

Draft Technical Brief

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Strategies for Improving the Lives of Women Aged 40 and Above Living with HIV/AIDS

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

This EPC evidence report is a Technical Brief. A Technical Brief is a rapid report, typically on an emerging medical technology, strategy or intervention. It provides an overview of key issues related to the intervention—for example, current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Although Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions, the decision to request a Technical Brief is not solely based on the availability of clinical studies. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a summary of ongoing research, and information on future research needs. In particular, through the Technical Brief, AHRQ hopes to gain insight on the appropriate conceptual framework and critical issues that will inform future research.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

If you have comments on this Technical Brief, they may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by email to epc@ahrq.hhs.gov.

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We are indebted to [REDACTED NAME], who is a social worker at the Miriam Hospital, RI, for her help in describing the services provided in her facility, and for identifying and helping us present in a factually accurate manner four vignettes that illustrate key issues without compromising people's privacy.

In designing the study questions, the EPC consulted several Key Informants who represent the end-users of research. The EPC sought the Key Informant input on the priority areas for research and synthesis. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches, and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any conflicts of interest.

The list of Key Informants who provided input to this report follows:

[REDACTED]

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Strategies for Improving the Lives of Women Aged 40 and Above Living with HIV/AIDS

Structured Abstract

Background. While in its early years the HIV epidemic affected primarily the male and the young, nowadays the HIV-infected population comprises approximately 24 percent women, and its age composition has shifted towards older ages. Many women over 40 who live with HIV/AIDS also live with the medical and social conditions that accompany aging.

Objectives. This work aims to identify and characterize empirical studies that provide information on strategies for the comprehensive management of women over 40, including transgender women, who live with HIV.

Approach. With input from a diverse panel of content experts and other stakeholders, we develop an evidence map to characterize empirical studies of strategies for improving the comprehensive care of older women who live with HIV/AIDS and apply to today's U.S. setting. We outline resources that are available to these women in a purposeful sample of six states (Rhode Island, Mississippi, Alabama, New York, [Southern] California, Texas), and illustrate the importance of having integrated care by virtue of four vignettes.

Findings. We identified 890 citations that address questions in the three areas of interest and have enrolled aging women who live with HIV/AIDS. Of these, only 37 (4 percent) reported results of interest among older women who live with HIV/AIDS, or examined interactions between gender and older age that would allow predictions in this subgroup. A minority of the 37 eligible studies focused on populations facing obvious challenges, such as immigrant women, women who had suffered physical abuse, transgender women, and women recently released from prison. No studies focused on women caring for dependents, including children and grandchildren, those diagnosed in old age or those who have adequate health insurance. The state resources' survey turned up a sizeable number of testing, housing, medical and mental health, and social support resources in the largest cities, and much smaller numbers or even no resources in the median and smallest cities.

Interpretation. The evidence-base that is directly applicable to aging women who live with HIV/AIDS in the U.S. is limited. We make observations to inform the prioritization of future research.

Introduction

Background

At the end of 2013, an estimated 933,941 people were living with human immunodeficiency virus (HIV) infection in the United States. While in its early years the epidemic affected primarily the male and the young,¹ nowadays the HIV-infected population is approximately 24 percent women and its age composition has shifted.² The percentage of HIV-infected people aged 50 years and older grew from 24 percent in 2005 to 42 percent in 2013, and is projected to top 50 percent by 2020.²⁻⁴ Thus, the management of this population who live with HIV /AIDS represents a relatively new challenge.

, This Technical Brief (TB) aims to identify and characterize the empirical studies that provide information on strategies for the comprehensive management of older women, including transgender women (people who were born male but identify as women), living with HIV.

The population of older women who live with HIV/AIDS comprise two distinct sub-populations-women who contracted the virus at young age and have survived into their middle and late years and women who were newly-infected at an older age. It is estimated that 17 percent of the approximately 44,000 newly-infected people in 2014 were aged 50 or older, although a breakdown by gender is not readily available.² Age at infection may be important, because the natural history and prognosis of HIV and acquired immunodeficiency syndrome (AIDS) among those with HIV surviving into older age appear to be distinct from those newly-infected at an older age.⁵ Further, compared to people who were infected young, people contracting HIV at an older age are not diagnosed as promptly and tend to start treatment at a more advanced stage. Possible explanations include that sexually active older people may be less aware of their risk; may underestimate the likelihood that their partners can have HIV; may be more likely to engage in unprotected sex (because pregnancy is not an issue); and may be less likely to discuss sexual health with their doctors than younger people.⁶

Aging with HIV infection also presents special challenges for preventing and managing comorbid conditions. Older women with HIV may have an increased risk for cardiovascular disease, osteoporosis, and certain cancers than their uninfected counterparts. HIV-positive antiretroviral-treated aging women who achieve viral suppression are in a generalized status of immune activation and therefore may be at an increased risk of age-associated end-organ diseases compared to uninfected age-matched controls.⁷ Polypharmacy is another common concern because of the many comorbidities are related to HIV or aging, including cardiovascular disease, hypertension, type 2 diabetes, obesity, chronic kidney disease, bone disease, hyperlipidemia, cancer, depression, and neurocognitive impairment. Interactions between antiretrovirals and the numerous other medications taken for these chronic diseases can pose significant clinical problems.^{8,9}

Women over 40 living with HIV/AIDS also face issues related to the interaction between menopause, hormone replacement therapy, and HIV and antiretroviral treatments. There have been inconsistent and inconclusive reports regarding HIV and menopause. Some studies report menopause at an earlier age among HIV-infected women.¹⁰⁻¹⁵ However, many of these studies have a small sample size, involve only HIV-infected cohorts without a control, or do not account for confounding factors, such as history of drug use, current smoking, lower BMI, or race. Menopausal transition may affect a woman's quality of life by altering her mood or causing sexual dysfunction and accelerates the onset and progression of chronic diseases of aging, including cardiovascular disease, hypertension, diabetes, and reduced bone mineral density.¹⁶⁻²¹

The effect of hormonal replacement therapy, as well as its pharmacological interactions with antiretroviral treatments, is also not well understood.

In terms of affect and psychosocial wellbeing, older women with HIV infection are likely to be depressed and lonely,^{22, 23} and many women are further burdened with taking care of elderly parents or grandchildren.²⁴ The stigma associated with HIV infection is a particular concern among older women living with HIV, who may already feel isolated because they have lost partners and friends;²⁵ these feelings may be exacerbated by the responsibility of dependent care. Stigmatization can contribute to depression and worry, negatively affecting quality of life, and may prevent women from disclosing their HIV status or from seeking HIV care.²⁶

African American/Black and Latina/Hispanic women are disproportionately affected by HIV, compared to women of other racial descent. At the end of 2013, an estimated 61 percent of women who live with HIV/AIDS in 2014 were African American, 17 percent were Latinas, and 17 percent were White, although a breakdown by age is not readily available in the CDC Surveillance Report.² African Americans/Blacks and Latinos/Hispanics over 50 years of age have much higher rates of new diagnosis than Whites,⁶ although a breakdown by gender is not readily available. Race is associated with many socioeconomic and demographic factors related to health inequities, including low educational attainment, low income or poverty, low health literacy, lower proportion with insurance, higher rates of comorbidity, and higher rates of drug abuse, all of which may have a bearing on the comprehensive management of women living with HIV.

Special consideration should be given to women who identify as lesbian, bisexual or transgender (born male, but identifying as women). For women who identify as lesbian, HIV infection may be diagnosed belatedly, because it may be considered less likely than other diagnoses. Although HIV transmission is generally low after unprotected lesbian sex. A woman may have contracted the virus from a past heterosexual experience, or through other routes such as injection drug use.²⁷⁻³⁰ Transgender women are also vulnerable, for medical and social reasons. They are often subjected to violence and face depression and stigma.³¹ They may get hormonal therapy to change their appearance, which can impact their risk for cardiovascular disease, osteoporosis, and perhaps cancers.³²⁻³⁶ Finally, transgender women still face health issues associated with their biological sex, such as prostate cancer,³²⁻³⁴ and this should be factored into their medical care.

Ideally, the care of older HIV-infected women should integrate biomedical, behavioral, and social interventions.⁹ However, the current system of care in the United States does not support a comprehensive model that can provide a tailored approach for older HIV-infected women. For example, women have to move between a primary care provider, a gynecologist, and several specialists for their medical needs. Many health care providers have not been trained to deal with an aging population with HIV, and relatively few centers provide comprehensive psychosocial and case-management services for older women with HIV/AIDS. Even current guidelines for HIV testing, HIV treatment, and the management of conditions that accompany aging do not explicitly address the aging patient with several comorbidities.³⁷⁻⁴¹

Objectives

The OWH commissioned this Technical Brief through AHRQ's Evidence-based Practice Center Program. The OWH posed a broad set of guiding questions to communicate their priorities. Starting from the below-listed guiding questions we defined three conceptual areas of interest to organize this work.

In Area 1 we grouped guiding questions that pertain to **measuring the impact of strategies for engaging with resources that aim to enhance the wellbeing of aging women who live with HIV/AIDS or barriers to engaging with such resources**. Example guiding questions include:

- What is the impact of health care services, programs, and policies focused on women ages 40 and older (in medical settings, in community settings, and in common sub-populations, such as women who have experienced trauma, incarceration, violence, poverty, or substance abuse)?
- What services and programs are most likely to keep aging women living with HIV in health care (either medical or community based care)?
- What resource level factors affect initial or continued engagement with a program?
- What are the barriers facing aging women who live with in their initial or continued engagement with a program?
- What are characteristics of individual HIV positive women over 40 years of age who stay in the continuum of care (sociodemographic or cultural, psychosocial, criminal history, or clinical, personal, and family medical and mental history)?
- Where are the gaps in knowledge about effective programs for aging women who live with HIV/AIDS?

In Area 2 we grouped questions about **measuring the impact of insurance on women's well-being**. Example questions include:

- What is the effect of insurance coverage for aging women who live with HIV/AIDS?
- Do the Affordable Care Act requirements for HIV/AIDS care impact the care these women receive?

In Area 3 we grouped questions about **the diagnosis or management of comorbidities, or the role of comorbidities in predicting all-cause mortality or HIV-related disease progression**. Example questions include:

- What factors impact mortality, quality of life, health, and psychosocial outcomes in aging women who live with HIV/AIDS?
- What tools are readily available or routinely used to screen, diagnose, monitor or otherwise manage such women who also have co-occurring conditions?
- Are any such tools reliable in the entire spectrum of severity represented in aging women who live with HIV/AIDS?

This Technical Brief is slated to inform the deliberations of a meeting convened by the OWH consisting of local and national HIV policy experts. The meeting will serve as a venue to discuss future research needs directed towards filling the gaps in the evidence identified in this paper. To this end, and with input from a diverse panel of content experts and other stakeholders, we develop an evidence map to characterize empirical studies of strategies for improving the comprehensive care of older women who live with HIV/AIDS and apply to today's U.S. setting.

We outline resources that are available to these women in a purposeful sample of six states, and illustrate the importance of having integrated care by virtue of four vignettes.

Methods

The Technical Brief comprises an evidence map of the published literature on questions pertinent to women, aged 40 and above, who live with HIV/AIDS. It provides a high-level overview of the amount and type of resources that appear to be available to these women in a purposeful sample of six U.S. states.

Key Informants

We formed a panel of eight Key Informants comprising experts in the care of HIV patients, and especially of aging women, nationally recognized researchers, policy makers, state government (department of health) officials, and nationally recognized advocates for women who live with HIV/AIDS. We solicited the panel's input in two teleconferences and over email until we deemed that we had sufficiently discussed all of the relevant themes. The interactions with the Key Informant Panel were facilitated by the EPC and revolved around the following questions:

- (1) What are the salient differences between women 40 years old and older and younger women living with HIV?
- (2) Which subgroups face more challenges/barriers? What are the major barriers?
- (3) What are commonly accepted ways to organize medical, behavioral or social intervention-based strategies for improving the life of women who live with HIV/AIDS?
- (4) How does a woman, her physician, or her case manager go about identifying what resources are available to her?

