
Medical, Social and Supportive Services for Older Adults with HIV

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Abstract

Older people living with HIV are increasingly requiring formal supportive community-based services. Supportive services are essential to medical care and treatment for older people living with HIV/AIDS. This chapter considers Andersen's behavioral model of health services, and explores the predisposing, enabling, and need factors that affect service utilization among the older HIV population. The Andersen model provides a lens to understand the need for supportive services to go beyond primary medical care. Examples of such services and referrals typically include medical and non-medical case management, clinical provider referrals, mental health and substance use treatment, housing assistance, legal services, nutrition, transportation, home care, emergency assistance, patient education support groups, and other programs such as the AIDS Drug Assistance Program and secondary prevention services. Barriers to assistance and support, and consequences and resources for caregivers are addressed. Aspects surrounding structural inequities, multiple-minority status, and HIV stigma are examined with the goal of offering insight and advocacy ideas for community-based providers and policy makers. In future, the healthcare and supportive services infrastructure must be better equipped to manage the distinctive treatment and care needs of HIV-positive older adults.

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Worldwide trends suggest a 'graying' of the HIV epidemic with an increasing proportion of people with HIV aged 50 years or older. This demographic shift is not limited to resource-rich settings: one 2014 study in sub-Saharan Africa reported the greatest number of people with HIV 50 years of age or older being enrolled in HIV programs to-date [1]. By 2020, more than 70% of Americans with HIV are expected to be age 50 and older [2]. Currently, life-saving treatment in the form of highly active antiretroviral therapy (HAART) has transformed HIV from a terminal illness it was decades ago into a chronic, albeit serious, condition, and dramatically increased life expectancy of older people with HIV (OPWH).

However, new challenges have accompanied this success. While we witness a burgeoning number of OPWH, this population also faces high levels of comorbidities portending greater caregiving needs as they grow older. But many OPWH lack sufficient informal social support resources, and it is not clear how existing informal and formal support mechanisms will be able to address the complex needs of this growing population in the future [3, 4]. To complicate further, older people living with HIV must also cope with normative age-related changes in physical functioning that are unrelated to HIV, and often diminished vitality, poor financial situations, and social role loss. These individuals also cope with ostracism, fear, and stigma that still accompany HIV [5], and the taboos around sexuality and older adults that still pervade society [6, 7].

This chapter examines formal, community-based services and their role in supporting aging individuals with HIV. Formal services are distinguished from informal social supports, in that the latter is typically obtained from the social network of family, friends, and neighbors, is voluntary, and for the most part, unpaid [8]. Informal caregivers perform tasks to help OPWH remain healthy and active in their communities through assisting with instrumental and personal activities of daily living, including help with medication, housekeeping (cooking, cleaning), providing rides or escorts to medical appointments, financial management, advice, and vital emotional support [9].

In contrast, formal supports include services provided by professionally trained paid employees, such as the personal care assistant who may help with bathing, or providers such as case managers. Formal caregivers include health professionals, behavioral health specialists, and social workers who are trained and compensated for their work. The trained volunteers associated with AIDS service organizations (ASOs), AIDS care teams, and hospice programs also fall into this category. In many cases, formal support is accessed when the needs of the older individual outstrip the ability of informal caregivers with regard to time, resources, or skills (e.g., nursing care) [8].

Both formal and informal supports play a role in the lives of OPWH, and both types matter. Formal and informal support networks often work in tandem, and both are needed to help an older person thrive and maintain their independence in the community [8]. Therefore, optimal supports for older adults occur when these 2 systems work together. For example, without a personal care assistant (formal support), an older client's informal caregiver (a partner or child) who has a job, may need to miss work or find a creative way to assist the OPWH in his/her care.

