Understanding late HIV diagnosis:

A retrospective review of the last 100 diagnoses in Lewisham

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BACKGROUND

Late HIV diagnosis, which is defined as a CD4 count of less than 350 cells/mm^3 at the point of diagnosis, has important consequences for individuals and for whole populations.

Importance of late HIV diagnosis to individuals

- Individuals diagnosed late with HIV have a mortality within the first year of diagnosis that is ten times higher than those diagnosed promptly.[1]
- In fact, 90% of HIV-related deaths in the UK occur in individuals that were diagnosed late.[2]
- Individuals diagnosed late have higher rates of opportunistic infections and diseases (both at the time of diagnosis and throughout their lives. Opportunistic HIV-related diseases include:
  - ***bacterial diseases*** such as tuberculosis (TB, caused by *Mycobacterium tuberculosis*), *Mycobacterium avium* complex disease (MAC), bacterial pneumonia and septicaemia
  - ***protozoal diseases*** such as *Pneumocystis carinii* pneumonia (PCP), toxoplasmosis, microsporidiosis and cryptosporidiosis
  - ***fungal diseases*** such as candidiasis, cryptococcosis (cryptococcal meningitis (CRM)) and penicilliosis
  - ***viral diseases*** such as those caused by cytomegalovirus (CMV), herpes simplex and herpes zoster virus
  - ***HIV-associated malignancies*** such as Kaposi sarcoma, lymphoma and squamous cell carcinoma

Population-level impact of late HIV diagnosis

- Late diagnosis represents a missed opportunity to initiate treatment (which prevents onward transmission of HIV).
- Late awareness of HIV positive status increases the risk of onward transmission both through viral load remaining high without treatment and people not altering their behaviour to prevent transmission.
- Furthermore, late diagnosis is expensive – direct medical costs in the first year after HIV diagnosis are twice as much for late diagnosed individuals, largely due to higher inpatient costs.

Late HIV diagnosis in the policy arena

Late HIV diagnosis is a priority area, as highlighted by the following bodies, recommendations and guidelines – most of which support routine/universal testing to promote early diagnosis:

- Public Health Outcomes Framework (Health and Social Care Bill), 2012[3]
  - *Late presentation (CD4<350) is an outcome indicator for local authorities*
- House of Lords Select Committee on HIV/AIDS, 2011[4]
  - *Government endorsed BHIVA and NICE guidance to increase HIV testing in high prevalence areas*
- National Institute of Clinical Excellence (NICE)[5]
  - Pathways: HIV testing and prevention, 2019
  - Guidance: HIV testing: increasing uptake among people who may have undiagnosed HIV (NG60), 2016
  - Quality standards: HIV testing: encouraging uptake (QS157), 2017
  - Shared learning: Sexual health in practice training to increase HIV testing in primary care, 2017
- NHS London Prevention Network , 2009 – "*reduce the proportion of very late diagnosis (<200) by 2010-11 in all London PCTs*" [6]
- BHIVA National HIV Testing Guidelines, 2008 (currently being revised) - *routine HIV testing of all general medical admissions (15-59 year olds) in high prevalence areas (>2/1000)* [1]

THE LONDON BOROUGH OF LEWISHAM

With a population of 301,300, Lewisham is the 14th largest borough in London by population size and the 6th largest in inner London.

HIV in the London borough of Lewisham

This review focussed on the last 100 HIV diagnoses in the Alexis clinic (University Hospital Lewisham's HIV clinic).

Lewisham has a very high prevalence of HIV, at a rate of:

- 31 new diagnoses per 100,000 population aged 15+ (2017 data) [7]
- 8.36 per 1,000 among persons aged 15-59 (2017 data) [7]

Between 2015 and 2017, 39.6% of new diagnoses in Lewisham were late diagnoses (CD4<350) [7]

Figure 1. Map of Lewisham (red) in London

AIMS

- To identify the factors (including demographics and health service use) that are associated with lateness of diagnosis at the Alexis clinic (HIV clinic in University Hospital Lewisham)
- To identify and explore possible missed opportunities for earlier diagnosis

METHODS

- A retrospective review of the clinical records of the last 100 diagnoses made at the Alexis clinic (an HIV clinic situated in the London borough of Lewisham - an urban high-prevalence area) was performed.
- Time of diagnosis was defined at the first positive HIV test in the UK.
- CD4 count at diagnosis was used as a proxy for 'lateness' of diagnosis.
- Multiple linear regression was performed to identify if any of the following risk factors were associated with lateness of diagnosis: age, sex, ethnicity, country of birth, time in the UK, sexual orientation, location of diagnosis & self-reported history of seroconversion.
- A further qualitative analysis of very-late diagnoses (CD4<200), including reviewing GP records to identify missed opportunities, is ongoing.

