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"Out of Care" HIV Case Investigations: A Collaborative Analysis across Six States in the Northwest US

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Abstract

Background—HIV care continuum estimates derived from laboratory surveillance typically assume that persons without recently reported CD4 count or viral load results are out of care.

Methods—We conducted a multi-state project (Alaska, Idaho, Montana, Oregon, Washington and Wyoming) to ascertain the status of HIV cases that appeared to be out of care during a 12 month period. We used laboratory surveillance to identify cases in all states but Idaho, where viral load reporting is not mandatory, requiring us to rely on clinic records. After complete investigation, we assigned each case one of the following dispositions: moved out of state, died, in HIV care, no evidence of HIV care, or data error.

Results—We identified 3,866 cases with no CD4 count or viral load result in a ≥12 month period during 2012-14, most (85%) of which were in Washington or Oregon. A median of 43% (range:

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20%-67%) of cases investigated in each state had moved, 9% (0%-16%) had died, and 11% (8%-33%) were in care during the 12 month surveillance period. Only 28% of investigated cases in the region and a median of 30% (10%-57%) of investigated cases in each state had no evidence of care, migration, or death after investigation.

Conclusions—Most persons living with HIV in the Northwest US who appear to be out of care based on laboratory surveillance are not truly out of care. Our findings highlight the importance of improving state surveillance systems to ensure accurate care continuum estimates and guide Data to Care efforts.

Keywords

HIV care continuum; Engagement in care; Retention in care; HIV surveillance; Public health; Data to Care

INTRODUCTION

Persons living with HIV (PLWH) who are poorly engaged in HIV medical care have worse health outcomes and may be more likely to transmit HIV than persons engaged in continuous care and treatment.[1-3] Historically, national surveillance data suggested that retention in HIV care was the point of steepest drop-off in the HIV care continuum in the U.S, prompting the National HIV/AIDS Strategy to focus on retention in care as a key area for improvement and public health agencies to begin investing substantial efforts to identify and reengage persons in HIV care.[4,5] While the issue of patient disengagement from HIV care is crucial, the prevalence of the problem is less certain. In 2014, the U.S. Centers for Disease Control and Prevention (CDC) released a national estimate for the HIV care continuum, which suggested that only 46% of HIV-diagnosed persons (and 40% of all HIV-infected persons) in the U.S. were receiving HIV medical care in 2011.[4] A widely referenced study based on a similar estimate reported that the majority of new HIV infections (61%) are transmitted by persons who are HIV-diagnosed but not retained in medical care.[3] However, subsequent reports suggested that the estimate of 46% retention in care was too low. Several cities and states reported estimates of the HIV care continuum that were substantially higher than national estimates,[6-10] and in 2016 the CDC updated the care continuum data to estimate that 71% of HIV-diagnosed persons received medical care in 2013.[11] Accurate estimates of the HIV care continuum are crucial. To the extent that the proportion of PLWH out of care is overestimated, policy makers and public health leaders are likely to misjudge the potential impact of efforts to promote patient reengagement in HIV care.[3,12]

At the state and local level, many health departments use laboratory surveillance data to identify persons who are out of HIV care and work to reengage them in HIV care.[13-16] This strategy, termed “Data to Care” and supported by CDC,[17] relies on accurate HIV surveillance data to identify out-of-care persons. The process of investigating cases with no recent laboratory reports not only provides an opportunity to re-engage out-of-care persons, but also improves the quality of HIV surveillance data and increases the accuracy of care continuum estimates. The cases of PLWH for whom a health department has no recent laboratory reports are a heterogeneous group. Some are truly out of care, but others are

missing laboratory reports because they have moved out of state and established medical care elsewhere or are in-state but did not have laboratory results captured in the surveillance system. Others have died, but the death was not identified through routine surveillance procedures.[18] Differentiating persons who have moved out of the area from persons who are out of HIV care is a major challenge for health departments, and the extent to which migration of PLWH varies geographically is not known.

