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The utility of population-based surveys to describe the continuum of HIV services for key and general populations

Wolfgang Hladik, **Irene Benech**, **Moses Bateganya**, **Avi J Hakim**
Division of Global HIV/AIDS, Center for Global Health, Centers for Disease Control and Prevention, Atlanta, GA, USA

Summary

Monitoring the cascade or continuum of HIV services – ranging from outreach services to anti-retroviral treatment – has become increasingly important as the focus in prevention moves toward biomedical interventions, in particular, ‘Treatment as Prevention.’ The HIV continuum typically utilises clinic-based care and treatment monitoring data and helps identify gaps and inform program improvements. This paper discusses the merits of a population-based survey-informed continuum of services. Surveys provide individual-level, population-based data by sampling persons both in and outside the continuum, which facilitate the estimation of population fractions, such as the proportion of people living with HIV in care, as well as the examination of determinants for being in or outside the continuum. Survey-informed cascades of services may especially benefit key populations at increased risk for HIV infection for who social marginalisation, criminalisation, and stigma result in barriers to access and retention in services, a low social visibility, mobility, and outreach-based services can compromise clinic-based monitoring. Adding CD4+ T-cell count and viral load measurements to such surveys may provide population-level information on viral load suppression, stage of disease, treatment needs, and population-level transmission potential. While routine clinic-based reporting will remain the mainstay of monitoring, a survey-informed service cascade can address some of its limitations and offer additional insights.

Keywords

Continuum of HIV services; cascade of services; care and treatment; population-based surveys; key populations; HIV

Introduction

Recent years have seen a shift in human immunodeficiency virus infection (HIV) prevention with the advent of evidence-based biomedical interventions best epitomised by the concept of ‘Treatment as Prevention’[1] defined as HIV prevention methods that use antiretroviral therapy (ART) in HIV-positive persons to decrease the chance of HIV transmission

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Corresponding author: Wolfgang Hladik, CDC MS E-30, 1600 Clifton Rd, Atlanta, GA 30333, USA., wfh3@cdc.gov.

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independent of CD4 T cell count. Viral load suppression through ART and the consequent immunological recovery provides the potential for near-normal life expectancy[2,3] minimises HIV transmission[4,5] and is integral to reaching the Joint United Nations Programme on HIV and AIDS' (UNAIDS) goal of 90% of people living with HIV (PLHIV) knowing their serostatus, 90% of diagnosed PLHIV receiving ART, and 90% of people receiving ART achieving viral load suppression.[6] The potential impact of ART on population-level health has enhanced the utility of HIV testing as a gateway to a range of clinical services, including linkage to and retention in care, ART initiation, and adherence to treatment. On a programmatic level, these serially linked events are necessary to achieve the desired outcome of sustained viral load suppression, a pivotal goal both for individual and population health. Ideally, all HIV-infected persons would get diagnosed, initiate treatment, and achieve 100% viral load suppression. However, not all HIV-infected persons may access or may stop using these services at any stage, and so the proportion of people living with HIV (PLHIV) reaching a particular stage is getting successively smaller with each step, a phenomenon often termed the treatment cascade or 'continuum of HIV care,' as described by Gardner et al.[7] With multiple entry and drop-off points, evaluating the uptake of services through such a 'cascade' or 'continuum' is therefore an important tool for evaluating a population's access to and uptake of HIV services as well as the associated outcomes and impacts.[8,9]

Graphs or tables describing the continuum are typically constructed and described using both public health and clinic-based monitoring data. This paper discusses the utility of population-based surveys as a complementary data source, especially in resource-limited settings. We examine the structure and merits of the current continuum constructed using clinic-based monitoring data, the potential for using population-based surveys to describe the continuum and the advantages and limitations of survey-informed compared to clinic-based monitoring systems. While these considerations may apply to both the general population and key populations at increased risk for HIV infection, we pay special attention to the latter, which includes sex workers (SW), men who have sex with men (MSM), transgendered persons, and people who inject drugs (PWID).