Using the Andersen Model to Understand Service Use among Older Adults with HIV

Andersen proposed a conceptual model to explain utilization of health services, which has been generalized to examine formal service use in a variety of domains [10, 11]. The Andersen model contains 3 sets of predictive factors: predisposing, enabling, and

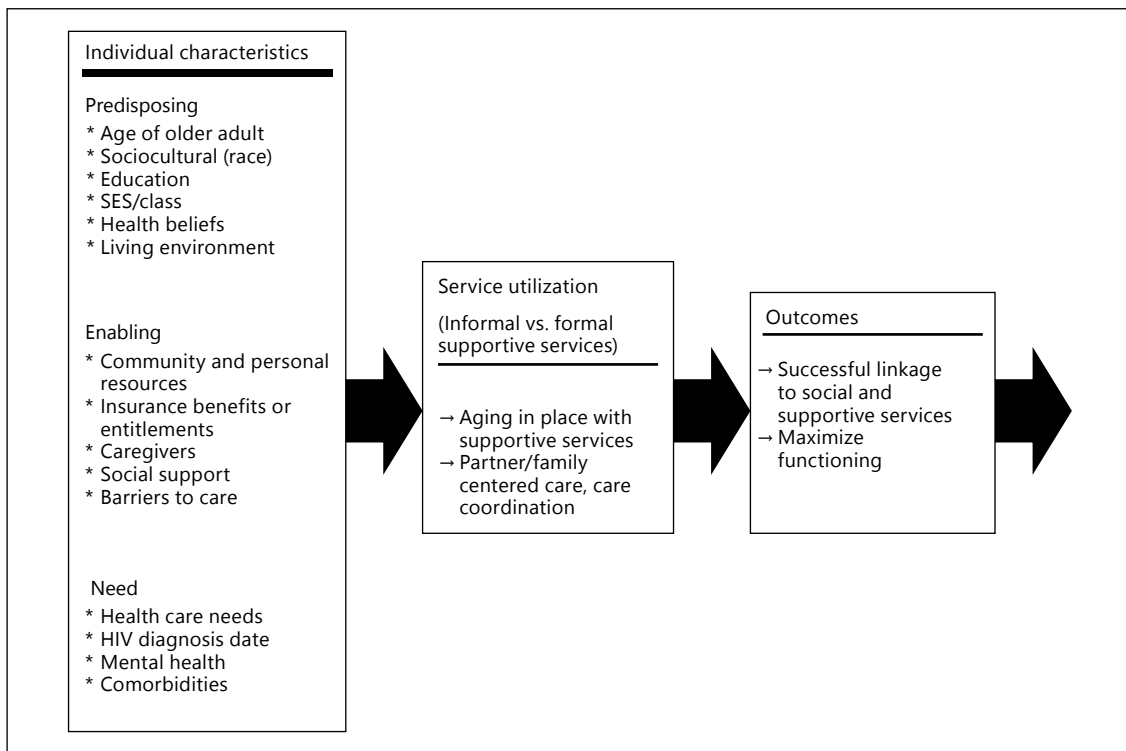


Fig. 1. Access to and use of supportive services among older adults living with HIV/AIDS (Andersen [10]).

need. Figure 1 portrays components of the Andersen model and envisions what formal service providers must consider to best help older people living with HIV/AIDS [3, 10]. When assessing and helping older people living with HIV/AIDS, these multiple individual characteristics require consideration.

Predisposing factors comprise demographic, social, and cultural characteristics, such as age, race/ethnicity, education level, class/socioeconomic status, health beliefs, and living environs (e.g., at home, in a long-term care or correctional setting, etc.). Such factors influence individuals to seek (or not seek) formal services to help them address their needs. Enabling factors are described by Andersen as one's community and personal resources (e.g., are they eligible for entitlements? who is the caregiver? how viable is their informal social network?), and barriers to care (e.g., lack of transportation) which can inhibit or promote service use. Need factors typically drive service utilization, such as health status (e.g., length of HIV and/or AIDS diagnosis, extent and severity of comorbidities), behavioral health needs (e.g., to what extent do co-occurring disorders exist, such as problem substance use, mental illness, etc.), and non-medical service needs (e.g., socialization, recreation, entitlement help). Applying the Andersen model to understand service utilization among OPWH, we will examine the predisposing, enabling, and need factors that characterize this population.