RESULTS

The clinical records (paper and electronic) were obtained for the last 100 HIV diagnoses. Five individuals were excluded prior to analysis due to missing data in at least 50% of the variables of interest. **Table 1** shows the breakdown of patient characteristics, with further information about location of diagnosis (of all 95 patients) given in **figure 2**.

Table 1. Patient characteristics (all 95 included in analysis)

Mean age, years	46	
Age group, years	18-24	7 (7%)
	25-34	22 (23%)
	35-44	28 (29%)
	45-54	21 (22%)
	55-64	15 (16%)
	65+	2 (2%)
Sex	Male	58 (61%)
	Female	37 (39%)
Ethnicity	White British	19 (20%)
	White other	6 (6%)
	Mixed White/Black	2 (2%)
	Black or Black British	32 (33%)
	Chinese	2 (2%)
	Other/unknown	34 (36%)
Country of birth	UK	28 (29%)
	Africa	40 (42%)
	Other	23 (24%)
	Missing	4 (4%)
History of seroconversion		17 (18%)
MSM		32 (55% of men)
Median CD4 at diagnosis (IQR)		245 (114-411)

Figure 2. Location of diagnosis of all 95 patients

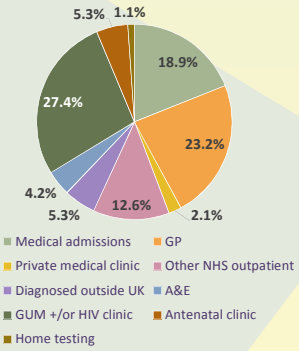

Table 2. Multiple linear regression model - variables that predicted CD4 count (as a proxy for late diagnosis)

Variable	β coefficient	P-value
Age	-5.66	0.01
Male sex	-91.17	0.12
African country of birth	-24.67	0.70
History of seroconversion	85.93	0.23

The CD4 counts at diagnosis ranged from 7 to 1166, with a median of 254.

- 63 of the 95 (66%) patients were late diagnoses (CD4<350)
- 34 (36%) were very-late diagnoses (CD4<200)
- 13 (14%) had an AIDS-defining illness at diagnosis

In our multiple linear regression analysis (**table 2**), age was the only risk factor that was statistically significantly associated with CD4 count, with a one-year increase in age at diagnosis associated with a lower CD4 count of almost 6 cells/mm^3 [β coefficient -5.66 (95%CI -9.98 to -1.34) p=0.01]. The other factors that were also associated with a lower CD4 count at diagnosis were male sex, African country of birth and no self-reported history of seroconversion, however these did not reach statistical significance due to the small sample size. In an analysis restricted to males, men who had sex with men had a CD4 count 15 cells/mm^3 lower (that is, later diagnosis) however this was of borderline statistical significance (β coefficient -14.72, p=0.08).

CONCLUSION

Better understanding of late diagnosis is critical to improving clinical pathways aimed at detecting early HIV, initiating prompt treatment and preventing onward transmission. This study highlighted that older people are more likely to be diagnosed later with HIV – some of this association may be due to stigma, both from health professionals less likely to consider HIV and offer testing in older populations, and from older individuals themselves less likely to seek or consent to HIV testing. The ageing process itself may also contribute to this decline in CD4. There are a number of important limitations to this study – including the small sample size and limited number of risk factors routinely recorded in the clinical records precluding which analyses could be performed. Nonetheless, this study does give some insight into the factors that are associated with lateness of diagnosis in Lewisham and we recommend other clinics to replicate these analyses locally. This study supports the role of routine, universal (opt-out) HIV testing to destigmatise HIV testing and promote early diagnosis. The ongoing qualitative analysis of clinical records of the very-late diagnoses identified in this review will shed more light on missed opportunities for diagnosis and offers a unique shared learning opportunity which extends beyond the HIV clinic, to all clinical care settings.

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