The HIV continuum of services

Commonly used steps in constructing the HIV continuum of services for different settings include determining (i) the number of diagnosed PLHIV; and (ii) the number or proportion of people linked to care, (iii) retained in care, (iv) initiating ART, (v) retained in ART, and (vi) with virologic suppression. At each stage some patients may stop utilising services for various reasons and to various degrees so that the resulting number of PLHIV with virologic suppression is often substantially smaller than the number of diagnosed PLHIV. The resulting cascade or continuum provides a powerful display of where rates of attrition are greatest and facilitates estimating the overall proportion of HIV-diagnosed patients who achieve viral load suppression. For example, data from the United States indicated that only an estimated 28% of PLHIV had achieved viral load suppression[10] whereas, in South Africa and Uganda a home-based counseling and testing initiative improved viral load suppression among PLHIV from 50% to 65%.[11] National governments, United Nations agencies, and large donors have developed monitoring frameworks that help populate the continuum of services through routinely reported data on key indicators from HIV service providers and national HIV programs.[12] Clinic-based monitoring will remain a key data source to monitor progress towards universal access to treatment and treatment-related indicators and outcomes such as attrition, viral load suppression, HIV drug resistance levels, and mortality.

Challenges and limitations of the clinic-based service continuum

While routine, clinic-based monitoring of service delivery plays an essential role in building the continuum of services, it is also subject to some inherent limitations. The quality of clinic data may vary due to the lack of or suboptimal adherence to rigorous data protocols in many (resource-limited) settings, resulting in incomplete, inaccurate, or delayed reporting.[13–15] Most clinic-based services data (using records from health care settings) typically originate from standard pre-ART and ART registers and are reported to Ministries of Health or donors on an aggregate level, leaving them unsuitable for individual-level analysis. The lack of unique identifiers and linked data systems further impedes the tracking of individuals across the health care system, challenging the distinction among persons lost to care, re-engaging in care, or transferring between clinics. Further, most clinic-based monitoring systems capture only those who access services but cannot inform about those who never enter the continuum of services or those who no longer receive care. Lastly, continuum of services describing key populations may underestimate clients in care or treatment if some clients fail to disclose their defining high-risk behaviors or if some programs do not specifically report on them, or overestimate numbers if patients enroll into care with several providers. A more intricate data issue may arise when each step in the cascade's data analysis is dependent on the previous which may lead to artificially lower proportions of people having suppressed viral loads.[16]

Key populations and the continuum of services

The importance of key populations for HIV control at the population level is well recognised in concentrated epidemics and increasingly so in generalised HIV epidemics. Key populations account for the majority of HIV infections in concentrated epidemics and are at the highest risk of infection in all epidemic settings.[17–22] The elevated HIV prevalence among key populations and the social and legal constraints they face suggest the need for more intense efforts to reach and provide HIV prevention, care, and treatment services for these populations compared to the general population. Modeling studies from industrialised settings[23,24] suggest that extraordinarily high levels of uptake through the entire range of services, in conjunction with condom use, are needed to curb the epidemic in MSM and possibly in other key populations. These findings are also likely to hold true for key populations in sub-Saharan Africa's generalised epidemics, warranting intensive efforts to examine service uptake among key populations.

Where programs are not tailored specifically for high-risk groups, key population members may not always be identified as such in routine clinic-based monitoring and reporting data may not indicate or disaggregate by risk behavior. Because of the criminalisation of certain high-risk behaviors in some countries,[25–27] key populations may not self-identify as such when accessing services[28] for fear of being reported or arrested. Such hostile legal environments are sometimes worsened by the accompanying social marginalisation, stigma, and discrimination toward key populations, which discourages individuals from disclosing to health care providers that they sell sex or inject drugs,[28] for example, lest they risk poor services or denial of services.[29–32] The loss of patients between each element along the continuum, the coverage reached for individual stages along the continuum, and the number and proportion of patients achieving viral suppression may therefore be markedly different for the general population and key populations, warranting analysis by population group. An added complexity is the lack or uncertainty of population size estimates for key populations, especially in resource-limited settings. While program data provide important count data, without accurate key population size estimates the relative uptake of services among key population members is unknown using clinic or service-based data alone.

The relative lack of clinic-based data for key populations makes population-based surveys in these populations a useful means to gather such data and to construct an accurate cascade that can inform planning of services. This may be more important in generalised epidemics where the focus of HIV control efforts is centered squarely on the general population and where accurate data on key populations are often sparse.