Predisposing Factors

Despite increasing rates of HIV among older people, this group continues to be unseen and marginalized in data collection, instruments, education and prevention programs, and treatment studies, to name a few. OPWH have been referred to as the 'overlooked epidemic', 'hidden population', and 'invisible epidemic' [12, 13]. Typically, older adult in the context of HIV infection is defined differently from the designation of old age in the general population. The Centers for Disease Control and Prevention (CDC) [14] categorizes older adults with HIV as being aged 50 or older. A person's life stage is always a consideration when providing supportive services due to changes in physiology, life circumstances, and emotional needs across the life span. Although the aging process for people with HIV is inadequately researched, OPWH on HAART can currently expect near-normal life expectancies [15]. However, their life stage may not always reflect their chronological age. OPWH may self-identify as older because they feel marginalized in society by age, as the US is extremely youth-oriented [16].

Many OPWH are members of historically disadvantaged groups, including gay/bisexual men and transgender women (GBT). Among those over 50 who are living with HIV, approximately 60% are GBT [14], sometimes referred to as men who have sex with men (MSM). As a group, lesbians have not manifested the same disproportionate rates of HIV infection as compared to other sexual and gender minorities, though it is important to note the historic role they have played in the epidemic with regard to advocacy and addressing the caregiving needs of those who are HIV positive. A subset of MSM does not embrace a gay or bisexual identity. Due to societal changes in attitudes and acceptance of homosexuality, it may be more common for older MSM to be married to or have been married to a woman than it is for younger MSM. Some MSM may seek sex in casual relationships or have dual lives, one as a married man and the other as a gay man [17].

Sexual and gender minorities tend to suffer from health disparities that result in higher levels of illness, disability, and premature death than observed in the general population [18]. In a large national US study of older lesbian, gay, bisexual and transgender (LGBT) adults, 50% had disability, 33% reported depression, and about 33% did not have a will or durable healthcare power of attorney [19]. Most research about the older gay and bisexual population has been conducted with Caucasians, thereby leaving critical gaps in provider's understanding, 'including potential models from communities in which the older LGBT population is well integrated' [20]. Thus, the literature on older gay/bisexual men along with transgender women remains underdeveloped, particularly for bisexual and transgender groups. Within this literature, diversity with regard to race/ethnicity, income and education is extremely under-researched, and the intersection of multiple disadvantaged and stigmatized identities among older LGBT individuals is not well understood. However, one study on service utilization among older HIV-infected adults found that sexual identity and gender were not strongly related to service utilization [3].

Little empirical research focuses on the service needs of older adults who are LGBT. These populations must often be creative in accessing supportive services and rely on chosen family (i.e., non-kin) rather than risk the possibility of being discriminated against by homophobic and transphobic service providers [3, 20–23]. Knochel et al. [20] found the lesbian and gay population to be incredibly invisible in both the gerontology literature and in the planning and provision of senior services. Mental health and substance use treatment utilization is low in this population [23].

Often providers fail to recognize and treat the person when they disclose their sexual orientation. Consequently, medical and social service providers may not fully understand the lifelong experiences of discrimination of these clients who came of age in an era of homophobia prior to the 1969 Stonewall Rebellion and the advent of the HIV/AIDS epidemic in the 1980s [20]. This lack of cultural competence on the part of service providers and clients' fear of discrimination often keeps individual caregivers, be it LGBT themselves or caring for LGBT people, from accessing services [22]. As a result, caregivers of older LGBTs may shoulder a greater amount of responsibility for a longer time than other caregivers [24].

Unfortunately, these negative life experiences of abuse and stigma have conditioned many OPWH who require supportive services to be mistrustful of mainstream institutions, including medical and social service providers. For example, treatment in long-term care and home health care settings is a major concern for older LGBT people due to unintended or unwanted disclosure of sexual orientation and/or gender identity to home health care workers, with concomitant fear of discrimination or retaliation [25]. Discrimination against LGBT older adults is well-documented; 13% of older LGBT adults had been denied healthcare or received inferior care and over 20% did not disclose their sexual or gender identities to their physician in one study [19].