We undertook a regional, multi-state project to ascertain the status of HIV cases without recent HIV-related laboratory test results—cases typically defined as being out of care —in order to assess the impact of migration, incomplete laboratory reporting, and unrecognized deaths on population estimates of retention in HIV care based on laboratory reporting. Prior work in King County, Washington demonstrated that individual case investigations led to a large decrease in the number of persons estimated to be out of HIV care.[18-20] However, the generalizability of this finding to other areas has been unclear. Local and state health department staff from six Northwest US states (Alaska, Idaho, Montana, Oregon, Washington, and Wyoming) and investigators from University of Washington (UW) Center for AIDS Research (CFAR) conducted a coordinated effort to refine estimates of retention in care with individual case investigation. The Northwest Health Department-CFAR Consortium was established to facilitate university and health department collaboration and to advance the regional mission of the UW.

METHODS

For the purpose of this project, we defined persons as “out of care” if they had no evidence of HIV medical care in a 12 month period after a full public health case investigation. In all states but Idaho, health department staff members investigated cases with no CD4 or VL reported to the health department for ≥ 12 months. Due to the lack of mandatory comprehensive VL reporting in Idaho, project staff investigated patients at the two largest HIV clinics in Idaho who had not completed a visit for ≥12 months. We standardized approaches to case investigation in all states to the extent feasible, but protocols necessarily varied slightly due to the administrative and legal environment in each area. Surveillance practices vary somewhat between states, and thus, the extent to which deaths and incomplete laboratory reporting had been ascertained prior to identifying cases for this analysis also varied. We used standardized methodology for defining the case dispositions in all six states. In the areas where the health department had previously undertaken systematic investigation of cases with no recent laboratory reporting, this required re-coding case dispositions in accordance with the standardized definitions.

Lists of cases for investigation

Project staff in each state identified cases for investigation that met 3 criteria: 1) reported to the state and included in the local Enhanced HIV/AIDS Reporting System (eHARS; the national HIV surveillance registry), regardless of the original state of diagnosis; 2) no CD4 or VL results reported to the health department during a 12 month period during October 2012 – April 2014 (the exact 12 month period varied by state); and 3) not already designated in the surveillance system as having died or moved to another state. In Idaho, project staff

identified cases that met 3 analogous criteria: 1) included in the clinic registry (all persons with confirmed HIV infection who completed ≥1 visit with a medical provider); 2) no visit completed in the prior 12 months, and 3) not known to have died.

Investigation Protocol

First we attempted to categorize listed cases as “moved,” “died,” or “in-care” by searching for each case in state-specific public health, administrative, and commercial databases (example protocol included in eMethods online only text). For all states, these included the HIV/STD surveillance systems and Accurint®, a Lexis Nexis® database that collates public records. Where available, we used AIDS Drug Assistance Program data, correctional system registries, and Department of Motor Vehicle records, and some sites used other locally available databases. We re-examined state and federal death records to identify deaths that had been missed by standard surveillance procedures for death ascertainment. CDC requires state and local health departments to match HIV case data to state and federal death records annually, but these are structured to minimize incorrect determinations that a person has died. When individual cases are investigated, some match incompletely to a death report, and, in combination with local information about the case, can be determined to be deceased. Some sites also searched electronic health records which health department surveillance staff members can access for case investigation purposes. If queries of all available databases did not define a person's location or care status, case investigators attempted to contact the case's last medical care provider, identified through association with the most recent laboratory report in surveillance or review of medical records, in order to define their care status or collect patient contact information.

If all of the above efforts failed to determine that a listed case had moved, died, or completed an HIV care visit during the surveillance period (i.e. year prior to identification of case for investigation), we tried to contact the case-patient directly. The methods for this varied by site according to local policies, but generally included contact attempts by phone, text message (if permitted locally), mail, and visits to the patient's home or place of work. Everyone who attempted to contact case-patients had appropriate training or experience to assist out-of-care persons in relinking to HIV care. For cases with evidence of care discovered during the case investigation, the disposition codes distinguished those who received care during the 12 month surveillance period, and were thus erroneously identified as out of care, from those with care only after the 12 month surveillance period, who we assumed had relinked to care after a 12 month out-of-care period.

Disposition Definitions

Upon completion of the case investigation, project staff assigned cases one of the following mutually exclusive dispositions: 1) moved, 2) died, 3) in care during the surveillance period, 4) out of care during the 12 month surveillance period with evidence of care after the surveillance period, 5) out of care during the surveillance period without evidence of care after the surveillance period, 6) data error (e.g. duplicate case record) or 7) not locatable. For the analysis, we consolidated case dispositions into the following mutually exclusive categories: moved, died, in care during the surveillance period, no evidence of care during the surveillance period, and data error. The definitions of case investigation dispositions and

the categories we used for this analysis are summarized in **Table 1** and detailed in the protocol in **Supplemental Digital Content**.