Based on feedback from Key Informant discussions we refined study eligibility criteria and data extraction items for the evidence map. The discussions with the key informants are discussed further in the Summary and Implications section of this report.

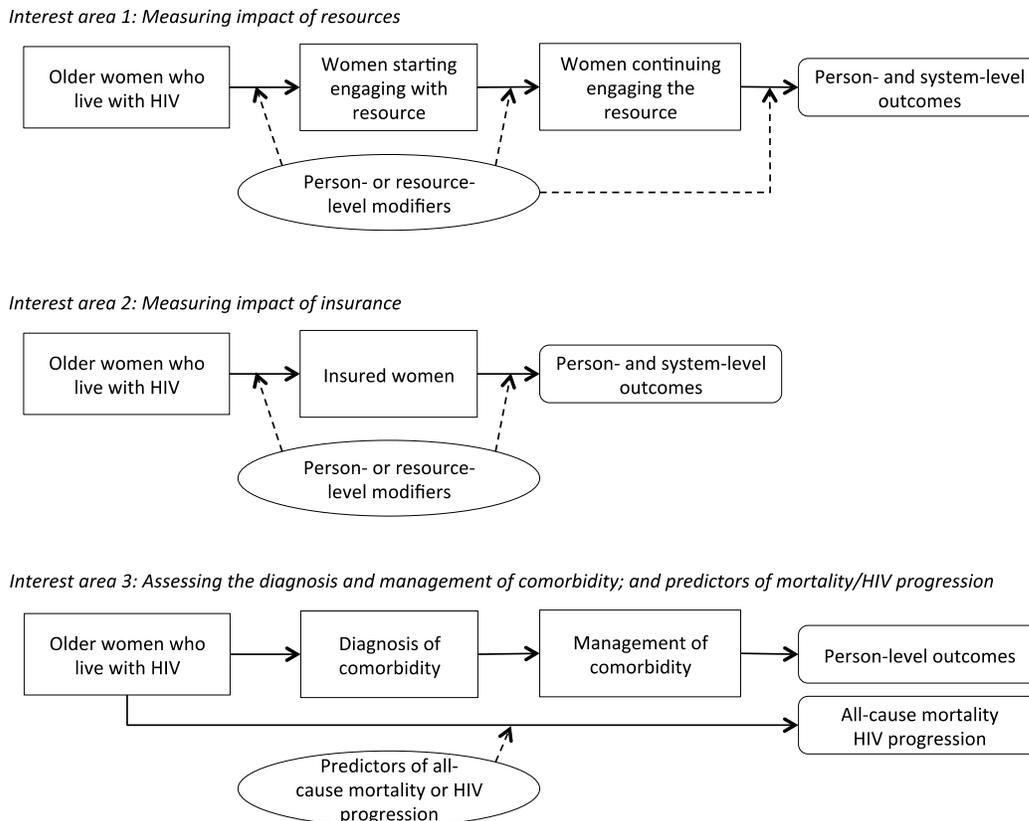
In addition, Key Informants conjectured that very few publications would be eligible in the three areas of interest, and that some observations that were important to them were unlikely to be gleaned from an evidence map of the published literature. These include the central role of case-managers in helping people navigate a "highly fragmented" system and the risk of underdiagnosis of HIV infection in older sexually active women, as well as issues faced by aging women who live with HIV/AIDS while caring for dependents and women who are medically well but emotionally burdened or socially stigmatized. As described in the Vignettes section, we collaborated with a social worker from the Brown University-affiliated Miriam Hospital to identify and present four vignettes that capture the aforementioned themes. We use these real (but anecdotal) cases to paint a more vivid picture about the importance of these themes and to motivate the prioritization of any associated research gaps in the research needs.

Evidence map

We created a compendium of empirical studies that apply to women over 40 who live with HIV/AIDS to inform the three areas of interest described in the guiding questions. The first area includes studies that measure the impact of strategies for engaging with existing resources, including medical, social, or other services or programs bundling services and strategies that aim to improve the lives of women who live with HIV/AIDS on a range of outcomes. We also include studies describing barriers to access of such resources. The second area includes studies that measure the impact of various levels of insurance coverage on outcomes. The third area pertains to studies that assess the performance of diagnostics for co-occurring disease, or assess

the effects of treating co-occurring diseases (such as depression or heart disease) or risk factors (such as high blood pressure or low bone mineral density) on person-level outcomes. **Figure 1** summarizes the three areas of interest.

Figure 1. Analytic Framework



For the first interest area (measuring the impact of strategies for engaging with resources), women over 40 who live with HIV/AIDS may engage with resources transiently or in a continued fashion, and this engagement affects person- and system-level outcomes. A range of modifiers affect the likelihood of engaging or continue engaging a resource. The second interest area includes studies that measure the overall impact of insurance on person- and system-level outcomes, irrespective of whether it is mediated by women’s use of specific resources. Again, a range of modifiers affect the likelihood that insurance impacts on outcomes. The third interest area includes studies that assess the performance of tests for diagnosing co-occurring diseases, treatments for managing such diseases on person-level outcomes, and predictive models of all-cause mortality or HIV infection progression.

Eligibility Criteria

Eligible studies pertained to women aged 40 years and older who live with HIV, an operational age cutoff to identify premenopausal women who are less likely to bear children, as well as peri- and postmenopausal women. Studies with broader enrollment, e.g., enrolling both sexes or all ages were excluded, unless they reported results for strata where at least 75 percent of the participants were women over 40 years or modeled interactions between gender and an older-age cutoff.

All patient-level and system-level outcomes were eligible. Examples of person-level outcomes included clinical outcomes, such as mortality and morbidity, mental health, function, quality of life as measured by each study, and out-of-pocket costs. Examples of system-level

outcomes included total costs or changes in the proportion or number of women undergoing a public health intervention, such as screening or engaging with an eligible resource.

Eligible resources were services providing medical, behavioral, or social support, or programs that bundle several such services. This definition encompasses all hospital-, clinic- or community-based strategies that promote women’s wellbeing. The following are indicative examples: A clinic providing routine HIV, general medical, or mental health care represents a service providing medical support. A program for helping women facing addiction problems may provide medical, behavioral, and social support. A case-management intervention that assists women to apply for Ryan White programs or housing subsidies is an example of a social support service.

In the first area of interest, we included (1) randomized trials, nonrandomized comparisons of cohorts, or before-after studies that measured the relationship between using an eligible resource and person- or system-level outcomes or examined modifiers of said relationship^a; and (2) cohorts, surveys, or qualitative research studies describing barriers faced by women when engaging with eligible resources.

In the second area of interest, we included randomized trials, nonrandomized comparisons of cohorts, and before-after studies measuring the association between various levels of insurance coverage (including none) and person- or system-level outcomes.

In the third area of interest, we included (1) cross-sectional, case-control or cohort studies of the sensitivity and specificity of tests, including imaging tests, laboratory measurements, and clinical scores, for diagnosing the presence of co-occurring diseases, including but not limited to infections (such as hepatitis C, tuberculosis, and opportunistic infections, cancers, or dementia); (2) randomized and nonrandomized comparative studies of the management of co-occurring diseases^b or established risk factors for major diseases^c; (3) predictive models of all-cause mortality or of HIV infection progression.

We excluded studies that analyzed fewer than 10 women who are older than 40 and live with HIV, because they were unlikely to yield precise or broadly applicable conclusions. For feasibility, we excluded studies completed longer than 10 years ago, because older empirical data are less likely to be relevant to today’s setting. Because the main focus of the Technical Brief is to inform about the U.S. setting, we did not include studies conducted exclusively in other countries. We excluded studies not reporting empirical data, such as theory expositions, modeling studies of the effects of policies, and opinion pieces.

^a Person-level modifiers include sociodemographic factors (e.g., race/ethnicity, income, marital status, insurance coverage, highest educational attainment), cultural factors (e.g., immigrant status), psychosocial factors (e.g., social or family support), criminal history, or clinical, personal and family medical and mental history factors (e.g., cancer, heart disease, addiction problems, mental health problems). Examples of resource-level modifiers are case management, or using a multidisciplinary team.

^b Such as cancer, infections (including hepatitis C, human papilloma virus [HPV], tuberculosis, osteomyelitis, AIDS defining infections such as *Pneumocystis carinii* pneumonia [PCP], etc.), neurocognitive impairment (including HIV-associated dementia), cardiovascular disease, mental health (depression, PTSD, bipolar, schizophrenia), addiction and substance abuse (heroin, cocaine, prescription drugs, alcohol, smoking, “party” drugs such as MDMA [Ecstasy], flunitrazepam [Rohypnol], ketamine), musculoskeletal disease (e.g. osteoporosis, rheumatoid arthritis) and other age-associated end-organ diseases not mentioned here (by reviewer consensus).

^c Such as hypertension, hyperlipidemia, diabetes, obesity, osteoporosis, and low bone mineral density measurements.

Literature Identification and Tracking

A medical librarian designed and implemented searches in PubMed, PsycINFO, CINAHL, and SocINDEX for terms related to HIV or AIDS, crossed with general terms on interventions, policies, services, or programs. We limited the search to studies published after 01/01/2005, published in English, and having at least one author with a U.S. affiliation, as described in the eligibility criteria. The search was last run on February 10, 2016 and is reported in full in **Appendix A**.

Four reviewers screened the same 400 abstracts to pilot citation screening criteria and ensure their uniform understanding and application. We iteratively assessed discrepancies as a group until all screeners were uniform in their assessments. After this pilot phase, citations were single-screened by a human reviewer, and double-checked against the predictions of the machine learning algorithms implemented in *Abstrackr*, a system for semi-automating citation screening tasks developed by Brown University's Center for Evidence-based Medicine.⁴² All potentially eligible citations were retrieved and screened in full text for eligibility.

For all papers reviewed in full-text we recorded reasons for exclusion. For papers on studies that likely enrolled at least 10 women who live with HIV/AIDS and are older than 40 and are excluded only because they report no subgroup-specific information or pertinent interaction analyses, we recorded to which area of interest they would be included had they reported the missing information. This provides an indication of the volume of information that is potentially available for secondary data analyses.

Data Abstraction and Data Analyses

From each eligible article we extracted bibliographic information (first author, journal, year of publication), study name (as applicable), location where the study was run, enrollment years, sample size of women who live with HIV/AIDS (largest analysis per study for women of all ages and over 40 years), study design (randomized trial, nonrandomized comparative, observational), and for comparative studies, the compared interventions.

Studies rarely reported detailed information on women who are older than 40 years and live with HIV; thus, we recorded the following information for all women enrolled in each study: mean age and age range or proportion of women older than an eligible age cutoff; menopausal status (percent pre-, peri- or post-menopause); percent having contracted HIV in older age (at 40 years or older); race ethnicity (percent White, Black/African American, Asian, Latino/Hispanic, Native American, Pacific Islander, other); insurance coverage status (percent with no insurance, private insurance, Medicare, Medicaid or other public); percent having dependent care, having a supporting partner or other social support (as defined by study), experiencing violence at home, being illegal immigrants, using drugs (when results were reported per substance, the highest percentage reported), having been in prison, having a history of mental health problems; percent of transgender women, lesbian women, women in monogamous relationships; median income, percent below the federal poverty level; percent who completed high school; and percent unemployed.