The potential of surveys to describe the continuum of services

A population-based, survey-described continuum can be estimated through the use of a dedicated survey instrument to collect self-reported respondent characteristics related to each stage of the continuum. These questions may probe exposure to mobile HIV services (peer or outreach services), HIV testing and counseling, HIV-positive serostatus knowledge, linkage to and retention in care, as well as initiation and retention in ART (Figure 1). Questions may probe service utilisation both for the past – ‘Have you ever been in HIV care?’ – and present: ‘Are you currently enrolled in HIV care?’ Where feasible, surveys that include the collection of biological specimens and the measurement of biological markers of HIV infection (antibody or antigens, viral load) and treatment (ARVs) can inform respondents’ HIV serostatus, treatment eligibility (CD4 T-cell count), current treatment (ARVs), and viral load suppression. Such a survey-derived diagram of the continuum is based on population-based data as the sample includes HIV-negative and HIV-positive respondents in and outside the continuum.

Individual-level data analysis

Survey data are analysed on the individual level, allowing for the stratification of services along the continuum by important behavioral or demographic sub-groups that may have distinct patterns of service uptake, e.g. street versus venue-based SW, young versus old MSM, female versus male PWID, or, in the general population, by age group, residence, or gender. Clinic-based reporting data usually are analysed at the aggregate level, although the expansion of electronic medical record systems or chart abstraction may make individual-level data analysis more common and much more insightful as it then may correlate individual patient characteristics with outcomes of interest.

Capturing the population ‘outside’ the continuum

Population-based surveys that specifically target key populations use complex sampling designs such as respondent-driven sampling or time location sampling. These sampling designs may capture the entire universe of key population members, i.e. both in and outside the continuum of services, and allow for the estimation of population fractions (rather than patient fractions) for each stage in the continuum of services. Survey questions may probe reasons for having exited a particular stage of the continuum (attrition) or for never having entered or reached it. The examination of such factors can inform service providers and policy makers in their efforts to improve access to and retention in services. The reasons for being outside the continuum of services are manifold and may well differ for key and general populations, such as lack of serostatus knowledge, fear of stigma or disclosure, distance, transport costs, fees or time, poor service or stock-outs, or religious reasons. Because each of these warrant different actions their identification and characterisation is important to know.

Survey-informed key population-specific continuum of services

Specific to key populations, the social marginalisation, stigma, and discrimination that prevent them from identifying themselves or being recorded as such in many routine health care settings can more easily be overcome in the survey context. Representative population-based surveys may estimate service uptake starting outside the clinic setting to include outreach or peer-based services, thus enabling the creation of a more comprehensive continuum than what most clinic-based systems can produce. Population-based surveys may facilitate better planning for services such as HIV testing and counseling, prevention messages, and delivery of preventive interventions. Such surveys sample both HIV-uninfected and -infected people, and may refer undiagnosed HIV-infected survey respondents to care.[33]

Survey-based biomarker data to examine the continuum of services

Testing for HIV and often other biomarkers is already recommended and has become routine in many HIV-related surveys, including general population-based surveys such as Demographic Health Surveys and AIDS Indicator Surveys and key population surveys.[34,35] In addition to HIV prevalence estimates, surveys have the potential to provide population-level estimates of viral load, the proportion of HIV-infected individuals with suppressed viral load, and the distribution of CD4 T cell counts. Viral load suppression serves as the desired endpoint of ‘Seek, Test, Treat, and Retain’ efforts.[36] Summary viral load measures are useful indicators to monitor the magnitude of potential onward transmission of HIV in populations, reflecting the concept of ‘Treatment as Prevention’ on an aggregate level. Routine treatment program data are unable to monitor this endpoint at the population level because they do not capture individuals with undiagnosed HIV infection or those who exited care. Further, in some resource-limited settings regular clinic-based viral load monitoring among patients on ART is still not routine.[37] Population-based surveys can provide estimates of viral load for HIV-infected persons in and outside the continuum, as e.g. demonstrated in a large survey in Swaziland.[38] Linking these data with services across the continuum opens up the possibility of more accurately and objectively measuring impact at different stages. For example, viral load measures, including viral load stratification by serostatus knowledge, care status, or treatment status can be used to estimate impact of interventions. With the expansion of treatment availability and a growing number of Treatment as Prevention (TasP) pilots or test and treat demonstration projects for key and other populations, the prevalence of detectable viral load among PLHIV will become an important additional indicator alongside HIV seroprevalence and incidence.

Challenges of using survey data to describe the continuum

Table 1 provides an overview of how survey- and clinic-based monitoring data can describe the continuum. Using survey data to describe the service continuum is not without limitations or challenges.

