality and select characteristics*



*Variables included: group birth cohort, sex, race/ethnicity, birth region, interaction terms between birth cohort and survival time
^R/E: race/ethnicity; NH: non-Hispanic

ADDITIONAL KEY INFORMATION

[a] Identified by AIDS case reporting; interpret with caution
[b] Identified by AIDS and/or HIV case reporting
[c] Identified by universal name-based HIV case reporting
[d] Includes 26 cases with 'Unknown' region of birth, who were excluded from statistical models

Contact: pcholli@cdc.gov

Disclaimer: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.