We made two conservative assumptions for this categorization. First, we dispositioned cases that could not be located despite thorough case investigation as having "no evidence of care." Although investigation might have suggested that the case-patient had not been in the area for many years, without strong evidence of relocation we categorized them as out of care. Second, we assumed that case-patients who resumed care after the surveillance period, but had no evidence of care during the 12 month surveillance period, had been out of care during the surveillance period before relinking to care after the surveillance period. Because we had evidence of recent care, we did not systematically attempt to contact these persons, and we did not interview these persons to ascertain their care status during the surveillance period.

Data Analysis

We calculated a period prevalence of the proportion of PLWH defined as out of care prior to case investigations and a revised period prevalence after case investigations. The revised proportion calculation removed cases determined to have had died or moved from the denominator and cases determined to have received care during the surveillance period from the numerator. We report the pre- and post-investigation population estimates by state, and describe the median and range for each disposition status. We excluded King County cases from Washington state cases for this analysis because the initial investigation of King County cases began 7 years earlier and results have been reported elsewhere.[18]

The case investigations undertaken in each state were not subject to review by Institutional Review Boards (IRB) because they were conducted as a public health activity. The tabulation and reporting of investigations from participating states received a non-research determination from the University of Washington IRB.

RESULTS

We identified a total of 3,866 HIV cases in the 6 states that had no reported CD4 or VL (or in Idaho, completed care visits) for ≥12 months, representing 25% of all HIV cases in the region and a median of 26% (range 3-37%) of cases in each state. Most (85%) of the cases identified for investigation were in Oregon and Washington. A larger proportion of cases appeared to be out of care based on clinical records in Idaho (37%) than in all other states based on surveillance data (≤31%). Case dispositions were as follows [median % (range across sites)]: moved, 43% (20%-67%); died, 9% (0%-16%); in care, 11% (8%-33%); no evidence of care, 30% (10%-57%); and data error, <1% (0%-1%). In sum, a median of 70% (range 43%-90%) of cases in each state and 72% of all cases investigated in the region had an explanation other than care disengagement for the apparent gap in care.

Table 2 shows the investigation outcomes by site. The percentages of cases eligible for investigation and dispositioned into each category varied substantially between the states. In Idaho, a larger proportion of cases were dispositioned as having "no evidence of care," which primarily reflected a proportionately larger number of cases with unknown

dispositions in Idaho. Wyoming had an unusually low percentage of cases that appeared to be out of care prior to investigation but also a small number of total cases.

As shown in **Table 3**, after adjustment for the results of case investigations, the estimated percentage of PLWH who were out of care decreased from 25% to 8% overall and from a median of 26% (range 3%-37%) to 9% (2%-24%) in each state. The estimated number of PLWH residing decreased by 13% (N=1993) in the region overall and by a median of 14% (1%-19%) in each state.

DISCUSSION

After comprehensive investigation of HIV cases in six states with no CD4 or VL reported for 12 months or more, 72% were found to have a reason other than care disengagement for the gap in laboratory reports. Even the remaining 28% with no evidence of care – 8% of all HIV-diagnosed persons in the region – likely overestimates the out-of-care population because we defined cases as out of care if we could not definitively establish that they had moved or died. Our findings demonstrate that the vast majority of persons with diagnosed HIV infection in the Northwestern U.S. are in HIV care. These results highlight opportunities to improve the quality of HIV surveillance data in order to facilitate accurate estimation of the care continuum and efficient Data to Care efforts. They also suggest that the potential value of reengagement efforts for out-of-care PLWH may be overstated and greater emphasis should be placed on increasing engagement among persons who are sporadically or marginally engaged in care.