According to the CDC, 40% of OPWH in the US are heterosexual cisgender men and women [14]. An egregious myth is to consider HIV to be a 'gay' disease that does not affect heterosexuals. However, heterosexual intercourse is now responsible for numerous transmissions worldwide. In particular, older Black men represent 68% of all heterosexually acquired HIV cases among US men in 2011 [14], and heterosexual transmission has become increasingly frequent since the start of the epidemic [26]. Financial challenges affect people aging with HIV, especially African Americans [27]. Many older adults may experience economic disparity; however, minorities, especially African American women, have disproportionately been affected by poverty and HIV [14, 28, 29].

Enabling Factors

According to Andersen [10, 11], enabling factors are those that can either facilitate or serve as barriers to service utilization. Many barriers to service utilization for OPWH are structural and arise from the composition and dynamics of the formal service sector. Barriers to assistance and supportive services in the US include inadequate funding and human resources, inappropriate policies, inadequate and unresponsive

services, poor service coordination, and negative attitudes, abuse, and stigma. People who require supportive services are usually more vulnerable than those who do not. OPWH have needs for which assistance and supportive services are not neatly packaged into what a single provider can offer.

Furthermore, many OPWH lack informal social support resources, which may facilitate greater reliance on formal, community-based services. Many OPWH, including heterosexuals, often rely on chosen families of lovers, friends, and acquaintances rather than their families of origin (i.e., blood relatives) similar to the social network dynamics observed in LGBT communities [30]. Reliance on chosen families has the potential to stir up challenging issues regarding legal recognition of decision-making by non-kin caregivers, such as power of attorney or healthcare proxies [31]. Research has characterized how the social networks of OPWH may be characterized as fragile, given the lack of family involvement, poor perceived availability and adequacy of social support, and high degrees of social isolation [32]. This network fragility can drive formal service use as described by Cantor's Hierarchical Compensatory Theory of Social Support. According to this theory, when older people need assistance they prefer kin, first turning to close family such as spouses and children [8, 33]. When close family are not available, more distant relatives, friends, and neighbors are engaged. When these latter supports are not available, formal services are accessed. Formal services may also be utilized when the capacity of informal caregivers exceeds the needs of the older adult, for example, when advanced medical care in the home is required [8].

HIV stigma can inhibit the use of formal services. Cahill and Valadez [34] have aptly noted how HIV-positive people aged 50 years or older are typically more socially isolated than their younger counterparts. This isolation typically occurs because they may still be trying to conceal their HIV status, or they have sustained relentless social stigma associated with AIDS. HIV stigma, which refers to discrediting and discrimination directed towards people thought to have HIV, is a complicated process. Emler's 2006 qualitative study used 25 in-depth interviews, to examine whether OPWH experienced both ageism and HIV stigma [35]. He discovered that 68% of respondents did experience both; however, the experiences were often distinct. Nine themes emerged from Emler's study; interviewees reported experiencing rejection, stereotyping, fear of contagion, violations of confidentiality, and internalized ageism.

Whether an older adult has contracted HIV from sexual activity or injection drug use [36, 37], both modes of transmission are laced with stigma and may alter one's access to supportive services. Unfortunately, because of the ongoing misperception that HIV is a gay disease, people who are homophobic perpetuate stigma and discriminate against people. OPWH are affected differentially by stigma, depending on their sexual orientation, gender, and social networks. In reality, older adults who live with HIV may experience multiple stigmatizing attributes [34]. Newly diagnosed/infected people, even older people, are more likely to report feelings of stigma and 'blame' for their disease, and need help to adjust their medication regimen.

Because medical, social, and supportive service providers have not received adequate training, they may continue to be ageist and stigmatize the LGBT community [38], which presents barriers to OPWH who are sexual minorities. Fredriksen-Goldsen and Muraco [18] studied aging in non-heterosexual populations and found that predictors of poor mental health included experiences of discrimination by healthcare providers, loneliness, living alone, low self-esteem, internalized homophobia, and being victimized because of either their sexual orientation or gender identity/expression. Jessup and Dibble emphasize how the intersection of ageism and heterosexism is causing sexual minority elders to have ‘fewer resources in the community and within healthcare systems for prevention, earlier diagnosis and assessment and treatment, thereby keeping them from accessing or seeking help’ [23].

