Supportive Services for Women Living with HIV/AIDS: The Facts

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Introduction

Supportive services are fundamental to making health care work for women living with HIV/AIDS (WLWHA). WLWHA face unique challenges to accessing and staying in care. Often low income, WLWHA tend to be significantly burdened by childcare and other responsibilities that regularly distract from or limit access to medical care. Social services help stabilize low-income women living with or at risk of HIV by providing a safe home, sufficient food, necessary child care, transportation to and from appointments, and an advocate to assist with pressing legal or mental health needs. When these needs are met, women can tend to the details and routines of their own health and healthcare.

Because of the strong impact they have on maintenance in care and treatment and improved health outcomes, supportive services are elemental to achieving this country's HIV policy objectives. The National HIV/AIDS Strategy for the United States (NHAS), released in July 2010, set out three main goals: 1) reducing the number of people who become infected with HIV, 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related health disparities.[1] Supportive social services for women are instrumental in achieving precisely these three goals. These services reduce health disparities by addressing the unique barriers and challenges faced by women living with HIV/AIDS; increase access to care for women, improving adherence and optimizing health outcomes; and reduce new infections by decreasing infectiousness through retention in care and minimizing risk-taking behaviors. As women have become a larger proportion of those infected with HIV, investment in social services is essential to realizing the triple goals of the NHAS.

Women Living with HIV/AIDS

Endemic Barriers Hinder Care and Treatment for Women Living with HIV/AIDS

As the HIV epidemic in the United States increasingly impacts low-income individuals and people of color, the number of women living with HIV/AIDS has risen dramatically. Women represented a small minority of AIDS diagnoses in 1985 (8%), but this percentage more than doubled by 1995 (20%) and tripled by 2000 (27%), approximately where it remains today.[2] In the period between 1999 and 2003, new AIDS diagnoses among men rose only 1%, while diagnoses among women rose 15%.[3]

This growing number of WLWHA experience unique challenges related to care. Research indicates that women living with HIV have more difficulty accessing care than men.[4] One study of 2,864 PLWHA in the U.S. found that women were more likely than men to report needs competing with healthcare and that these competing needs strongly predicted high rates of hospitalization.[5]

WLWHA are also more likely then men to be poor. Nearly two-thirds of all women living with HIV and receiving medical care report annual incomes below $10,000 (64%), compared with 41% of men.[6] WLWHA are also less likely to be privately insured than men with HIV (14% of women compared to 36% of men), and they are more likely to be on Medicaid than men (61% of women compared to 39% of men).[7] Further, many WLWHA are caring not just for themselves, but also for others. In fact, 60% of women in HIV care have minor children, and 76% of those women have minors living with them (versus 18% and 34%, respectively, of men).[8]

Among women living with HIV and receiving medical care, nearly two-thirds report incomes below $10,000 a year, compared with 41% of men.[9]

HIV/AIDS related disparities are significant not only between men and women but also among women of different racial backgrounds. The well-documented relationships among HIV incidence, poverty and race that facilitate transmission, hinder treatment, and complicate outcomes are particularly marked among women of color. In 2009, the AIDS diagnosis rates for female racial minorities dwarfed those for White women. The diagnosis rate for Black women

compared with that for White women was 23:1, for women of multiple races it was 8:1, and for Latinas it was 5:1.[10]

The potent combination of poverty and family responsibilities raises endemic barriers to effective treatment for women living with HIV/AIDS. Research shows that lower socio-economic status contributes to decreased adherence to HIV therapy. This decreased adherence arises in large part from (1) financial constraints that limit ability to pay for transportation, child care, and other needed services, and (2) preoccupation with immediate concerns, such as poor or unstable housing. [11] The NHAS recognizes that "people with competing demands and challenges meeting their basic needs for housing, food, and child care often have problems staying in care."[12] Services for women must address both women's unique caregiving responsibilities and the additional financial pressures experienced by so many WLWHA in order for care, treatment, and prevention strategies to be effective.[13,14]