Our findings confirm prior demonstrations that HIV care continuum estimates derived from laboratory surveillance without adjustment for out-migration overestimate the number of HIV-diagnosed persons and underestimate retention in care and viral suppression.[18,19,21] Although our analysis was limited to one geographic region, preliminary reports from other regions demonstrate that our experience is not unique. Health departments in several areas of the U.S., including the South, have also reported that a substantial proportion -- typically half or more -- of cases that appear to be out of care based on surveillance data are found not to be out of care when investigated.[22-26]

Surveillance data are critical to public health efforts to improve the HIV care continuum. Estimation of the continuum is an iterative process, and published estimates are necessarily works in progress. With improvements in state and national HIV surveillance data, particularly improved case deduplication, HIV care continuum estimates are becoming more accurate. However, conclusively defining which PLWH have moved out of a state remains challenging and cumbersome with current methods. Through the routine interstate duplicate review (RIDR), CDC notifies state health departments of some cases with potential duplicate reports in ≥2 jurisdictions. However, our findings demonstrate current limitations of this process for identifying out-migrated cases at the state level. Complete reporting of CD4 counts and VL in all U.S. states and territories and procedures for rapidly sharing HIV surveillance information between jurisdictions are crucial. An innovative project in the District of Columbia, Maryland, and Virginia validated a novel data-sharing method to match data across the three jurisdictions.[27] The automated algorithm matched records from

over 21,000 persons in approximately 22 minutes. The method was not only accurate and efficient, but also addressed several major barriers to data sharing between jurisdictions. Assessing the potential of such an approach to facilitate cross-state data sharing should be a high priority for future work.

Our results highlight some opportunities to improve health department Data to Care programs. Although investigation of all cases without laboratory reports in the past year can find some out-of-care patients, this approach is relatively inefficient. Focusing on cases with recently reported unsuppressed viral loads, rather than cases with no recent laboratory reports, may be a more effective way to identify persons who can benefit from interventions to improve engagement in HIV care and treatment. Health department Data to Care efforts can also be improved by coordinating with HIV clinic-based patient retracing efforts.[28-31] Sharing data between HIV surveillance systems and HIV clinic medical records can improve the efficiency of each approach.[30] Linking HIV surveillance data in real time with STD partner services[32] and with electronic health records through automated health information exchanges[33] can further enhance surveillance-based outreach and clinic-based patient retracing efforts. Expanding information exchanges to other areas, such as jails, could also be explored.

The key strengths of this study were its population-based approach and our use of standard disposition definitions to facilitate comparison between states. Our study also had important limitations. Differences in surveillance procedures prior to this analysis and variations in case sampling strategies and investigation protocols limit the direct comparability between states. Although this could bias our estimates, it does not detract from our main finding that most cases were not actually out of HIV care. Compared to the U.S. as a whole, the Northwest states have relatively low HIV morbidity, and it is uncertain how these findings would apply to all other areas of the country. However, the consistency of our findings with preliminary reports from other regions of the U.S.[22-26] demonstrates that our results are not wholly attributable to a regional aberration. In areas with high HIV prevalence, investigating every HIV case missing recent laboratory reports as we have done might not be feasible, but random sampling of cases for investigation can achieve the goal of improving HIV care continuum estimates.[34]

In summary, we have shown that comprehensive investigation of individual HIV cases with no evidence of care in a 12 month period substantially reduced estimates of the percentage of PLWH who were out of care. The case investigation efforts we describe improved the quality of our state surveillance systems and consequently increased the accuracy of our surveillance-based HIV care continuum estimates. Insofar as we have found that the problem of patient non-retention is not as prevalent as commonly estimated, these findings provide reason for optimism. The HIV care system in our region is not failing, and the overwhelming majority of persons with diagnosed HIV infection are receiving medical care. Our experience also demonstrates several areas for improvement and opportunities ahead for health departments undertaking Data to Care efforts.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Disposition Definitions and Data Sources for "Out of Care" HIV Case Investigations