The problem of HIV stigma goes beyond those identified as gay or bisexual; all OPWH may face stigma-related lack of access to testing, treatment, and care. Due to HIV stigma, heterosexuals may be challenged to access supportive services simply because an HIV diagnosis can associate them with homosexual and/or drug use behaviors. As a result, medical, social, and supportive care services go unaddressed. Examples of ‘unattended to needs’ include mental health services for depression, anxiety or substance use, unstable housing, food insecurity, lack of economic and employment opportunities, assistive living, home healthcare, and so on [39–43]. Older heterosexuals, including those who are injection drug users, experience a high degree of HIV stigma and ageism. Consequently, this group may perceive less social support, and feel less in control of their life circumstances.

Need Factors

OPWH present with myriad needs, and seek community-based services to meet those needs [3]. The older adult population with HIV has a median age of 58 years, a chronological age that does not reflect the functional age of this population. Older adults with HIV are developing clinical symptoms of multimorbidity, namely multiple comorbid conditions, occurring 15–20 years earlier than expected [44–54]. A 2015 study of older adults with HIV details a spectrum of geriatric syndromes found in a sample whose average age was 57 [55]. In fact, the number of reports finding the typically geriatric-associated syndrome of frailty in HIV patients in their 5th and 6th decades of life is increasing [56–64]. Thus, the functional age of this older adult population is at least 20–25 years greater than their chronological age.

The mental and physical health of older adults with multiple minority status are affected by psychiatric symptoms and structural inequities in systems that find it continually easy to stigmatize and scapegoat those with HIV [60]. Thus, it is not surprising that OPWH are not typical of the aging population without HIV. Rates of depression are up to 5 times higher in OPWH compared to the general population [65], and OPWH evidence higher rates of suicidal ideation that contribute to reduced health outcomes. Rates of substance use are also increasing in the over 50 population, thereby highlighting the need for provider’s attention to mental and physical health

outcomes that require supportive services [23]. As they age, many OPWH use alcohol, tobacco, and other substances often as a self-medication strategy, further compromising their health [32]. They report difficulties with tasks of daily living, including housekeeping, transportation, meal preparation, employment, finances, and accessing entitlements [3]. Given their lack of informal social resources and social isolation, it is not surprising that the greatest reported services need among OPWH is opportunities for socialization [3]. Consequently, the provision of medical, social, and supportive services is essential for ensuring a decent quality of life for OPWH. If individual characteristics and service utilization aspects are understood, then the expected outcome for the older person living with HIV/AIDS would be that they would be successfully linked to medical and social/supportive services, and have the resources to maximize their physical and emotional functioning.

Medical and Social Supportive Services for OPWH

The preceding review of the predisposing, enabling, and need factors that characterize the burgeoning population of OPWH underscores the importance of providing needed supportive services that span the bio-psycho-social spectrum of care. One can roughly divide service providers into those addressing medical and health-care needs and those characterized as social services. However, in reality, these services exist on a continuum and may address multifaceted and overlapping needs. For example, in some instances ASOs may provide clinical medical services and social services at the same site. As another example, HIV case management programs may provide referrals for housing or employment opportunities to address social needs, but these may be in service of addressing medical needs such as strengthening care engagement and adherence to HAART [66]. Geriatric and gerontological care models and principles provide a valuable perspective on the service delivery system for OPWH as they emphasize considering the client in their environment with the goal of maximizing function through leveraging available personal and social resources [67]. Innovation is required on the part of providers, and segregated service settings may not be conducive to optimal client outcomes. Person-centered services, as prescribed by geriatric care models, can be very beneficial by allowing OPWH to be involved in decision-making and choose among supportive services they receive.

Medical assistance and social supportive services are complex because they are provided by diverse sources, funded in different ways, and delivered in many different locations. The cost of formal care and supportive services may be met with increased state and national government funding, insurance, charitable or voluntary sector, or through out-of-pocket payment from clients. Most likely, a combination of funding methods will be required to meet a growing demand for services in light of flat or reduced government support.