For studies in the first area of interest (measuring impact of strategies for engaging with resources or barriers to engaging with resources), we recorded the name of the program (if applicable), its objectives (as described by the authors), and whether it included medical services (general or specialist care, including mental health and substance abuse); psychosocial (assistance with applications for housing, financial support, AIDS Drug Assistance Program

enrollment, job searches, etc.); case management; general or HIV specific health education; and services aimed at reducing HIV or other sexually transmitted disease (STD) transmission; along with the primary outcome by which the impact of the resource was measured (the first-mentioned outcome in the results, if there were several). For studies of barriers, we recorded what these barriers hindered (e.g., screening for cancer, engaging in care), along with categories of person-level (sociodemographic, cultural, psychosocial including insurance status, criminal history, medical history, mental health) and system-level modifiers that were examined in each study.

For studies in the second area of interest on the overall effect of insurance, we recorded the reported levels of insurance coverage and the outcomes by which the impact of insurance coverage was measured.

For the third area of interest, we extracted whether the study was about the diagnosis or management of a co-occurring condition or risk factor and the type of condition or risk factor (mental health, cardiovascular disease, etc.) and whether the paper described a predictive model of all-cause mortality or HIV infection--sociodemographic, psychosocial (including insurance status), cultural, criminal history, medical, mental health progression, and, if yes, the category of predictive factors it examined.

All data were extracted in a predefined electronic form by a single investigator. Extracted data are in **Appendix D**. We used descriptive statistics to summarize findings.

Illustration of salient issues

Vignettes from the Immunology Clinic at Miriam Hospital, RI

One of the key uses of evidence maps is to identify research gaps. We present four anecdotes (vignettes) that illustrate different issues in the care of women who live with HIV/AIDS. We collaborated with a social worker who coordinates the comprehensive management of people who live with HIV in a well-integrated and nationally recognized center at the Immunology Clinic at the Miriam Hospital in Rhode Island. This clinic was chosen because our team's clinical expert works there and gave us detailed information. The vignettes touch on the following themes: the role of case-managers in coordinating people's care and helping people navigate a "highly fragmented" system; the risk of underdiagnosis of HIV infection and concomitant late-initiation of treatments in older sexually active women; the range of issues faced by aging transgender women, women who live with HIV/AIDS while caring for dependents, and women who are medically well but emotionally burdened or socially stigmatized.

All vignettes are factual, but all identifying information has been redacted and pseudonyms are used. There are no risks to the respective patients. The four anecdotes are provided for illustration. They do not touch on all important issues faced by women who live with HIV/AIDS. We do not imply that the described management of patients in the vignettes was optimal, and we do not use the vignettes as evidence to support specific conclusions.

Outlining Available Resources in a Purposeful Sample of Six States

Because the published literature is unlikely to provide descriptions of resources that are in place in the U.S., we conducted a Web site survey of the amount and type of resources that appear to be available to older women who live with HIV/AIDS in a purposeful sample of six states, namely Rhode Island, New York, Texas, California, Mississippi, and Alabama. These states are diverse in terms of geographical location, HIV prevalence overall and among women,⁴³ political culture, health systems, per capita income, and proportion of women with HIV who are foreign born or belong to a racial minority. For example, New York, Texas, and [southern] California are among the regions with the highest number of women living with HIV infection in the nation.⁴⁴ Alabama and Mississippi have disproportionately large number of African American women who live with HIV/AIDS. This sample is not meant to be a representative sample of the 50 states, but rather aims to illustrate variability.

We performed systematic Web searches, emulating a Web-savvy, persistent patient or provider who is not familiar with the resources available in these states, and who wishes to find information about them. This approach was chosen because it may inform, at a high level, on the density of different type of resources in these states. It corresponds to an “upper bound,” Of what might be available to an educated patient or, more likely a case-worker, who needs to find out what resources are available in an unfamiliar area. Clearly, many older HIV-infected women are unlikely to have this sort of access to or familiarity with the Internet, but the patient navigators and social workers who work with them should.

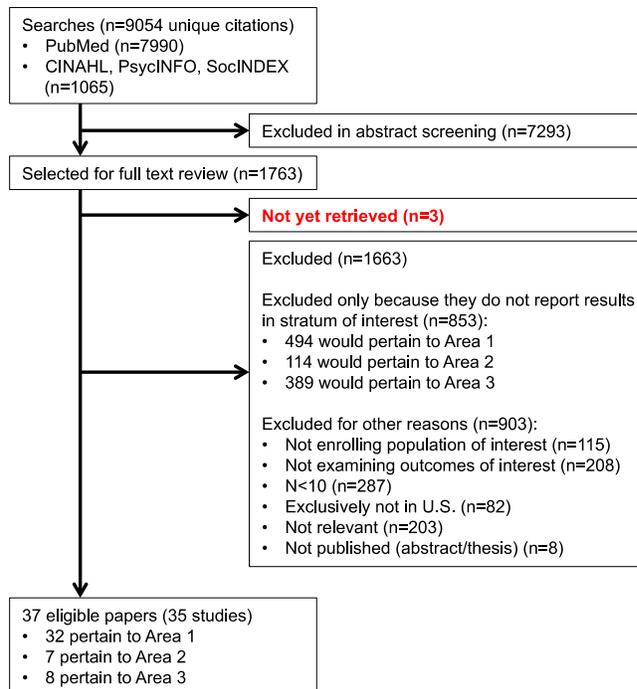
We summarize our findings to provide an indication of how easily one can identify local resources. To capture variability between urban and rural settings we summarize the number of AIDS.gov-registered facilities providing HIV testing, housing assistance, health services, Ryan White-funded HIV Care entities, mental health, substance abuse and family planning services in three cities in each state. We selected the largest, smallest, and median city in terms of population size in the most recent census on states’ governmental Web sites. We obtained information by searching AIDS.gov’s program locator (<https://locator.aids.gov/>), for a 20 mile radius around from each city center. We also conducted general web searches and searches of Web sites of departments of health in the six states.

Findings

Evidence Map

We screened 9054 unique abstracts for eligibility, of which 1763 were selected for full text review. In the end, 32, 7, and 8 papers were eligible for the three areas of interest, respectively (**Figure 2**). Of the citations that were excluded in full text review, 853 were excluded because they did not provide information on strata of women who live with HIV/AIDS and are at least 40 years old or did not analyze interactions between gender and older age. These studies typically enrolled a broader population, but opted to not provide results or analyses for the population of interest, and would be otherwise eligible. Thus, in principle, an additional 494 papers would have been eligible for interest area 1 (284 on measuring the impact of a resource and 271 characterizing barriers to accessing resources); another 114 for area 2, on the overall impact of insurance; and another 389 for area 3, including 280 papers on the diagnosis or management of comorbidities and 211 on models predicting all-cause mortality or disease progression based on treatments received and other factors.

Figure 2. Literature flow^a



Area 1: Studies measuring the impact of strategies for engaging resources or describing barriers to accessing resources

Thirty-two papers were eligible for this first area of interest; 16 were studies that quantified the impact of strategies for engaging resources and 18 were about barriers to accessing resources (one paper was about both).⁴⁵⁻⁷⁶ **Table 1** summarizes the characteristics of the women enrolled in

^a **NOTE FOR THE DRAFT:** As of this writing, 3 papers have not been retrieved. Based on their abstracts, it is highly unlikely that any of them will be eligible upon full text review. They will be considered during the final report.

these studies. Most studies were conducted in urban centers, such as New York, San Francisco, Atlanta, Boston, and Philadelphia, though a few focused on rural populations or examined differences between rural and urban populations. While all included studies were published after 2005, they analyzed populations enrolled as early as the mid-1990s. Studies included an average of 70 women (nine included more than 200 women).

Results in **Table 1** pertain to women of all ages, not only to those older than 40 years. Mean ages ranged between 36 and 57 years, and no study provided results in the elderly. No study reported the women's menopausal status or the age at which they contracted HIV.

Among the studies that reported information on the racial descent of participants, the median proportion of African American, Latino/Hispanic, and White women was 78, 15, and 14 percent, respectively. Three studies enrolled a small proportion of Native American women, and one included Pacific Islander women. No study reported enrolling Asian women.

On average, 20 percent of women reported having a spouse or partner, 58 percent perceived having adequate social support, and 31 percent cared for a dependent, but such information was provided in less than a third of the included studies. Among studies listing such information, the average proportion of women who had annual income less than approximately \$10,000, were unemployed, had not finished high school, used illegal substances, or had mental health problems ranged between 31 and 75 percent. Only one or two studies reported on the proportion of women who were illegal immigrants, experienced violence, or had a history of incarceration.

On average, 73 percent of women had some form of public insurance (Medicare or Medicaid), 15 percent had private insurance, and 27 percent had no insurance, but this information was reported in only seven studies.

Finally, the vast majority of studies did not explicitly report information on women's sexual preferences or gender self-identification. For example, no study reported the proportion of women who have more than one concurrent sexual partner, four studies included a minority of women who identified as lesbian or bisexual, and one study enrolled only transgender women.

Table 1. Characteristics of women in papers measuring the impact of strategies for engaging resources, or assessing barriers to engaging resources (Area 1)

Characteristic	Papers reporting information (% out of 32)	Median (25th, 75th)	Range
Publication year	32 (100)	2013 (2010, 2014)	2006 to 2016
Number of included women (all ages)	32 (100)	70 (30, 157)	15 to 1701
Enrollment start year	24 (75)	2006 (2002, 2010)	1994 to 2014
Enrollment duration, years	24 (75)	2 (1, 4)	1 to 6
<i>Information on age</i>			
Women, proportion >40 years*	10 (31)	79 (76, 100)	48 to 100
Mean age, years	24 (75)	45 (43, 47)	36 to 57
At or after menopause, %	0 (0)	NA	NA
Contracted HIV at older age, %	0 (0)	NA	NA
<i>Racial and ethnic descent</i>			
White, %	15 (47)	14 (8, 30)	1 to 50
Black/African American, %	28 (88)	78 (59, 86)	16 to 100
Latino/Hispanic, %	18 (56)	15 (10, 28)	2 to 55
Asian, %	0 (0)	NA	NA
Native American, %	3 (9)	7 (4, 9)	4 to 9
Pacific Islander, %	1 (3)	7 (7, 7)	7 to 7
Other racial/ethnic descent, %	12 (38)	6 (3, 15)	1 to 100
<i>Other sociodemographic factors</i>			
With a social support circle, %	7 (22)	58 (47, 62)	11 to 85
Married/with partner, %	12 (38)	20 (16, 30)	12 to 73
Caring for a dependent, %	7 (22)	31 (24, 55)	16 to 100
With annual income <\$10,000, %	15 (47)	64 (50, 76)	33 to 94
Illegal immigrants, %	1 (3)	48 (48, 48)	48 to 48
Unemployed, %	13 (41)	75 (68, 80)	33 to 100
Have not finished high school, %	22 (69)	39 (32, 50)	7 to 80
With history of incarceration, %	1 (3)	100 (100, 100)	100 to 100
Experiencing violence, %	2 (6)	17 (5, 29)	5 to 29
Using illegal substances, %	8 (25)	46 (27, 100)	14 to 100
With mental health problems, %	7 (22)	55 (38, 76)	4 to 78
<i>Insurance status</i>			
Without insurance, %	5 (16)	27 (9, 35)	8 to 39
With public insurance, %	7 (22)	73 (61, 100)	60 to 100
With private insurance, %	5 (16)	15 (5, 15)	4 to 18
<i>Gender identity and sexual orientation</i>			
Transgender women, %	2 (6)	50 (0, 100)	0 to 100
Lesbian or bisexual women, %	5 (16)	11 (7, 17)	0 to 33
Without sexual concurrency, %	0 (0)	NA	NA

* Or older than another eligible age-cutoff

Studies measuring the impact of strategies for engaging resources

Sixteen papers on 13 unique studies measured the impact of engaging with various services or with programs bundling several services (**Table 2**).^{45, 61-73, 75} Eight RCTs (described in ten papers^{61-67, 70, 71, 75}) randomized between 30 and 184 participants to either receive or not receive a

program or to receive different programs. The programs include a health promotion intervention aimed at reducing cardiovascular disease risk, a motivational intervention for quitting smoking, three educational interventions aimed at reducing alcohol consumption and risky sexual behavior, a writing intervention to address perceived HIV stigma, and Structural Ecosystems Therapy to promote healthy relationships within and outside the family and address relapse prevention and medication adherence. Of these eight programs, two had a medical component, seven had a psychosocial component, none had case management, six had an educational component, and four had an STD prevention component (**Table 2**).

