International Journal of Population Data Science

Record linkage augments cancer ascertainment in HIV cohorts in South Africa

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Objectives

Sub-Saharan Africa is the region most heavily affected by the HIV/AIDS epidemic. HIV increases the risk of developing cancer but the ascertainment of cancers in patients attending antiretroviral therapy (ART) treatment programs might be incomplete. To estimate the under-ascertainment of cancer we compared incidence rates of AIDS-defining cancers in South African HIV cohorts with and without cancer case ascertainment through record linkage with the National Cancer Registry.

Approach

We used the data of adult ($\geq$16 years) HIV-positive persons receiving care between 2004 and 2011 at one of four ART programs in South Africa. These programs collaborate with the International Epidemiologic Databases to Evaluate AIDS Southern Africa (www.iedea-sa.org) and collected data for AIDS-defining cancers but not for other cancers. To improve cancer ascertainment we probabilistically linked patient records (using first name, surname, age, and gender) from two HIV cohorts with the cancer records of the South African National Cancer Registry. We calculated incidence rates per 100,000 person-years after starting ART for the AIDS-defining cancers, i.e. Kaposi sarcoma (KS), invasive cervical cancer (ICC) and non-Hodgkin lymphoma (NHL). We compared incidence rates before and after inclusion of record linkage identified cancer cases using the attributable fraction of cancers identified with 95% confidence intervals (CI).

Results

A total of 49,207 adults starting ART in South Africa were included. 65% of patients were female, median age at starting ART was 35 years (interquartile range 30-41 years). We identified a total of 471 incident cancer cases. With record linkage the incidence increased from 81 to 292 for KS, from 1 to 119 for NHL and 12 to 497 for ICC per 100,000 person-years. The attributable fraction of cancers identified was 72% (95% CI 63-79%) for KS, 98% (95% CI 94-99%) for NHL and 98% (95% CI 95-99%) for ICC.

Conclusion

Ascertainment of cancer in HIV program data in African settings is incomplete. This case study has shown that probabilistic record linkage to cancer registries is both feasible and essential for cancer ascertainment in HIV cohorts in South Africa.

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