Table 1. Examples of formal supportive services for older people living with HIV/AIDS

Support services for old (50–64), old-old (65–84) and oldest-old (≥85) HIV-infected people are varied:

Home care

Aging in place with caregivers (family, friends, neighbors; informal support)

Aging in place with formal home healthcare

Teletherapies (supportive-expressive or coping group)

Medical/long-term care

Continuing care communities and assisted living

Intermediate care facilities (ICF level of care or assisted living)

Skilled nursing facilities (SNF level of care – long-term care)

Examples of community-based care

Adult day healthcare (ADHC)

Family-based services (FBS)

Job training program (JTP)

Legal advocacy services

Outreach to homeless

Prevention program for sex workers (e.g., project voice: housingworks.org HEAL)

Health library

Needle exchange and overdose prevention program

Mental health and substance abuse counseling (e.g., MALE center, Boston MA – for gay/bisexual men – aac.org)

Peer support – delivered by PLWH, provides individual and group support programs to reduce isolation and improve client's ability to manage their health.

Rental and utility assistance – deliver short-term emergency assistance to PLWH who face eviction, unaffordable housing, and high utility bills.

HOPWA

Volunteer-based support services: grocery shopping and small errands assistance; respite care

Computer assistance; friendly visits; reassurance phone calls; minor home repairs; meals on wheels; discounted/access to medical alert devices; education, training and support groups; transportation.

Dental care assistance

Insurance continuation assistance program

HRSA part B support services – Ryan White Care Act

Faith-based organizations or pastoral care services

Types of medical care and social/supportive services are depicted in table 1 with examples of existing formal supportive services available to OPWH. If OPWH have medical and/or social service needs, an array of programs may be accessed whether the older person resides in their own home, in a continuing care or assisted living community, or in a residential long-term care setting.

Medical and Healthcare-Related Supportive Services

Medical supportive services in this chapter refer to formal services that come from paid healthcare providers and social service providers (e.g., medical case management) that are embedded in medical care organizations.

The changing demographics of the HIV epidemic, along with the growing complexity of medical care, have created major challenges for healthcare professionals who provide curative and palliative care. For people receiving medical care services, decisions must still be made about when to start HAART, which drug combinations

to use, and how to manage viral resistance and drug-specific toxicities. Therapeutic regimens often must be modified for people who are homeless and those with comorbidities, such as mental illness and chemical dependence [39, 40]. Early intervention services are available in many regions. The goal of such programs is to keep HIV-positive men and women healthier for longer periods. Physicians, knowledgeable in the latest HIV treatment guidelines, provide specialty appointments in infectious disease clinics.

Government-sponsored service delivery has traditionally focused on institutional care, such as hospitals or skilled nursing facilities (nursing homes) that are reimbursed through Medicaid and/or Medicare. Governments have also provided community-based services such as home healthcare or adult day care. As HIV-infected people age, the need for personal assistance services appears to be increasing. Paid personal care, for example, has traditionally and predominantly been provided by women, and often older women of low social status [68]. Little research has explored to what extent OPWH, many of whom cope with inadequate incomes, are receptive to caregivers who are themselves financially disadvantaged. When remaining at home is no longer an option due to complex health needs such as frailty, institutional-based care may be accessed, including palliative and/or hospice care.

In addition to physical healthcare needs, behavioral healthcare to address mental health issues are also provided by this sector. To manage physical limitations, grief from loss, and legal or financial difficulties, counseling and psychotherapeutic services may be helpful to OPWH. Some HIV-infected people may frequently experience depression or problematic substance use, but may be unable to access supportive services to manage these challenges [69]. Given the high rates of mental distress reported by OPWH [65], this is one arena where provider innovation is essential. Some innovations developed to-date involve the mechanism for delivering services. Research has been conducted on the utility of telephone-administered supportive-expressive group therapy or coping effectiveness training to reduce depressive symptoms in HIV-infected older adults [70]. Heckman et al. [70] noted how HIV-infected older adults have complex medical and mental health needs, tend to be diagnosed later in the course of their HIV disease, experience greater cognitive dysfunction, have lower CD4 cell counts and higher viral loads, and survive for shorter periods of time after progressing to AIDS. Because the same OPWH have comorbid health conditions and significant concerns about confidentiality or are geographically isolated from traditional mental health resources, teletherapy, especially supportive, expressive group therapy, may be much more practical than face-to-face interventions and may help to lessen depression, psychiatric symptoms (e.g., anxiety, hostility, somatization), and to decrease unprotected intercourse and increase immune function [70].