The outcomes measured include adherence to health care or medication, undergoing cancer screening, smoking cessation, experiencing psychological distress or HIV-related stigma, substance abuse, and disclosure of HIV status to potential sexual partners.

An additional six studies assessed the impact of engaging with programs in a qualitative fashion. Three^{45, 68, 69} were based on interviews of 15 to 21 participants, a fourth examined a cohort of 364 participants in a stress-management intervention,⁷⁶ and two examined programs aimed at reducing substance use.^{72, 73} These programs included a joint venture with pharmacies to promote ART adherence, a peer-support program to provide social support; a program to link HIV positive women to care; a social-support program for substance abuse; a multifaceted program that integrated patient navigation, mental health counseling, and support groups; and the largest study evaluated a program designed to enhance quality of life, thereby reducing depression and increasing medication adherence. Of these six programs, two had a medical component, four had a psychosocial component, three had case management, four had an educational component, and one had an STD prevention component (**Table 2**).

Table 2. Characteristics of studies of strategies to promote women’s engagement with resources

Author (year)	Study location	Women (% who are >40y)	Mean age	Intervention or comparison	Intervention objective	Medical Component	Psychosocial Component	Case management Component	Health education Component	STD prevention Component	Outcomes measured
<i>Randomized controlled trials</i>											
Abel (2006) ⁷⁵	Texas	44	44	Writing intervention	Reducing perceived HIV stigma	No	Yes	No	No	No	Perceived HIV stigma
Chander (2015) ⁷⁰	Baltimore, MD	148 (NS)	44	Brief alcohol intervention	Reducing drinking; reducing risky sexual behavior	No	Yes	No	Yes	Yes	Alcohol consumption, sexual behavior, HIV outcomes
Echenique (2013) ⁷¹	Miami	106 (100)	NS	Project ROADMAP, Reeducating Older Adults in Maintaining AIDS Prevention	Reducing sexual risk behavior	No	Yes	No	Yes	Yes	Sexual risk behavior/HIV knowledge
Feaster (2010) ^{62*}	Florida	156 (NS)	36	Structural Ecosystems Therapy vs usual care	Promote healthy family and social relationships	No	Yes	No	Yes	No	Self reported medication adherence
Feaster (2010) ^{63*}	Florida	126 (NS)	43	Structural Ecosystems Therapy vs usual care	Address relapse prevention and medication adherence	No	Yes	No	Yes	No	Self reported substance abuse, medication adherence
Mitrani (2012) ^{65*}	Florida	126 (NS)	43	Structural Ecosystems Therapy vs usual care	Address relapse prevention and medication adherence	No	Yes	No	Yes	No	Psychological Distress and Drug Abstinence (Brief Symptom Inventory, self reported illicit drug use)
Teti (2010) ⁶¹	Philadelphia (PA)	184 (NS)	40	Protect and Respect vs educational information	Decrease riskful sexual practices	No	Yes	No	Yes	Yes	Self reported disclosure of HIV status to partners; condom use
El-Bassel (2011) ⁶⁴	Atlanta (GA), LA (CA), NYC (NY), Philadelphia (PA)	158 (NS)	NS	Risk reduction intervention vs health promotion intervention	Influence behaviors linked to chronic disease, including diet and exercise	Yes	No	No	Yes	Yes	Mammography screening
DeMarco (2013) ⁶⁷	Boston (MA)	110 (100)	NS	Sistah Powah Structured Writing Intervention vs attention control	Increased use of cognitive behavioral self-help programs, regular medical and HIV care, psychosocial support	No	Yes	No	No	No	Adherence to health care: keeping appointments, safe sex, testing for comorbidities, needle care, lifestyle factors
Manuel (2013) ⁶⁶	San Francisco (CA)	30 (NS)	49	Motivational Interviewing vs prescribed advice	Smoking cessation	Yes	Yes	No	Yes	No	Smoking intensity and cessation
<i>Observational studies</i>											
Cocohoba (2013) ⁴⁵	San Francisco (CA)	17 (NS)	NS	Pharmacy intervention	Promote ART adherence	Yes	No	Yes	Yes	No	ART adherence
Dutcher (2011) ⁶⁸	US urban rural regions	15 (NS)	NS	Peer support	Social support	No	Yes	No	Yes	Yes	Care adherence/housing status

Author (year)	Study location	Women (% who are >40y)	Mean age	Intervention or comparison	Intervention objective	Medical Component	Psychosocial Component	Case management Component	Health education Component	STD prevention Component	Outcomes measured
Kupprat (2009) ⁷²	New York	46 (NS)	47	Social support substance use and mental health services	Substance abuse treatment, mental health services, case manager, support groups	Yes	Yes	Yes	No	No	Attendance, reception of therapy
Proeschold-Bell (2016) ⁷³	North Carolina	76 (NS)	46.5	Substance Use Treatment Integrated Care from Social Workers and HIV Medical Providers	Substance use treatment	Yes	Yes	No	Yes	No	Alcohol/drug use
Sullivan (2015) ⁶⁹	Chapel Hill (NC)	21 (NS)	45	Guide to Healing Program	Link HIV infected people to care	No	No	Yes	Yes	No	Self reported ART adherence and medication management; accessing resources, including medication assistance, and community based services
Weiss (2015) ⁷⁶	Miami (FL), NYC (NY), (NJ)	364 (NS)	45	SMART/EST Women's Program	Enhance quality of life	No	Yes	No	No	No	Depression, medication adherence

*These papers refer to the same study.

LA: Los Angeles; NYC: New York City; SMART/EST: Stress Management And Relaxation Training/Emotional Supportive Therapy.

Studies of barriers in accessing resources

Eighteen observational studies^{45-60, 72, 74} evaluated barriers to care in populations ranging from 17 to 1701 women. Almost all of the barriers studied involved engaging or retention in HIV care, though one each evaluated cancer screening, accessing program services, and using the internet. **Table 3** shows information on the barriers for the studies that evaluated them. Of the 14 studies that evaluated barriers to accessing care or retention in care, the barriers were sociodemographic in 12, cultural in 6, psychosocial in 11, having to do with criminal history in one, having to do with medical history in 12, and having to do with mental history in 6. Two studies reported on barriers to cancer screening that were sociodemographic, psychosocial, and medical in nature,^{50, 57} and a third evaluated barriers to adherence to treatment in the context of a pharmacy program that were psychosocial and medical.⁴⁵ Two studies, both by Blackstock et al., evaluated barriers having to do with using the Internet, either in general or to access social support. These studies identified barriers from nearly every aspect (sociodemographic, cultural, psychosocial, medical history, and mental history),^{46, 48} which may inform the design of Web-based programs, as well as strategies to enhance their uptake and use.

The most commonly cited system- or provider-level factors were lack of transportation and logistical challenges, including navigating, wait times, clinic hours, and insurance-related bureaucracy (6 studies), and relationship with the provider (4 studies).

Table 3. Characteristics of studies of barriers to accessing resources

Author (year)	Study location	Women (>40y)	Mean age	Barriers to...	Person-level modifiers examined						System-level (including caregiver-related) modifiers examined	
					Sociodemographic	Cultural	Psychosocial	Criminal history	Medical history	Mental history		
<i>Studies of barriers for accessing care or remaining in care</i>												
Burke-Miller (2006) ⁴⁹	Various urban*	1701 (48)	NS	Accessing care	Yes	Yes	Yes	No	Yes	Yes	None	
Blackstock (2015) ⁴⁷	Various urban**	748 (NS)	42	Accessing care	Yes	No	Yes	No	Yes	Yes	Transportation	
Williams (2013) ⁶⁰	Various urban***	350 (NS)	41	Accessing care	Yes	No	Yes	Yes	Yes	Yes	Intensity of care services received in jail	
Tello (2010) ⁵⁷	Baltimore (MD)	200 (76)	46	Accessing care; cancer screening	Yes	No	Yes	No	Yes	No	Transportation, relationship with provider	
Toth (2013) ⁵⁸	(NC)	164 (NS)	46	Accessing care	Yes	Yes	Yes	No	Yes	Yes	Transportation, financial, other logistical	
Sevelius (2014) ⁵⁵	San Francisco (CA)	58 (81)	NS	Accessing care	Yes	Yes	Yes	No	Yes	No	Provider/staff cultural competence, integrated trans-related/HIV care, confidentiality	
Stevens (2009) ⁵⁶	(WI)	55 (NS)	41	Accessing care	No	No	No	No	No	No	Insurance logistics, transportation, financial, provider turnover	
Fletcher (2014) ⁵⁰	Houston (TX)	33 (NS)	51	Cervical cancer screening	No	No	Yes	No	Yes	No	Transportation, wait times, scheduling	
Quinlivan (2013) ⁵⁴	(NC)	30 (67)	45	Accessing care	Yes	Yes	Yes	No	Yes	Yes	Navigating labs, transportation and parking, logistics, relationship with providers	
Vyavaharkar (2008) ⁵⁹	(SC)	22 (NS)	44	Accessing care	Yes	Yes	Yes	No	Yes	No	Relationship with provider	
Pivnick (2010) ⁵³	Bronx (NY)	21 (NS)	48	Accessing services	Yes	Yes	Yes	No	Yes	No	None	
McDoom (2015) ⁵²	Boston (MA)	20 (100)	57	Accessing care	No	No	Yes	No	No	No	Relationship with provider	
Kempf (2010) ⁵¹	Alabama (AL)	39 (77)	46	Retention in care	Yes	No	Yes	No	Yes	No	Transportation, clinic hours, flexible scheduling	
Kupprat 2009 ⁷²	New York	46 (NS)	47	Engaging in care	Yes	No	No	No	Yes	Yes	Those receiving services at a medical model agency more likely to utilize therapy	
Sarnquist 2011 ⁷⁴	California	64 (49)	NS	Seeking care	Yes	No	No	No	Yes	No	Transportation, navigating healthcare system	
<i>Studies of barriers to other goals</i>												
Blackstock (2015) ⁴⁶	Bronx (NY)	103 (100)	50	Using the Web	Yes	Yes	Yes	No	Yes	Yes	Place of medical care (clinic, private PCP vs healthcare for homeless, methadone clinic, visiting PCP)	
Blackstock (2015) ⁴⁸	Bronx (NY)	27 (NS)	49	Accessing Web-based social support	Yes	Yes	Yes	No	Yes	No	None	
Cocohoba (2013) ⁴⁵	San Francisco (CA)	17 (NS)	NS	Adhering to ART	No	No	Yes	No	Yes	No	Privacy, pharmacy location, presence of drug-seeking or intoxicated pharmacy patrons, relationship with provider	

*NYC (NY), Washington (DC), Chicago (IL), LA & San Francisco (CA).

**Brooklyn (NY), Chicago (IL), LA (CA), Miami (FL), San Antonio (TX), Springfield (MA), Alabama (AL), (NC), Longview (TX)

***Atlanta (GA), Chester (PA), Chicago (IL), Cleveland (OH), Columbia (SC), New Haven (CT), New York city (NY), Philadelphia (PA), Providence (RI); Springfield (MA)

ART: antiretroviral therapy; NS: not stated.

