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Article

HIV in Japan: Epidemiologic puzzles and ethnographic explanations

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ABSTRACT

Japan is widely perceived to have a low level of HIV occurrence; however, its HIV epidemics also have been the subject of considerable misunderstanding globally. I used a *ground truthing* conceptual framework to meet two aims: first, to determine how accurately official surveillance data represented Japan's two largest epidemics (urban Kansai and Tokyo) as understood and experienced on the ground; and second, to identify explanations for why the HIV epidemics were unfolding as officially reported. I used primarily ethnographic methods while drawing upon epidemiology, and compared government surveillance data to observations at community and institutional sites (459 pages of field notes; 175 persons observed), qualitative interviews with stakeholders in local HIV epidemics ($n = 32$), and document research ($n = 116$). This revealed seven epidemiologic puzzles involving officially reported trends and conspicuously missing information. Ethnographically grounded explanations are presented for each. These included factors driving the epidemics, which ranged from waning government and public attention to HIV, to gaps in sex education and disruptive leadership changes in public institutions approximately every two years. Factors constraining the epidemics also contributed to explanations. These ranged from subsidized medical treatment for most people living with HIV, to strong partnerships between government and a well-developed, non-governmental sector of HIV interventionists, and protective norms and built environments in the sex industry. Local and regional HIV epidemics were experienced and understood as worse than government reports indicated, and ground-level data often contradicted official knowledge. Results thus call into question epidemiologic trends, including recent stabilization of the national epidemic, and suggest the need for revisions to the surveillance system and strategies that address factors driving and constraining the epidemics. Based upon its utility in the current study, ground truthing has value as a conceptual framework for research and shows promise for future theoretical development.

1. Introduction

Japan is widely perceived as a country with a low level of HIV occurrence (Suguimoto et al., 2014; Koerner & Ichikawa, 2011; Kihara & Komatsu, 2003; Wada, Funada & Shimane, 2013). Surveillance data present in Japanese government reports support this perception (Ministry of Health, Labour and Welfare, 2001, 2014, 2015); however, close scrutiny of the reports also reveals that key information is not included. This represents an opaqueness that has long hindered an accurate portrayal of HIV in Japan and which has been the source of considerable misunderstanding in the global health community.

Available epidemiologic information, based almost entirely upon government surveillance data, thus could indicate a very low HIV burden in Japan that is real, including remarkably low risk in the general population; or it could mean that a significantly larger HIV epidemic is being obscured. Due partly to a dearth of social science and qualitative research, little is known about how well available surveillance data capture the reality of HIV in Japan, and there is much to learn about why recent trends have been occurring. Accordingly, I conducted a study that had two main aims. The first was to determine how accurately official surveillance data represented the HIV epidemics in two metropolitan areas (Kansai and Tokyo) as understood and experienced on the ground in 2013. The second aim was to identify explanations for why the HIV epidemics were unfolding as officially reported. In meeting these aims, examination of surveillance data uncovered conspicuous epidemiologic puzzles. Ethnographic research revealed explanations for these puzzles, including factors that drove and constrained the epidemics. As an initial step in articulating the epidemiologic puzzles, it is first necessary to outline what is known of the epidemiology.

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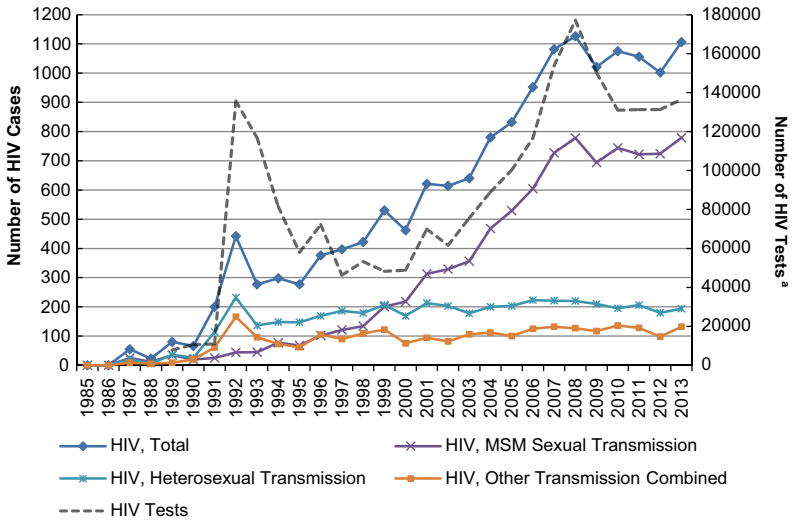

Fig. 1. New HIV cases and HIV tests in Japan, 1985 – 2013 (Source: own construction, data from Ministry of Health, Labour and Welfare) (Ministry of Health, Labour and Welfare, 2001, 2014). [a]Disaggregated annual HIV testing data reported by MHLW start in 1989. The aggregate total prior to1989 is 47,470 tests.