Reporting bias.—In population-based surveys HIV-related stigma may prevent some survey respondents from revealing that they are HIV-positive or that they are already accessing HIV care and treatment services.[39] Refusal of blood draws or HIV testing, if substantial, may bias HIV prevalence estimates and other estimates.[40]

Measurement error.—Respondent health literacy or memory of important health care events may be expected to be imperfect. For example, some respondents may have trouble distinguishing between pre-ART care and ART or accurately recall the date they enrolled in HIV care and treatment, or their last CD4 T cell count or viral load value. Both reporting bias and inaccurate recall may be partially overcome by adding relevant biomarkers to the survey, albeit at an increase in cost and complexity: HIV serology, CD4 T cell count, viral load, and ARV metabolites.

Cost.—The marginal returns of adding data measures and biomarkers to population-based surveys can be substantial. Still, longer survey interviews may increase the burden for respondents and require more staff time. Further, survey sample sizes are calculated to meet a desired precision around the most important measure, e.g. HIV prevalence. Because most survey-described stages along the continuum of services apply to PLHIV only, surveys will often require sample sizes larger than typically obtained in order to estimate these steps along the continuum with sufficient precision.

Where surveys costs are deemed too high, large-scale HIV testing and counseling campaigns may be seen as an alternative. Such campaigns provide tangible programmatic benefits (uptake of HIV serostatus knowledge, referral of PLHIV to care although with a likely reduction in representativeness).

Representativeness.—Key population surveys typically lack proper sampling frames. Investigators may resort to alternative ways of estimating sampling probabilities[41,42] or construct makeshift sampling frames.[43] Non-representative samples may yield biased estimates for the continuum and other variables. The limited geographic scope of key population surveys, which are often conducted in the capital or other large cities where access to services may be greater, is not conducive to the generation of national-level estimates, although key populations are concentrated in urban settings.

Timeliness.—The periodic or one-time nature of surveys does not lend itself to the production of continuous data as routine clinic-based reporting does. The importance of monitoring the service continuum at the population level therefore reinforces the call to transform one-time survey efforts into standing surveillance systems that include regularly repeated population-based surveys in key locations or nation-wide for both general and key populations.

Proposed continuum of services data elements to be measured in population-based surveys

Many population-based surveys to date already measure discrete elements of the continuum of services without being sufficiently comprehensive to display the entire continuum of services or examining determinants for being outside the continuum. Good examples include Kenya's AIDS Indicator survey[44] or South Africa's national household-based HIV survey.[45] A standardised systematic approach is warranted to measure the entire continuum through the use of a dedicated data instrument and, where feasible, biomarker collection. Such a data instrument can easily be embedded into existing questionnaires. At a minimum, instruments should address each step of the continuum of services: exposure to outreach services, HIV testing, linkage to and retention in care, and initiation and retention on ART. Additional questions may probe elements within a particular stage such as additional support services (i.e. family planning), past opportunistic infections screening and treatment (i.e., tuberculosis), or the timing of events (i.e. entry and exit) for each applicable step in the continuum. To maximise a survey's potential, such instruments could also collect additional data on the reasons why respondents never accessed a particular service, were non-adherent in care or treatment, re-engaged service providers, or left a particular service entirely. Surveys may probe perceived poor services or denial of services due to stigma or discrimination as additional reasons for being outside the continuum. Qualitative interviews may provide further context to respondents' perceptions and decision-making. Conversely, survey investigators may explore why respondents actually do access services. These supplementary data elements may not be available through routine clinic-based reporting, highlighting the value added with population-based surveys. The repeated conduct of such surveys at regular intervals (e.g. every 2 years) would allow the measurement of trends over time and contribute to program evaluation.

Analysis of survey-derived continuum of services data

A population-based survey capturing data on the entire continuum offers a range of possibilities during data analysis to more effectively characterise program efforts. It is important that sample sizes be large enough to allow for a meaningful analysis of the various segments of the HIV-positive population at each step of the continuum. Survey data derived through complex sampling designs (such as respondent-driven sampling) would warrant appropriate weighting to yield population estimates. Using the ultimate endpoint of viral load suppression, a complete survey data set would allow not only for the estimation of the proportion of people with suppressed viral load but also the population-attributable fraction of each step along the continuum. Subject to sufficiently large sample sizes, investigators can stratify the continuum data by categories such as age, gender, location, or behavioral characteristics, such as sex work status of MSM or location where sex is sold. Those outside the continuum constitute an important comparison group, allowing for the examination of factors associated with poor or no uptake of services (i.e. being outside the continuum of services). Population-based survey-derived findings may be compared to clinic-based descriptions of the continuum of services provided they can be matched by time and place, thus allowing a key population survey-derived continuum of services to be compared with the clinic-based uptake of services in the general population or survey findings to be compared with routine clinic-based reporting for the same key population.