Area 2: Studies measuring the effect of insurance on outcomes

Seven eligible papers evaluated the overall effect of insurance coverage levels on outcomes (**Table 4**). Six of them also assessed barriers facing HIV infected people who wish to engage resources, and these are included among the studies described in the previous section.^{45-47, 49, 56, 58} These six studies reported the impact of different levels of insurance coverage on engagement with or retention in care, satisfaction with care, antiretroviral adherence, and Internet use. The seventh study evaluated the association between insurance coverage levels and successful management of major depressive disorder.⁷⁷ Because of the overlap in the included studies, the study and population characteristics in **Table 4** are qualitatively similar to those in **Table 1**. The seven studies report no information on several characteristics of interest, including proportion of women with a spouse or partner who is available, illegal immigrants, history of incarceration, who identify as lesbian, bisexual or transgender, or have multiple concurrent sexual partners.

In no study did more than 18 percent of the women have private insurance. Where it was reported, between 60 and 100 percent of women had public insurance, and between 7 and 35 percent had no insurance. In all studies level of insurance coverage was one of several predictors in a regression model. We deem it unlikely that their results can be interpreted as good estimates of the causal effect of insurance on outcomes, despite having done no formal risk of bias analysis for them. These studies were not designed to estimate the causal effect of insurance, did not use causally explicit analyses, and each considered and controlled for different variables.

Table 4. Characteristics of women in papers measuring the impact of insurance on outcomes (Area 2)

Characteristic	Papers reporting information (% out of 7)	Median (25th, 75th)	Range
Publication year	7 (100)	2013 (2009, 2015)	2006 to 2015
Number of included women (all ages)	7 (100)	164 (55, 748)	17 to 1701
Enrollment start year	6 (86)	2005 (1994, 2010)	1994 to 2014
Enrollment duration, years	6 (86)	2 (2, 4)	1 to 4
<i>Information on age</i>			
Women, proportion >40 years*	2 (29)	74 (48, 100)	48 to 100
Mean age, years	5 (71)	43 (42, 46)	41 to 50
At or after menopause, %	0 (0)	NA	NA
Contracted HIV at older age, %	0 (0)	NA	NA
<i>Racial and ethnic descent</i>			
White, %	5 (71)	18 (11, 32)	1 to 36
Black/African American, %	7 (100)	60 (55, 68)	53 to 85
Latino/Hispanic, %	6 (86)	26 (7, 30)	3 to 35
Asian, %	0 (0)	NA	NA
Native American, %	2 (29)	6 (4, 9)	4 to 9
Pacific Islander, %	0 (0)	NA	NA
Other racial/ethnic descent, %	3 (43)	5 (2, 6)	2 to 6
<i>Other sociodemographic factors</i>			
With a social support circle, %	0 (0)	NA	NA
Married/with partner, %	3 (43)	16 (16, 34)	16 to 34
Caring for a dependent, %	2 (29)	27 (24, 31)	24 to 31
With annual income <\$10,000, %	3 (43)	63 (50, 73)	50 to 73
Illegal immigrants, %	0 (0)	NA	NA
Unemployed, %	3 (43)	70 (58, 78)	58 to 78
Have not finished high school, %	5 (71)	35 (35, 37)	17 to 47
With history of incarceration, %	0 (0)	NA	NA
Experiencing violence, %	1 (14)	29 (29, 29)	29 to 29
Using illegal substances, %	3 (43)	28 (14, 38)	14 to 38
With mental health problems, %	5 (71)	51 (38, 55)	4 to 100
<i>Insurance status</i>			
Without insurance, %	4 (57)	11 (8, 20)	8 to 27
With public insurance, %	2 (29)	67 (61, 73)	61 to 73
With private insurance, %	3 (43)	15 (15, 18)	15 to 18
<i>Gender identity and sexual orientation</i>			
Transgender women, %	0 (0)	NA	NA
Lesbian or bisexual women, %	0 (0)	NA	NA
Without sexual concurrency, %	0 (0)	NA	NA

* Or older than another eligible age-cutoff

Area 3: Studies on the diagnosis or management of comorbidity, or on predictive models

Eight papers (seven studies), with sample sizes between 46 and 1234 participants were deemed eligible (**Table 5**).^{63, 65, 70, 77-81} Because of the overlap in the included studies, the study and population characteristics in **Table 5** are qualitatively similar to those in **Table 1**. The eight

publications report no information on several characteristics of interest, including proportion of women with a spouse or partner who is available, illegal immigrants, history of incarceration, women who identify as lesbian, bisexual, or transgender or have multiple concurrent sexual partners. No study informed on diagnosis, screening, or monitoring of comorbidities among HIV-infected older women; six reported information on the management of comorbidities; and two reported on predictive models of HIV progression or overall mortality in the presence of comorbid conditions.

Of the six studies that included information on management of comorbidities, two pertained to depression, three to alcohol and other substance abuse, and one to cardiovascular disease.^{63, 65, 70, 77-80} Of the two studies that pertained to depression, one examined whether psychopharmacologic and psychotherapeutic treatment of depressed HIV-women met standards defined in the best practice literature and assessed predictors of standard-concordant care,⁷⁷ and the other examined whether antidepressant use by HIV-positive patients results in better employment rates.⁷⁸ Among the three studies that pertained to drug and alcohol abuse, one evaluated a family-based intervention (Structural Ecosystems Therapy) compared to a psychoeducational intervention for seropositive women who recover from drug abuse.^{63, 65} Another informed on associations between heavy alcohol consumption and antiretroviral treatment initiation and mortality,⁷⁹ and a third evaluated a brief alcohol intervention in seropositive women with heavy drinking problems.⁷⁰ Finally, a cohort study informed on rates of acute myocardial infarction among HIV-positive patients with cardiovascular risk factors.⁸⁰

Two eligible cohort studies described models predicting HIV progression or overall mortality among aging HIV-infected women with comorbidities.⁷⁹⁻⁸¹ The first predicted clinical progression HIV disease based on illicit drug use and various sociodemographic factors (such as age, race, and sexual history) and medical history factors (such as antiretroviral use, CD4 cell counts, and CDC category of HIV disease at baseline).⁸¹ Another predicted all cause mortality among aging HIV-infected women with substance and alcohol abuse problems based on sociodemographic factors (age and race), medical history factors (including using various drugs, alcohol and tobacco, having hepatitis C, prior antiretroviral therapy, CD4 counts, and viral load), and mental health factors (history of depression).⁷⁹

Table 5. Characteristics of women in papers on the diagnosis or management of comorbidity, or of predictive models (Area 3)

Characteristic	Papers reporting information (% out of 8)	Median (25th, 75th)	Range
Publication year	8 (100)	2010 (2008, 2013)	2006 to 2015
Number of included women (all ages)	8 (100)	700 (137, 1101)	126 to 1234
Enrollment start year	8 (100)	1996 (1995, 1998)	1994 to 2006
Enrollment duration, years	8 (100)	4 (3, 8)	2 to 10
<i>Information on age</i>	0 (0)	NA	NA
Women, proportion >40 years*	7 (88)	43 (38, 43)	36 to 44
Mean age, years	0 (0)	NA	NA
At or after menopause, %	0 (0)	NA	NA
Contracted HIV at older age, %	4 (50)	14 (13, 28)	11 to 40
<i>Racial and ethnic descent</i>	7 (88)	79 (53, 84)	35 to 86
White, %	5 (62)	15 (12, 30)	12 to 30
Black/African American, %	1 (12)	1 (1, 1)	1 to 1
Latino/Hispanic, %	0 (0)	NA	NA
Asian, %	0 (0)	NA	NA
Native American, %	2 (25)	13 (9, 16)	9 to 16
Pacific Islander, %	3 (38)	58 (33, 58)	33 to 58
Other racial/ethnic descent, %	0 (0)	NA	NA
<i>Other sociodemographic factors</i>	0 (0)	NA	NA
With a social support circle, %	4 (50)	50 (50, 55)	50 to 60
Married/with partner, %	0 (0)	NA	NA
Caring for a dependent, %	2 (25)	19 (5, 33)	5 to 33
With annual income <\$10,000, %	4 (50)	57 (38, 75)	35 to 75
Illegal immigrants, %	0 (0)	NA	NA
Unemployed, %	0 (0)	NA	NA
Have not finished high school, %	4 (50)	100 (80, 100)	59 to 100
With history of incarceration, %	3 (38)	100 (32, 100)	32 to 100
Experiencing violence, %	1 (12)	14 (14, 14)	14 to 14
Using illegal substances, %	1 (12)	74 (74, 74)	74 to 74
With mental health problems, %	0 (0)	NA	NA
<i>Insurance status</i>	0 (0)	NA	NA
Without insurance, %	0 (0)	NA	NA
With public insurance, %	0 (0)	NA	NA
With private insurance, %	8 (100)	2010 (2008, 2013)	2006 to 2015
<i>Gender identity and sexual orientation</i>	8 (100)	700 (137, 1101)	126 to 1234
Transgender women, %	8 (100)	1996 (1995, 1998)	1994 to 2006
Lesbian or bisexual women, %	8 (100)	4 (3, 8)	2 to 10
Without sexual concurrency, %	0 (0)	NA	NA

* Or older than another eligible age-cutoff

Illustration of Salient Issues

As described in the Methods section, to better appreciate the issues that pertain to caring for aging women in particular, we interviewed a social worker at the Immunology Clinic at the Brown-affiliated Miriam Hospital, a well-organized, nationally recognized center that provides

integrated general medical and specialist care, as well as mental health and social support to people living with HIV. The following are four factually accurate vignettes, selected in collaboration with the social worker, that illustrate challenges faced by aging women who live with HIV/AIDS.

Four Vignettes

The following vignettes emphasize the need for case management and individualized care, and give an indication of the range of needs that various older women have and the barriers they face in accessing care.

M.W.

M.W. is a 40-year-old transgender woman, who first transitioned to a girl with the aid of hormones at age 15. She contracted HIV 10 years ago, and is on treatment with good disease control. She had silicone injections for breast augmentation by “someone in a hotel room” and developed recurrent mastitis and severe scarring. She also developed renal failure and has been on dialysis for 8 years. She developed compartment syndrome from fistula infiltration, which left her with healing scars. She also has multiple catheter related scars on her chest. In addition, she has hypertension, hepatitis C, and recurrent moderate major depressive disorder. For the last several years she has avoided living as a woman, because she is seeking approval from her adopted family and living in environments where she feels stigmatized, as well as because of the scars on her body from medical procedures affect her body image. She acknowledges that her avoidance of living as a woman has contributed to poor self-hygiene behavior.

M.W.’s battles with depression, chronic disease, stigma, and lack of social support have had major adverse impact on her well-being and adherence to HIV and other medical care, and have led to her no longer identify as a transgender woman. Transgender women can easily fall through the current highly fragmented system of care, much like M.W. did during several periods of her life.

K.P.

K.P. was diagnosed with AIDS in her 80s. She had been generally healthy but started losing weight, with night sweats, poor appetite and easy fatigue. She saw multiple physicians, but no clear diagnosis was made. She was admitted to the Oncology service for a full work up for a malignancy. She was wheelchair bound and extremely weak. Work up did not show any malignancy or rheumatologic disease. An intern suggested an HIV test, since all other tests were unremarkable. The HIV test came back positive, and her CD4 count was 10. No one thought to test her, as no one thought a woman in her 80s would be sexually active. She was started on antiretroviral therapy, and responded very well. She continues to be seen in clinic with good HIV control. She has gained back weight and is very active and ambulant.

The risk of HIV infection in aging and elderly women is often underappreciated, perhaps because of wrong assumptions about women's sex life in older age, leading to underdiagnosis and unnecessary suffering.

B.T.

B.T. is a 65-year-old woman diagnosed with HIV in 1989, probably from injection drug use. She was started on monotherapy at the time and has been on several regimens over the years, as newer medication classes have become available. She has suffered many treatment-related side effects, and for a time did not want to take her HIV medications. She tolerates newer medications well, takes them, and her HIV infection is now under good control. She is a chronic smoker, has chronic obstructive pulmonary disease, pulmonary hypertension, and hepatitis C. She has not used drugs for many years, but has "survivor's guilt" as she feels she should be dead like all of her contemporaries who shared needles with her and also contracted HIV. Her being the only one alive among their group depresses her gravely, even though she is doing well medically.