Social Services: Goals & Outcomes

Social Services Result in Beneficial Treatment and Public Health Outcomes

Recognizing that financial constraints and preoccupation with immediate needs present substantial barriers to accessing medical care, the NHAS underscores the fundamental role of social services in prevention strategies and encourages "policies to promote access to housing and supportive services … that enable people living with HIV to obtain and adhere to HIV treatment."[15]

Supportive services connect diagnosed individuals to care and help them remain in care and adhere to treatment regimens. Timely connection to and retention in medical care correlates both with better individual health outcomes for PLWHA and with better public health outcomes. Connection to care promotes adherence to treatment, a basic factor in the effectiveness of treatment, resulting in good health. Further, groundbreaking research has found that early and regular treatment virtually eliminated the risk of transmission between sero-discordant, couples.[16] Thus, adherence to treatment is an essential component of good health for PLWHA and their partners.

Studies have shown that adherence to HAART depends not only on regular access to medicine but also on regular visits to a clinic and regular interaction with a healthcare provider. One study of 423 patients receiving HAART between 1998 and 2004 found that the number of missed appointments and the number of days elapsed between each appointment strongly correlated with the occurrence of new AIDS-defining illnesses and death.[17] Additionally, patients receiving routine medical care are significantly less likely to engage in HIV risk behaviors.[18]

Interventions addressing pressures faced by people living with HIV/AIDS that promote compliance with HAART can extend life by 34.8 months.[19]

In light of the vital nature of adherence to HAART and retention in care to better health outcomes among PLWHA, the results of the research highlighted below are striking. Again and again, social services are shown to promote adherence to treatment and retention in care. Accordingly, supportive services are essential to management and prevention of HIV/AIDS in the U.S., but they are also particularly crucial for WLWHA who have a unique need for these services.

Housing

HIV and homelessness are intimately connected.

• Stable housing is the greatest unmet need of people living with HIV/AIDS.[20] At the same time, HIV prevalence among the homeless population is nearly nine times that of the general population.[21]

• Over 500,000 households in the United States with HIV/AIDS will require housing assistance at some point in their lives.[22]

• Homeless or marginally housed individuals are more likely to delay treatment, less likely to have regular access to care, less likely to receive optimal drug therapy, and less likely to adhere to their medication than are stably housed individuals—all of which increase the individual's viral load and decrease health outcomes.[23]

Housing services improve health outcomes.

• In a six-month longitudinal study of adherence to HAART (Highly Active Antiretroviral Treatment) regimens in New York City, residents in long-term housing were sixteen times more likely to report strong adherence to their treatment regimens than were unstably housed participants.[24]

• Persons with declining housing status are three times as likely to exchange sex for money or other needed goods, whereas persons with improving housing status reduce their risk behaviors by half.[25]

• Homeless or unstably housed persons are 3 to 6 times more likely to use hard drugs, share needles, or exchange sex than stably housed persons.[26]

• Women who are homeless are more likely to have been (and to continue to be) victims of abuse. In a study of HIV-infected adults, over 20% of women with HIV had experienced physical abuse since the time of their diagnosis.[27]

• Women who are homeless are more likely to use or abuse alcohol and illicit drugs—substance use can increase one's risk for HIV infection, either directly via IV drug use or indirectly by increasing risk-taking behavior.[28]

HIV prevalence among the homeless population is nearly nine times that of the general population.[6]

• Providing public funds for housing assistance has been demonstrated to be cost effective by "substantially reduc[ing] utilization of costly emergency and inpatient health care services"[29] – specifically demonstrated by two large-scale intervention studies.

• Savings in costly health care services greatly exceed the cost of housing assistance, making housing assistance programs an intervention that is both effective and cost-efficient.[30]

• Housing assistance has the potential to prevent future transmission of HIV, since providing individuals with housing assistance can reduce the prevalence of HIV risk behaviors and thereby reduce an individual's risk of contracting HIV.[31]

Case Management

Case management services are essential.