1.1. *Epidemiology of HIV in Japan*

From 1985, when the first diagnoses were reported, to the end of 2013, there were a cumulative 23,015 reported cases of HIV, of which 7203 (31.3%) were AIDS cases (Ministry of Health, Labour and Welfare, 2014). Notably, Japan's surveillance system defines HIV and AIDS cases permanently based upon the stage of infection at the time of initial diagnosis (Yoshikura, 2014). Additionally, these numbers do not include 1432 cumulative cases of HIV and AIDS among hemophilia patients iatrogenically infected through blood products, who are tracked separately from the Ministry of Health, Labour and Welfare (MHLW) surveillance system (Japan Foundation for AIDS Prevention, 2013a).

Regarding incidence, there were 1590 new HIV and AIDS cases in 2013 – the highest number of combined annual cases ever recorded in the country (Fig. 1). Of these, 1106 (69.6%) were new HIV cases, which was the second highest number on record. Yet, if only HIV is considered, Japan's national epidemic actually has been showing signs of stabilization in recent years (Ministry of Health, Labour and Welfare, 2014). New cases peaked in 2008 and have leveled off at approximately 1000 each year since then. This apparent plateau is a relatively late development, considering that new HIV cases reached their highest number globally from 1996 to 1999 and have been declining steadily since 2000 (UNAIDS, 2014a). However, if Japan's recent, putative trend continues, it could mark a crucial, positive shift in the epidemic.

The year 2008 also marked the peak in the number of reported HIV tests in Japan (177,156 tests). After this, tests dropped for two consecutive years and were basically flat from 2010 to 2013 (Ministry of Health, Labour and Welfare, 2001). Conversely, of the total new HIV and AIDS cases in 2013, 484 (30.4%) were new AIDS cases, which was the highest number ever reported (Fig. 2). Though there had been a drop in AIDS cases in 2012, the first since 2005, an upturn again in 2013 continued an overall increasing trend since 1985 and maintained a proportion exceeding 30% (Ministry of Health, Labour and Welfare, 2014). This is significant in a high-income country with an advanced medical system and wide use of effective antiretroviral therapy (Suguimoto et al., 2014; UNAIDS, 2014b; WHO, 2011; Hashimoto et al., 2004).

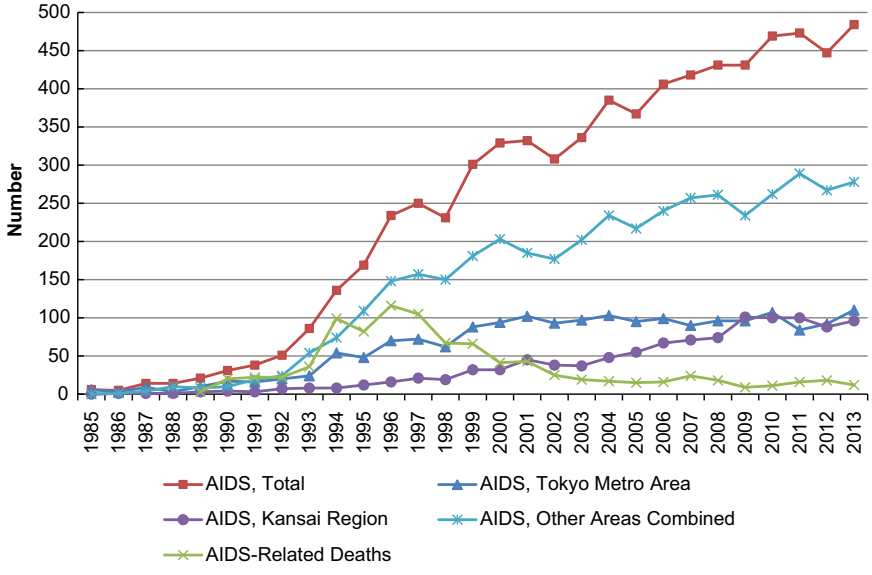

Fig. 2. New AIDS cases and AIDS-related deaths, 1985–2013 (Source: own construction, data from Ministry of Health, Labour and Welfare) (Ministry of Health, Labour and Welfare, 2014).