Women like B.T., who are doing well medically and do not face such basic needs as housing, food security, or insurance coverage can still struggle emotionally and socially. Challenges are magnified for women who do not have peer, community, or other social support.

C.W.

C.W. is a 50-year-old woman, diagnosed with HIV 18 years ago, in 1998. She regularly misses clinic appointments and does not regularly take her HIV medications, because she faces substance abuse issues. She has never had good HIV control, with a consistently low CD4 count and an always-detectable viral load. She has been in rehabilitation many times, but always relapsed. She has been in jail multiple times. She tried a methadone program but was discharged, due to continued use of cocaine and heroin. She was lost to follow up for three years before resurfaced in clinic in 2015. She says that she had no time to take care of herself, as a result of family problems: her older son was recently convicted for sex trafficking and sentenced to 10 years in prison, and her younger son has been detained in a juvenile facility for selling drugs.

Women like C.W. may face substance abuse, mental health, and family and social challenges that are so major, disorganizing, and detrimental that they take precedence over HIV-related medical care.

Web-survey of Available Resources for People Living with HIV in Six States

It is unlikely that the published literature provides a credible high level overview of the number and type of resources available today in the U.S. for people who live with HIV, and by extension, for older women who live with HIV/AIDS. The Key Informants, our technical expert, and the social worker who helped us identify the above-listed vignettes, all suggested that resources for HIV patients are not well integrated. It is not clear how most patients are linked to

HIV care resources, but it is likely that it comes through a combination of word of mouth referrals (e.g., from those who make the HIV diagnosis) and various community outreach programs.

We provide a high-level overview of the type and number of resources that are available and readily identified through focused and limited searches of the Internet in a purposeful sample of six states. We emulate a Web-savvy person (e.g., an HIV-infected woman, her provider, or her case manager) looking to identify resources for older women who live with HIV/AIDS in Rhode Island, Alabama, Mississippi, New York, Texas, and (the southern part of) California. The idea is not to suggest that women who live with HIV/AIDS should search the Internet to find resources; it is well appreciated that too many barriers exist for that to be effective.⁴⁶ Instead, we aim to outline information on the density of resources that exist in the six states and to provide high-level empirical data.

The exposition is as follows: **Table 6** provides information about the demographics of the HIV positive populations in the six states, obtained from the CDC and the states' Departments of Health. No data are readily available for most of the characteristics of interest (i.e., for the information on age, race, socioeconomic data, insurance status and sexual orientation in the rows of **Table 1**). Therefore, our ability to describe the population in these six states (and we suspect in other U.S. states) even at a basic level is hampered by lack of information.

Table 6. Characteristics of the population in the six states and across the U.S.

Characteristic	US	Rhode Island (state sources)*	New York	Alabama	Mississippi	Texas	California**
<i>General information</i>							
Number of people (percentage of women)	316 million	1.1 million	19.7 million	4.8 million	3 million	26.4 million	38.3 million
Number of women	160 million	542 thousand	10.1 million	2.5 million	1.5 million	13.3 million	19.3 million
Number of women over 40y	71 million	282 thousand	5.0 million	1.2 million	732 thousand	5.8 million	8.9 million
Number of women with HIV (percentage who are over 40 years)	225612 (NR)	NR (NR)	39209 (NR)	3848 (NR)	3156 (NR)	17350 (61)	14071 (NR)
Incident HIV cases in 2013 among women (percentage over 40 years)	8328 (NR)	16 (NR)	742 (52)	146 (35)	93 (16)	823 (39)	NR
<i>Racial information, among women over 40 years^a</i>	NR	NR	NR	NR	NR	NR	NR
<i>Other sociodemographic factors, among women over 40 years^b</i>	NR	NR	NR	NR	NR	NR	NR
<i>Insurance status, among women over 40 years^c</i>	NR	NR	NR	NR	NR	NR	NR
<i>Gender identity and sexual orientation, among women over 40 years^d</i>	NR	NR	NR	NR	NR	NR	NR

* Information on RI from the Immunology Clinic, which sees approximately 85% of the HIV population in the state in Table 7.

**Information on Southern California not available separately.

^a Percentages for White; Black/African American; Latino/Hispanic; Asian; Native American; Pacific Islander; Other

^b Percentages with a social support circle; married/with partner; caring for a dependent; with annual income <\$10,000; illegal immigrants; unemployed; have not finished high school; with history of incarceration; experiencing violence; using illegal substances; with mental health problems

^c Percentages without insurance; with public insurance; with private insurance

^d Percentages for transgender women; lesbian or bisexual women; with sexual concurrency

To provide some more context, for Rhode Island, we obtained information on some of these factors from the database of the Immunology Clinic at the Miriam Hospital, which covers an estimated 85% of the state’s HIV population. This information is listed in **Table 7**, for variables that are analogous, but not identical, to the ones in **Table 1**. Briefly, among the 359 women who are older than 40 years and live with HIV the majority (69 percent) is in the 40-55 year old bracket, and 43 percent are foreign-born. Most (67 percent) have been infected through sexual relationships, and 20 percent are likely to have been infected through injection drug use. Half report being currently single. The highest educational attainment is unknown in 44 percent, and 27 percent has not completed high school. This detailed information was not practically available from the other states, or at the U.S. level.

Table 7. Characteristics of the HIV-infected women older than 40 years in the Immunology Clinic at the Miriam Hospital in RI

Characteristic	Number	Percentage among women over 40 years
<i>Age information</i>		
Over 40 years	359	100
40-55 years	247	69
56-70 years	98	27
71-99 years	14	4
<i>Racial information</i>		
Latina/Hispanic	115	32
All other	244	68
<i>Place of birth</i>		
U.S. born	173	48
Foreign born	153	43
Unknown	33	9
<i>Infection route</i>		
Sexual	239	67
Injection Drug User	72	20
Receipt of Blood Transfusion	3	<1
Others/Unknown	45	13
<i>Marital/partnership status</i>		
Divorced	26	7
Married	85	24
Partnered	24	7
Single	181	50
Unknown	17	4
Widow	28	8
<i>Highest educational attainment</i>		
No schooling at all	11	3
Grade school	37	10
Some high school	50	14
High school	37	10
Some college	35	10
College	20	6
Vocational or technical	11	3
Unknown	160	44

<i>Other sociodemographics^a</i>	ND	ND
<i>Gender identity and sexual orientation^b</i>	ND	ND

Table 8 shows the number of centers offering services related to HIV testing, housing, general health, mental health, substance abuse and family planning, and the number of Ryan White HIV Care-funded programs located within a 20-mile radius from the center of a large, a median, and a small city in each of the six states, as registered in AIDS.gov. In the text we also list, for each state, pertinent information gleaned from the Web sites of the Departments of Health and from targeted general Internet searches. **Figures 3, 4 and 5** plot the density of each type of resource in the largest, median, and smallest city in the six states per 1000 inhabitants.

Table 8. Number of resources available in each the largest, median and smallest city in each state

State, Cities	HIV Testing	Housing Assistance	Health Centers	Ryan White HIV Care	Mental Health	Substance Abuse	Family Planning
Rhode Island							
Providence	16	6	38	3	69	57	19
Burrillville	20	5	30	3	48	44	15
Charlestown	3	0	4	3	5	9	2
New York							
New York City	329	20	309	51	253	582	108
Rochester	17	5	28	3	21	34	4
Little Falls	1	0	5	5	6	8	1
Texas							
Houston	44	14	54	9	21	62	12
Amarillo	7	1	3	3	4	4	1
Del Rio	2	0	3	4	1	0	0
Southern California							
Los Angeles	135	20	284	22	152	243	93
Escondido	23	3	33	3	19	33	21
Imperial	4	1	6	5	1	6	0
Mississippi							
Jackson	10	3	17	3	17	10	3
Tupelo	5	0	3	11	5	2	4
Mound Bayou	2	0	4	3	1	2	3
Alabama							
Birmingham	14	2	6	4	21	17	4
Dothan	4	0	3	5	4	5	1
Demopolis	3	0	4	6	5	1	1

Information for each city from <https://locator.aids.gov/>; the counts pertain to resources that are within 20 miles of the corresponding city or town center. Last accessed January 15, 2016. Cities in each state (or part of state) are ordered from largest to smallest in terms of population reported in the most recent census.

While there is variation across the six states in the number of facilities per 1000 inhabitants, it appears that, at least in the largest city in each state the density of facilities is comparable (**Figure 3**). Across the states, Texas appears to have the lower density of each type of facility;

^a Percentages with a social support circle; caring for a dependent; with annual income <\$10,000; illegal immigrants; unemployed; with history of incarceration; experiencing violence; using illegal substances; with mental health problems

^b Percentages for transgender women; lesbian or bisexual women; with sexual concurrency

however it is the largest state. When it comes to the median and smallest city in each state however, the variation is more notable, with Rhode Island being an outlier (**Figures 4 and 5**). Further, the median and smallest cities do not have at least one facility of each kind (**Table 8; Figures 4 and 5**).

Figure 3. Density of facilities per 1000 inhabitants in the largest city in each state (Table 8)

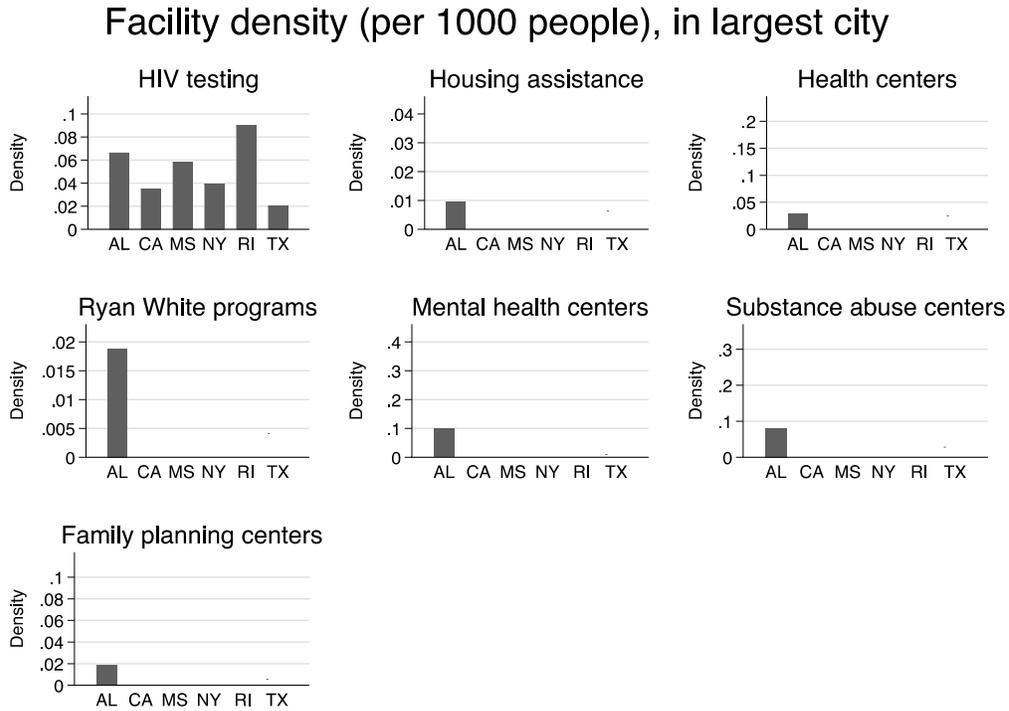


Figure 4. Density of facilities per 1000 inhabitants in the median city in each state (Table 8)