• Since HIV-positive women are disproportionately low-income,[32] managing their disease often includes confronting the challenges, stressors, and disruptions that accompany poverty—pressures that are significantly alleviated by case workers who can help a woman manage her illness.

Case management improves health outcomes.

• Case management can help patients overcome fears about treatment,[33] and increases the likelihood that recently diagnosed patients will seek medical treatment.[34] One study found that 78% of all PLWHA enrolled in case-management programs were linked to HIV medical care within 6 months of enrollment, a 30% increase over others.[35]

78% of all PLWHA enrolled in case-management programs were linked to HIV medical care within 6 months of enrollment, representing a 30% increase over those without case-management services.[19]

• Case management services positively influence the use of and adherence to antiretroviral therapy.[36,37] A 2006 study found that participants with consistent case management services were more than ten times likelier to demonstrate CD4 cell count improvements of 50% or more than people without such services.[38]

• Case management has the ability to improve service provision and treatment outcomes.[39]

• Case management facilitates the ability for clients to stay stably housed.[40]
• Case management attends to the needs of clients' families, which in turn affords women the time and energy to devote to their own care—often a secondary priority for HIV-positive women with families.[41]

Mental health needs are often present for WLWHA.

• Women with HIV experience far higher rates of poverty, homelessness, domestic violence and substance abuse than members of the general population[42]—and a positive diagnosis compounds and multiplies these stressors.[43]
• It is estimated that over half of HIV-positive women have at least one psychiatric condition; rates of post-traumatic stress disorder alone reach as high as 35%.[44]
• Psychosocial factors can have a significant impact on the progression of HIV,[45] and patients suffering from mental health disorders experience elevated rates of HIV-related morbidity and mortality.[46]
• HIV-positive individuals with mental health disorders have been found to have lower medication adherence and decreased use of medical care.[47]
• Half of women living with HIV/AIDS (WLWHA) have experienced sexual abuse,[48] which leads to major depression, anxiety, post-traumatic stress, and substance abuse.[49]

Mental health services reduce risk-taking and improve health outcomes.

• A 2004 study reports that women with a history of sexual violence who received services were 150% more likely to reduce risky sexual behaviors, and were more likely to adhere to their medication than women who did not receive services.[50]
• A 2007 study found that HIV-positive participants in mental health treatment programs experienced a decreased use of illicit drugs and alcohol, and improvements in mental health.[51]
• Mental health treatment programs are associated with potential cost-savings, including decreased emergency room visits, and inpatient hospital stays.[52]

Food

Adequate nutrition is essential for, but sometimes sacrificed by, WLWHA.

• Significant unintentional weight loss ("wasting") was identified by the CDC in 1987 as one of the defining conditions of HIV/AIDS.[53] Wasting leads to the loss of muscle mass, which inhibits normal activity,[54] and affects quality of life, health, and productivity.[55]
• HIV-positive individuals require roughly 10% more food energy than do their sero-negative counterparts;[56] individuals living with an AIDS diagnosis may experience food energy needs as much as 30% higher than others.[57]
• Weight loss can further weaken the immune system by depleting CD4 cells, which serve a crucial role in the body's overall immune response system.[58]
• More than 10% of female HIV patients report having foregone care to pay for basic necessities, while 7% report having gone without food or other basic necessities in order to pay for the cost of their medical treatment.[59]

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Food services are cost-effective and significantly improve outcomes.

• Nutrition services have the potential to be a cost-saving measure—in 2003 while the mean cost of in-home food delivery services was $1,507 per person per year, the average cost for a single day of hospital care for an individual with HIV/AIDS was $4,574.[60]
• Ensuring that women with HIV have access to quality food, receive regular nutritional counseling and maintain appropriate levels of physical activity can significantly reduce the

complications associated with wasting and malnutrition.[61]

Childcare and Mothering Concerns

Demands of childrearing are an impediment to self-care for WLWHA.