Categorization for Analysis	Case Investigation Disposition	Definition[a]	Data Sources
Moved	Moved	Confirmed – relocation confirmed by case or laboratory report to a health department in another state or case interview Presumed – Cases with evidence of relocation that do not meet criteria for confirmed relocation	• State-specific databases • Lexis Nexis database [a] • Medical records • Case interview • Social media • Family, friend or associate report during contact attempts
Deceased	Deceased	Official record of death	• Social Security Death Index • Lexis Nexis database • Obituary • Family, friend or associate report during contact attempts
In care	In state, evidence of care during the surveillance period (i.e. erroneously identified as out of care)	Documented CD4 or VL or confirmed completed HIV medical visit during the 12 month period with no reported labs (e.g. laboratory result not captured in surveillance system)	• Medical records • HIV medical provider • HIV clinical staff
No evidence of care	In state, evidence of care after the surveillance period (i.e. "relinked" to care)	Documented CD4 or VL or confirmed completed HIV medical visit after the investigation period (e.g. resumed care after 12 month out-of-care period)	Same as above
No evidence of care	Not locatable	Meets all of the following criteria: • No evidence of death, relocation, or HIV care • No contact information for case investigation • No match in Lexis Nexis database • No report to surveillance for ≥ 5 years [b]	• All data sources described above, plus • Ancillary public health databases (e.g. STD partner services, special project surveillance databases) • AIDS Drug Assistance Program databases
No evidence of care	Out of care	All cases that do not meet the criteria for case dispositions described above, including cases that relinked to care (had a reported CD4 or VL or completed a medical visits) after the 12 month "out of care" surveillance period.	• All data sources described above
Data Error	Data Error	Case not accurately defined as an HIV/AIDS case (e.g. duplicate cases or erroneous reports).	• All data sources described above

[a] For additional detail, see the full protocol for case investigation in Appendix 1

[b] In Idaho, we used analogous definitions for medical records in place of surveillance reports (i.e. dates of completed visits instead of dates of CD4 count or viral load results).

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Table 2

Number of HIV Cases Identified for Investigation and Outcomes of Case Investigation

	Oregon	Washington[a]	Alaska	Idaho[b]	Montana	Wyoming	Total	Median, % (range)
HIV-Diagnosed Persons,[c] No.	7661	5351	702	627	582	243	15,166	NA
Cases with no CD4 count or viral load result reported for ≥ 12 months, No. (% of HIV-diagnosed persons)	1626 (21)	1674 (31)	218 (31)	231 (37)	110 (19)	7 (3)	3,866	26 (3-37)
Outcome of case investigation, No. (% of investigated cases)								
Moved	867 (53)	551 (33)	120 (55)	47 (20)	74 (67)	2 (29)	1,661 (43)	43 (20-67)
Deceased	205 (13)	61 (4)	10 (5)	36 (16)	13 (12)	0	325 (8)	9 (0-16)
In care	181 (11)	559 (33)	22 (10)	18 (8)	11 (10)	1 (14)	792 (20)	11 (8-33)
No evidence of care	372 (23)	498 (30)	66 (30)	130 (56)	11 (10)	4 (57)	1,081 (28)	30 (10-57)
Data error	1 (<1)	5 (<1)	0	0	1 (1)	0	7 (<1)	0 (0-1)

NA, not applicable

[a] King County cases excluded because investigation of those cases began >5 years prior to the surveillance period for this analysis and did not differentiate cases found to have evidence of care during the surveillance period from cases with evidence of care after the surveillance period[15]

[b] Idaho cases were identified using clinic medical records instead of laboratory surveillance reports

[c] Prevalent HIV cases in the jurisdiction at the time of identification of cases for investigation

Table 3

Impact of Case Investigation on Estimated Number of HIV Cases and Percentage with No Evidence of Care for ≥12 Months

	Oregon	Washington[a]	Alaska	Idaho[b]	Montana	Wyoming	Total	Median
HIV Cases in Area								
Pre-investigation, No.	7661	5351	702	627	582	243	15166	NA
Post-investigation, No.	6588	4734	572	544	494	241	13173	NA
Relative decrease,[c] %	14	12	19	13	15	1	13	14
HIV Cases with no Evidence of Care for ≥ 12 Months								
Pre-investigation, No. (%)	1626 (21)	1674 (31)	218 (31)	231 (37)	110 (19)	7 (3)	3866 (25)	(26)
Post-investigation, No. (%)	372 (6)	498 (11)	66 (12)	130 (24)	11 (5)	4 (2)	1081(8)	(9)
Relative Decrease,[d] %	71	65	61	35	74	33	68	65

NA, not applicable

[a] King County cases excluded

[b] Idaho cases were identified using clinic medical records instead of laboratory surveillance reports

[c] Equation: (No. pre-investigation – no. post-investigation) / no. pre-investigation

[d] Equation: (% out-of-care pre-investigation – % out-of-care post-investigation) / % out-of-care pre-investigation

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