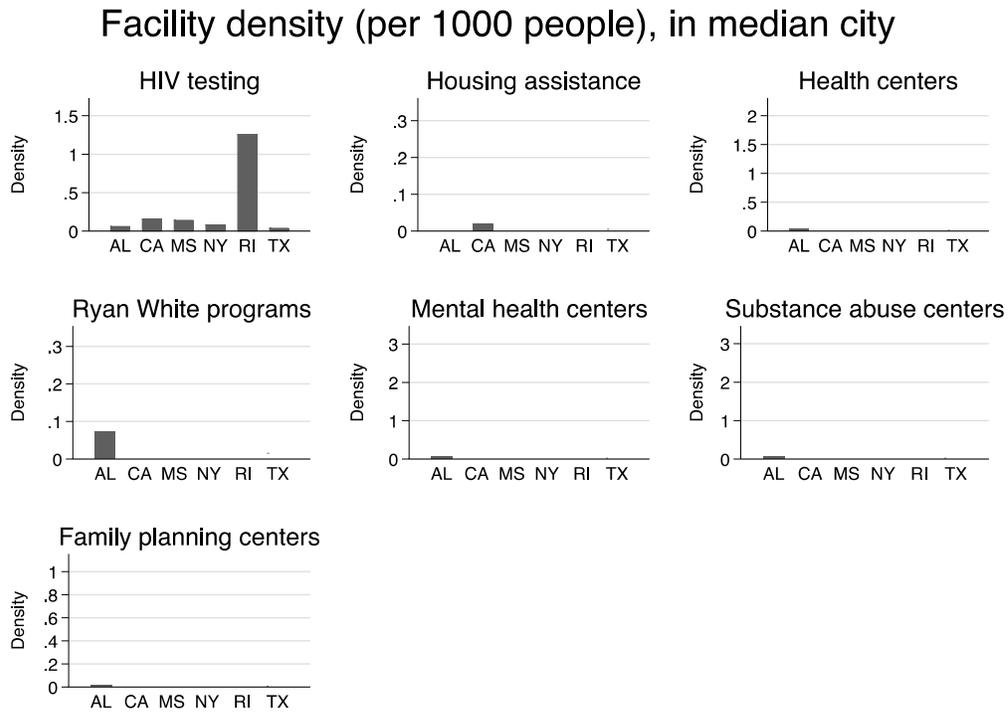
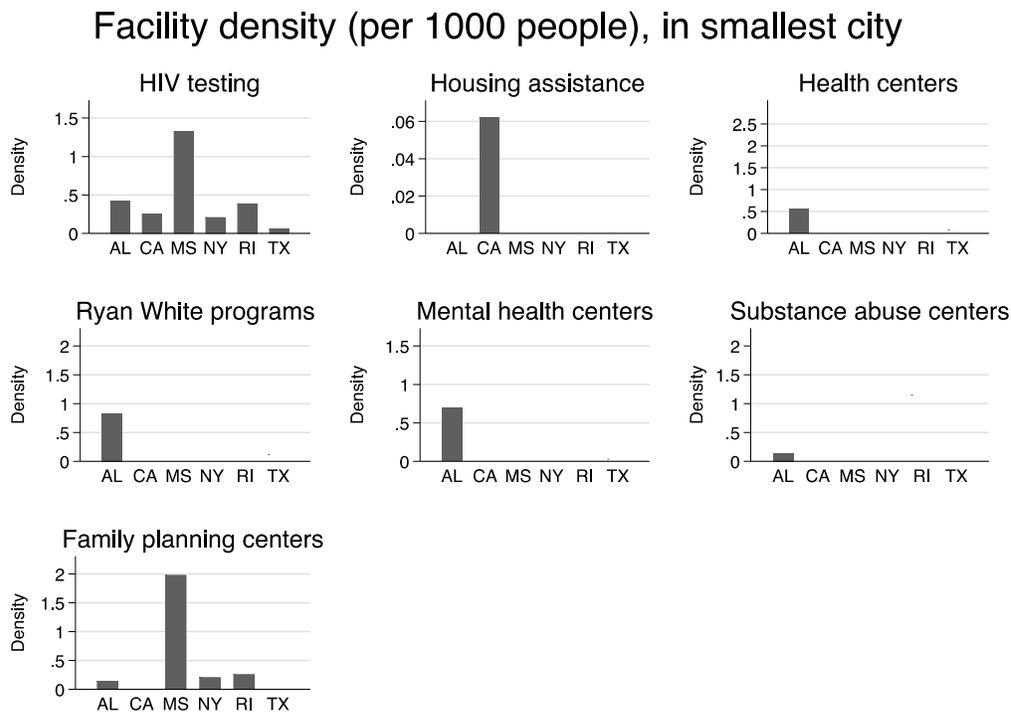


Figure 5. Density of facilities per 1000 inhabitants in the smallest city in each state (Table 8)



Rhode Island

A Google search for Rhode Island and HIV or AIDS yielded the Web site for the State of Rhode Island Department of Health (<http://www.health.ri.gov/diseases/hiv aids/>). This site includes educational information, publications, programs, regulations, and partners. There is an application for the Rhode Island AIDS Drug Assistance Program (ADAP) on the site, as well as a list of contact information for HIV/AIDS services and partners, including Ryan White HIV Care-funded programs. The programs listed range from clinics specializing in the medical care of HIV infected individuals to full service organizations that offer surveillance, anonymous testing, case management, clinical services, Sunrise House & Supportive Housing, prevention center (includes street outreach and needle exchange), and support groups. The AIDS Care Ocean State (<http://www.aids careos.org/Home.aspx>) offers services such as patient advocacy, transportation, medical and mental health referrals, emergency assistance, respite care, rental assistance, housing subsidies, evictions prevention, and counseling (clinical, individual, group, and family).

Rhode Island is a small state where an estimated 85 percent of the HIV population receives care in the Immunology Clinic at the Brown-affiliated Miriam Hospital. We provide a description of the clinic's operations, to give an appreciation of how patients are handled in everyday life. People with new HIV diagnosis are referred to the clinic by word of mouth, referrals, and through the clinic's substantial outreach efforts.

Services Provided by the Immunology Clinic at the Miriam Hospital, RI

The clinic staff, comprising a multidisciplinary team of physicians (including mental health professionals), nurses, case managers, social workers, interpreters, and general support staff provides coordinated initial, follow-up, and triage care for immunologic and infectious disease patients. For all newly diagnosed or referred people, an experienced nurse conducts the initial assessment of preferred language, social, medical and mental health needs. Subsequently, a social worker or other experienced trained professional will act as the person's case manager, using an interpreter, as needed. A nurse follows up after the initial assessment for further educational needs and to discuss medical questions. The case manager schedules the patient with a physician for an initial consult, triages the need for mental health or addiction support, and outlines an individualized multidisciplinary plan. The management plan is shared with the whole care team with the goal of providing a continuum of social and physical care.

People who present to the clinic have different needs, and thus the case manager must identify the most needed aspects of social and medical care. The case manager must act as the navigator of the patient through the existing system, because, existing resources within and outside the clinic are not otherwise integrated. For example, patient with housing needs may or may not be eligible for Part D Ryan White-funded programs, U.S. Housing and Urban Development programs (including Housing Opportunities for Persons With AIDS [HOPWA] programs), Salvation Army programs, or transitional assisted living programs that provide group or individual housing, depending on her income, insurance coverage, problems with the law, whether she is legally in the country, or whether she abuses drugs or alcohol. More generally, case workers work with other agencies in the state providing case management for HIV infected patients such as RI Project AIDS, AIDS Care Ocean State, and work with the state's Department of Health for contact tracing and finding loss to follow up patients.

Apart from housing, examples of social needs that the case manager caters to include but are not limited to food security; transportation; transitions from the hospital to a nursing unit, house, or other places providing hospitality; de novo or renewal applications to Ryan White Programs,

AIDS Drug Assistance Programs, or public insurance such as Medicare or Medicaid (which is covering HIV patients since the institution of the Affordable Care Act); organization of day-to-day tasks; communication with jail or prison personnel, police, judges or others from the justice department. The case manager also acts as a financial advocate for patients in need. Through various funding sources, including federal funding, hospital funds, in-kind-donations from pharmaceutical industry, and philanthropy, the clinic may cover application fees (e.g., for getting an identity card), burial expenses, drug co-pay, legal services, interpreter services, and many other unforeseen needs.

Alabama

A Google search for Alabama and HIV or AIDS yielded the Web site for the Division of HIV/AIDS Prevention and Care of Alabama Public Health (<http://www.adph.org/aids/>), which includes educational information, events, news, as well as links to services and care. There is an application for the Alabama AIDS Drug Assistance Program (ADAP) on the site, as well as a list of contact information for HIV/AIDS Program Coordinators in each of 11 areas of the state.

In the services section of the Web site is a list of links to 14 programs throughout the state. These range from clinics specializing in the medical care of HIV infected persons to full-service organizations that offer medical services (including obstetrics and gynecology services), housing, mental health, prevention/education, substance abuse treatment, and transportation. Most are based in a specific region of the state (north, south, central, Birmingham area, etc.), and receive Ryan White funds. Notably, the AIDS Alabama South (<http://www.southalabamacares.org/>) runs a monthly support group for HIV positive women. The AIDS Alabama (<http://www.aidsalabama.org/>) Web-based resource offers a zip-code-based locator for care in the state. The Birmingham AIDS Outreach (www.birminghamaidsoutreach.org) has a specific program focusing on Lesbian, Gay, Bisexual, Trans, and Queer (LGBTQ) people.

Mississippi

A Google search for Mississippi and HIV or AIDS yielded the Web site for the Mississippi State Department of Health (http://msdh.ms.gov/msdhsite/_static/14,0,150.html), which includes information on surveillance, epidemiology and research, education and policy, care and treatment, and public resources. There is an application for the Mississippi AIDS Drug Assistance Program on the site, as well as a list of contact persons for HIV/AIDS.

The programs listed on the site range from clinics specializing in the medical care of HIV infected persons to full service organizations that offer testing (conventional and/or rapid), counseling (includes support groups and one-on-one sessions), care and treatment (includes primary care, dental care, mental health care, etc.), legal services, and support services. Support services include drug purchases, transportation, childcare, emergency financial, housing (includes HOPWA), food, home care, respite care, and information dissemination (such as hotlines, electronic resources, print, etc.). Available programs and services can be searched by county and type of service. In addition there is a link for Your PSH (Personal Sexual Health), a free mobile app for Mississippi residents that gives users access to information and support for safe sexual health. The Mississippi GLBT Activism Society / Gay It Up! Mississippi links to specific programs for LGBTQ people. The Web site for Mississippi Center for Justice. This site includes information on employment, housing, and privacy rights for those living with HIV/AIDS.

New York

A Google search for New York and HIV or AIDS and programs yielded the New York State Living with HIV/AIDS site (<https://www.health.ny.gov/diseases/aids/general/resources/>), which contains a list of links broken down by topic: resource directories, family health care decision act, HIV uninsured care programs, child, family and others, Medicaid managed care, HIV special needs plans, and HIV and smoking. Under each topic it includes educational information, as well as introduction, policy, enrollment and contact information for HIV/AIDS services. There is an application for the New York AIDS Drug Assistance Program on the site.

These programs range from clinics specializing in the medical care for HIV infected individuals to full-service organizations that offer prevention education/risk reduction service, syringe exchange, opioid overdose prevention, STD screening, HIV testing, individual and group supportive counseling, case management, mental health, medical transportation, nutritional support, housing, and legal services. The services are also organized and provided by faith-based ministries, besides regular groups. LGBT Health and Human Services, and LGBT HIV/STD/hepatitis C Prevention Services, specifically addressing the needs of LGBTQ, are provided in all the regions of the state.

Texas

A Google search for Texas and HIV or AIDS yielded the Web site for the Texas Department of State Health Services (https://www.dshs.state.tx.us/hivstd/services/service_d.shtm). This site includes two main branches that deal with HIV/AIDS care: the Epidemiology and Surveillance Branch and the HIV/STD Prevention and Care Branch. The goals of these two branches are to provide HIV/STD education and information; collect, interpret, and distribute HIV data; give guidance and planning for HIV services; and provide medical supplies to prevent, manage, and treat HIV. This site also provides contact information for HIV programs organized by the program name, and information as to which programs accept patients regardless of immigration status.