• In New York City, women head 79% of the households with children that receive HIV/AIDS Services Administration funds.[62]

Women are 70% more likely than men to delay care because of competing caregiver responsibilities.[48]

• In one study, 59% of women surveyed cited childcare responsibilities as an overwhelming barrier to accessing the medical and social services needed to maintain their HIV treatment programs.[63]

• Another study indicated that service providers perceive childcare to be the biggest barrier to the effective provision of HIV/AIDS support services to female clients.[64]

• Few HIV service centers are equipped to provide childcare or even to offer child-friendly scheduling.[65]

• Data analysis from the HIV Cost and Services Utilization Study demonstrate that women are 70% more likely than men to delay care because of competing caregiver responsibilities.[66]

Childcare Services Make Medical and Social Services Accessible for WLWHA

• HIV support services can help to address both the logistical and psychological burdens that HIV-positive mothers experience. Service centers that offer flexible hours and low-cost or free childcare services can minimize the barriers HIV-positive women face in accessing needed care and services.[67]

Transortation

Lack of transportation is a principal barrier to care.

• According to one study of PLWHA, more than one-third went without care or postponed care due to lack of transportation or another competing need.[68]

• A 2005 study in North Carolina found that both rural and urban HIV/AIDS case workers reported lack of accessible transportation to be a barrier to medication adherence for clients: 58% of rural case managers and 30% of urban case managers rated lack of transportation a "major problem."[69]

• Researchers studying appointment attendance at a community HIV clinic in Brooklyn, New York found that lack of transportation contributed to missed appointments.[70]

58% of rural HIV/AIDS case managers in North Carolina report that lack of transportation is a significant barrier for their clients' medication adherence.[51]

Legal Services

Legal problems are often a barrier to good health.

• The primacy of legal services for HIV has prompted the Centers for Disease Control to issue a recommendation that all individuals receiving a positive diagnosis for HIV/AIDS be immediately referred to legal services.[71]

• Legal providers are essential as a partner in care in myriad ways, including representation in discrimination cases, family law matters,[72] immigration status adjustments, and debtor-creditor issues. • Legal services routinely help people living with HIV/AIDS access the public benefits for which they are eligible, or dispute improper terminations or cuts in assistance.[73]

• Many HIV-positive women depend on Supplemental Security Income (SSI), Social Security Disability Income (SSD), or private insurance payments—legal services attorneys work to win eligibility for these benefits, and to fight wrongful recoupments, so that the fight for financial survival need not constantly interfere with medical treatment, and the optimization of health.[74]

Legal services improve health and safety outcomes, and are cost-effective.

• Ensuring access to legal services for individuals with significant medical needs has been shown to have significant benefits—one study of cancer patients demonstrated that legal services helped to reduce anxiety and stress, alleviated financial worries and improved financial conditions, and maintained treatment adherence.[75]

• Access to legal services was one of the most important factors in achieving a twenty-one percent decrease in the reported incidence of domestic violence in the United States from 1993 to 1998.[76]

• Providing such assistance is also cost-efficient—a New York State Department of Social Services study of a homelessness prevention program focused on legal services found that the program generated a return of four dollars for every dollar of public funds invested.[77]

• The services provided to clients by legal services can help reduce the need for public assistance—in 2003, Legal Aid of Nebraska obtained over one million dollars in child support awards on behalf of its clients, promoting women's self-sufficiency by reducing their need for state-supported funds and other aid.[78]

Conclusion and Recommendations

Women living with HIV/AIDS often balance competing responsibilities, caring for themselves while also caring for others. At the same time most women are making difficult choices about how to allocate precious, limited resources: time, money, and energy. Supportive services, including housing, case management, mental health care, food, childcare, transportation, and legal services make it possible for WLWHA to better attend to their own health while also attending to others. Additionally, supportive services help poor women to comply with complex medical regimens, despite the rigors of living in poverty. For women living with HIV/AIDS, there can be no effective medical care without supportive services.

Cuts to supportive services for PLWHA will be universally devastating, but they will especially hurt women and the children and others for whom they care. It is abundantly clear that supportive services improve health outcomes, which in turn saves money now and in the future. Preservation of these services is sound policy for the health of individuals, families, and the public.

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