Conclusion

Realising the goal of an AIDS-free generation has increased the demand for accurate measures of exposure to, uptake of, and retention in key HIV services as well as health care outcomes. While this paper focuses on the continuum of services that starts with exposure to outreach and HIV testing and counseling, and ends with treatment-related viral load suppression, similar survey-described constructs have been envisioned for other continuums of care, such as PMTCT with its endpoints of HIV-negative children at 18 months of age and mothers on treatment, the detection and treatment of HIV-related opportunistic infections like TB, or the provision of pre-exposure prophylaxis. HIV-related population-based surveys historically focused on behavioral or other risk factors, with the later addition of HIV testing. Increasing affordability, availability, and ease of biomarker testing (i.e. CD4 T cell counts, viral load) and the shift in focus to biomedical, especially treatment-based, interventions suggests an expanded role for population-based surveys to describe the service continuum, characterise who is in it and who is not, and understand why some people are left out or choose to exit at different steps. As key populations are exposed to stigma, discrimination, and criminalisation, and continue to face important barriers to accessing health and HIV services, surveys can be a key data source to help inform much-needed improvements for key population programming. These crucial advantages offered by population-based surveys ought to be exploited by investigators and program implementers, and promoted by donors and policy makers.

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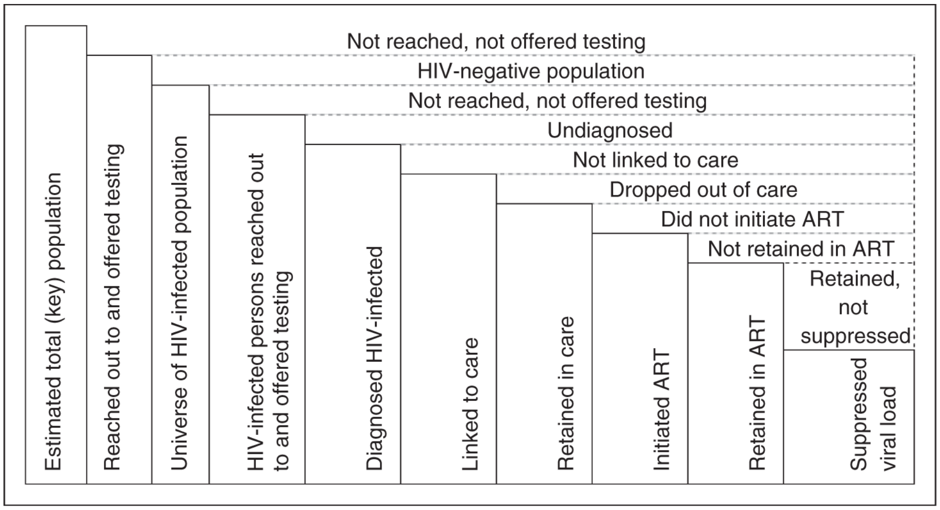

Figure 1.

Schematic of a continuum of services populated through survey data.

Table 1.

Characteristics of population-based and clinic-based continuum of services.

Characteristic	Population-based surveys	Clinic-based reporting
Population	Survey target population (general population or select key population)	Persons accessing services
Geographic scale	Defined by sampling area	Clinic, sub-national, and national level
Timing of data collection	Periodic	Continuous
Data source	Survey respondents	Routine clinic records
Data level	Individual level	Clinic level (typically)
Data accuracy	Subject to reporting bias, respondent health literacy, sampling error	Subject to clinic logbook quality and transcription errors
Accuracy of biomeasures	Subject to accuracy of recall (CD4+T cell count, viral load) but ameliorated if biomarkers are measured as part of survey	Subject to quality of data entry and data transcription
Estimating proportion accessing services	Yes	Not usually reported or difficult
Assessing determinants of service uptake, lack of service uptake, or exiting the continuum of services	Feasible	Not feasible (service uptake) or not always done (evaluating exits)
Distinguishing between exiting a service and transferring to another provider	Feasible	Often not reported, difficult to transcribe
Estimating (relative) size of population outside each care element	Feasible	Not feasible with clinic-based data alone