The city of Austin has a Web site (<https://austintexas.gov/department/austinhiv>) that provides information for HIV education, testing, treatment, counseling, and a list of available HIV clinics and resources in Austin, specifically resources that provide assistance with medical care providers, medication, mental health, substance abuse services, case management, transportation, housing, food/nutrition, and employment. The Waterloo Counseling Center in Austin (<http://www.waterloocounseling.org/index.html>) offers transsexual/transgender specific support.

Southern California

A Google search for Southern California and (HIV or AIDS) yielded the Web sites of the California State Department of Public Health (<https://www.cdph.ca.gov/>) and of the California HIV/AIDS Service Referrals (<https://npin.cdc.gov/ca/>). The first site includes educational information, data and surveillance, resources, laws and regulations, as well as a list of links of HIV/AIDS services for various needs. The second site provides contact information of HIV/AIDS services in a selected region of the state (areas close to the address inputted). There is an application for the California AIDS Drug Assistance Program on both sites.

The services listed on the site range from clinics specializing in the medical care of HIV infected persons to full service organizations that provide prevention education, counseling, HIV testing (conventional and rapid), case management, support groups (HIV-positive or negative), faith-based HIV service, financial assistance, food, housing, legal services, medication adherence

education and counseling, partner notification, and transportation. Our search did not turn up any programs that focus on woman, senior citizens or LGBTQ. A group called HOPE publishes a California Healthcare Resource Guide for Undocumented Immigrants at http://www.hopeact.latinas.org/site/c.btJSL7NPJqL8H/b.8756551/k.DD38/ACA_and_the_Undocumented_Population_Resource_Guide.htm

Summary and Implications

Summary of observations

We identified 890 citations that address questions in the three areas of interest and have enrolled aging women who live with HIV/AIDS. Of these, only 37 (4 percent) studies reported results of interest among older women who live with HIV/AIDS or examined interactions between gender and older age that would allow extrapolation to this subgroup. An additional 494, 114, and 389 papers would have been eligible for the three areas of interest, had they stratified and reported the required information on women age 40 and over. This observation is not surprising, because the limited space of a published paper does not suffice for examining the many subgroups of interest. It does, however, confirm the prediction of the Key Informants that evidence would be sparse. It may also have implications for future research investments, in that, in addition to gathering new data to address research gaps, a funder might consider a meta-analysis of individual-patient-level data from existing studies.

While some of the 37 eligible studies focused on populations facing obvious challenges, such as immigrant women,⁵³ women who had suffered physical abuse,⁴⁷ transgender women,⁵⁵ and women recently released from prison,⁶⁰ more studies are needed in these subgroups. No study focused on women caring for dependents, including children and grandchildren, or those diagnosed in old age. Similarly no study focused on women who face less obvious challenges, such as women who have adequate, private health insurance compared to those without adequate insurance. Women with adequate insurance coverage may paradoxically access a narrower range of resources, because they are not as widely exposed to community-based resources and other peer and social support services. In sum, the existing evidence base does not include a substantial number of studies that pertain directly to women who are over 40 and live with HIV. We discuss the implications of this observation for future studies in the Next Steps section.

We identified eight generally small (of fewer than 200 participants) randomized trials that examined the impact of strategies for promoting healthy family and social relationships and healthier lifestyle (promoting medication adherence, smoking cessation, safer sexual behavior, and practices to prevent chronic disease). Most included psychosocial and health education components, but none included a comprehensive case-management-based approach that would also encompass medical, mental health, and sexually transmitted diseases prevention-specific components. Only a handful of nonrandomized studies evaluated the effectiveness of strategies for promoting care. We also identified eighteen studies of barriers to accessing care in general or specific services in particular (e.g. cancer screening), which most commonly examined barriers related to sociodemographic, psychosocial, and medical factors. A minority examined barriers related to cultural factors, criminal history, or mental health. Several studies identified system-level barriers to engaging with care, including transportation, scheduling, insurance referrals, financial issues, and practical challenges, such as navigating a hospital building. Finally, very few studies examined the overall impact of insurance on outcomes, or the impact of comorbidity on the management of HIV infection or its progression. Thus, although we did not analyze the findings of the aforementioned studies in all clinical areas, it is highly unlikely that the identified body of evidence is close to maturity.

Our Web-based survey yielded a sizeable number of testing, housing, medical and mental health, and social support resources in the largest cities, and much smaller numbers or even no resources in the median and smallest cities in the six states. This survey was done to provide a

high level summary of the number and density of resources that are registered. The fact that fewer resources exist in smaller-sized cities is expected. The relative dearth of resources in smaller cities is particularly problematic for the geographically larger states, because the closest large urban center may be many miles away. Furthermore, even in urban centers where a very large number of resources may be concentrated, transportation can be a major problem. Traveling even a few miles in a big city can be difficult especially when one does not have private means of transportation and public transportation options are not convenient or too expensive.

Indirectly, our Web-survey informs about how difficult it is for someone who is not intimately familiar with HIV care in a city or a state to obtain basic information, using only the Internet. Because the U.S. health system is not integrated, the exercise is revealing. It is possible to identify a list of facilities that are related to HIV care, and the states' Department of Health Websites provide information that one can use as a starting point. In general however, this information is not very detailed, and it is not entirely clear how often it is updated. One would have to proceed with personal communications with point persons in the various facilities, for example, to get a description of what they offer and how they operate, and what aspects of their care are specific to women older than 40, living with HIV/AIDS.

Limitations

We developed an evidence map approach to describe the amount and type of practically available evidence, but do not summarize findings of eligible studies. For feasibility, we did not consider research completed longer than 10 years ago (specifically, earlier than 01/01/2005), because older empirical data are less likely to be relevant to today's setting. While it is plausible that earlier studies are applicable, important questions are often addressed by more recent replication studies, in which case they would be represented in the evidence map. Further, the more recent literature is probably more relevant for informing the future research agenda. We decided not to search EMBASE or any other large, international general database, and may have missed some relevant studies. We believe that the added benefit of searching multiple targeted databases was more cost and time efficient and would yield more relevant studies than a second large general database search.⁸²

Because the main focus of the Technical Brief is to inform about the U.S. setting, we did not consider studies conducted exclusively in other countries. This is probably most defensible for empirical studies pertinent to the first two interest areas (impact of resources on outcomes, and impact of insurance), which deal with questions that are quite specific to the US health system. Arguably, empirical studies in the third area of interest (diagnosis and management of comorbid conditions and predictors of patient-centered outcomes) are applicable irrespective of whether a study is conducted in the U.S. or in another country with advanced healthcare. However, given the interests of the OWH, and limitations of time and resources, we focused on the U.S.

We excluded studies not reporting empirical data, such as theory expositions, modeling studies of the effects of policies, opinion pieces, and non-systematic reviews.

Next Steps

Research Needs

The evidence map identified only 37 studies that report information in the subgroup of aging women who live with HIV/AIDS, or report conducting any analyses to determine the influence

of sex and older age on outcomes. Despite the fact that these 37 studies report information for older women who live with HIV/AIDS, they do not represent a mature evidence base. These studies do not provide insights into approach to care that are specific to whether women have contracted HIV at early versus at an older age; have acute and chronic comorbidities, including substance abuse and mental health problems; have different ethnic or racial descent; have different levels of insurance, income, wealth, social support, educational attainment; care for dependents; are illegal immigrants, experience violence, or have a history of incarceration; or identify as members of the LBGQT community.

The evidence-base is even more sparse if one considers that the identified studies focused on different research questions. We identified few and small randomized trials and observational studies on strategies for engaging resources and promoting women's well-being, which cannot possibly cover the range of practically implementable interventions that can be examined. By their nature such interventions are complex, in that they have many versions, and their implementation and deployment can depend on the targeted population. Evaluating complex interventions is a very challenging task, and often requires subgroup analyses and analyses of effect modifiers. In turn these generally require large sample sizes and robust and detailed data collection. We did not identify any such studies.

More generally, when the range of questions of interest is so large, and the directly applicable evidence-base is so limited, most, if not all, questions can be characterized as under-researched, and consequently, it is difficult to prioritize them for future research. For example, it is not obvious which of the aforementioned population subgroups represent more pressing priorities, nor according to which criteria research priorities should be ranked. One may, however, make some general observations, which may help those who prioritize research portfolios. Our suggestions are about practical ways to enrich the evidence-base on the issue at hand, and on research prioritization methods. We do not explicitly prioritize specific subpopulations or specific research questions.

1. A large amount of data have already been collected on women who are over 40 years and live with HIV in the context of studies that enrolled broader populations, but have not been analyzed for the subgroup of older women. In this work we excluded 853 studies that ostensibly enrolled women who live with HIV/AIDS and are over 40 years old but provide no analysis that pertain directly to this subgroup. Substantial economy of resources can be had by conducting re-analyses of existing datasets, with a focus on older women who live with HIV/AIDS.
2. It is probably true that the most relevant data for informing the care of aging women who live in the U.S. with HIV are those collected in such women. However for some questions, it is possible that inferences about this population can be generalized from studies that included broader populations, including studies that have enrolled men and women, younger and older patients, people who live outside the U.S., or even from studies of patients who have other chronic or sexually transmitted diseases. A plausible approach would be to prioritize analyses of existing large studies to see whether and how inferences would change in subgroups defined by gender or age. For example, if the natural course or general management of a chronic disease were not particularly affected by gender in interaction analyses, data from all genders would be considered for high quality policy making. Identifying which inferences can be generalized from other populations is difficult, but can be informed by empirical analyses of existing studies, as discussed above in first point.

3. Observing the great successes of clinical research consortia that were formed to address medical questions, such as the AIDS Clinical Trials Group network, and the Women's Interagency Health Study we believe that encouraging analogous consortia for addressing questions related to health services research, barriers, social interventions, economics and other aspects of living and aging with HIV might be fruitful (for example, the AIDS Clinical Trials Group Network has surveyed physicians to identify barriers to providing care to people with HIV/AIDS⁸³). Such consortia naturally result in networks of researchers oriented towards a comprehensive approach to care, inclusive of case managers, nurses, social workers, psychologists, and other experts, which could be leveraged to conduct high impact research and also to overcome practical challenges (e.g., the network can be used to refer a patient who moves to a new city to appropriate contact persons and services).
4. Finally, with respect to research prioritization methods, we wish to bring attention to three families of approaches, which, to our knowledge, are not widely utilized in health and medicine to inform the planning of the future research agenda. We believe that these approaches could inform the deliberations of decisionmakers about which research to fund next.
 - a. The first draws from statistical decision theory and economics and pertains to analyses of the expected value of information that would be obtained through new research.^{84, 85} The added value of this approach is that it can provide a ranking on which sources of uncertainty appear to be more pressing, according to the decisionmakers' criteria.
 - b. The second relates to optimizing the future research agenda through the lens of portfolio selection theory, and draws from finance and operations research.⁸⁶⁻⁸⁸ This approach may help construct a research portfolio that is diverse, and strikes a balance between exploitation (addressing questions that are readily answerable with little effort, and are likely to have impact) and exploration (addressing questions that may have a large impact, but may be higher-risk).
 - c. The third pertains to multiple criteria decision making (MCDM), which is a theory for analyzing decisional problems (such as what research to fund next) that are subject to many, and potentially conflicting optimality criteria.^{89, 90} Implicit MCDM methods are already used in research prioritization exercises that are based on expert committees. However, a more formal application of MCDM principles may enhance the efficiency and clarity of current processes, and perhaps increase the likelihood of high quality decisions. MCDM approaches can be qualitative or quantitative (Multiple Criteria Decision Analysis).

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