OPWH and their families often require care services that can be coordinated by medical case management, community-based medical care management, and nursing care management services [3]. Medical social workers assist people with HIV by addressing their most immediate needs and connecting them with ongoing case

management services. Public health nurses and medical social workers team up to provide care management services to people with severely disabling HIV or AIDS, and their goal is to help clients remain independent and at home as long as safely possible. Basically, the healthcare team coordinates services including medical care, treatment adherence, attendant care, nutritional care, nutritional counseling, mental health, substance use treatment and home delivered meals. Clinic-based services may also include counseling, education and prevention services, and assistance with partner counseling, medication adherence counseling, and AIDS Drug Assistance Program (ADAP) certification.

Medical case managers provide support to people with HIV whose health status does not require the services of a nurse case manager. Also, medical case managers frequently collaborate with physicians and other providers to encourage adherence to the medical treatment plan. Services in the medical sector often target keeping the OPWH connected to the healthcare system. Medical social workers, outreach workers, nurses and healthcare navigators work as a team to support HIV patients in making and keeping appointments, understanding their medications and accessing necessary clinical and support services [32, 71]. Insofar as outreach and linkage to care, outreach and support services are available in some communities to support clients who are out-of-care. Outreach referrals are made for people who have broken medical appointments, are missing labs, or who need medication adherence support. Outreach is also provided to HIV-positive people who have never been connected to care. Outreach activities include home visits, phone calls, collateral contacts, case conferencing, and so on to locate clients.

These types of supportive services are absolutely essential to assure that healthcare works for people living with HIV/AIDS. The National HIV/AIDS Strategy for the United States (NHAS) released in July 2010, established 3 goals, thereby recognizing the healthcare needs of HIV-infected people. The goals are to: (1) reduce the number of people who become infected with HIV; (2) increase access to care and optimize health outcomes for people living with HIV; and (3) reduce HIV-related health disparities. Supportive services are instrumental in achieving these goals [72].

OPWH with limited financial resources may need to access entitlement programs to meet their medical care needs, such as ADAP. ADAP pays for the often costly medications needed to treat HIV. To be eligible for ADAP, a person must be HIV positive, a resident of a particular state, and be over 18, have limited or no prescription drug benefits, and meet financial eligibility requirements. ADAP is a carve-out of the Ryan White CARE Act that provides millions of dollars for HIV medications for people who are uninsured. More than 70% of Ryan White HIV/AIDS program clients are people of color and in 2010, 39% of Ryan White HIV/AIDS Programs clients were MSM [2].

Because each state government administers its own ADAP program, there are many variations [73]: (1) eligibility criteria for program participation varies from 125 to 500% of the federal poverty level; (2) the types of drugs covered varies, with some

states having formularies that cover HAART medications only, while others have an open formulary covering any medication required by someone who is eligible for ADAP (e.g., cholesterol medications, mental health drugs, hepatitis treatments, etc.); (3) states vary in their requirement of co-pays for prescriptions; and (4) states differ in administration and distribution models, based on geography and demand for services. Historically, up to 9,000 people have been on ADAP waiting lists for life sustaining medications, and the ADAP Advocacy Association and other groups have pressured the US Congress to address this issue [74].

Some states offer health insurance premium payment programs that pay the monthly health insurance premiums for eligible residents with an HIV/AIDS diagnosis. These programs may be available to people with health insurance who are at risk of losing it, and to people currently without health insurance who would like to buy it. In these instances, medical social workers and other helping professionals can help clients with the application process and submit the completed application to the proper place. People who do not have private insurance can oftentimes call healthcare provider lines for free health advice or go to urgent care providers. However, those in rural areas may still have difficulties locating needed services. The Affordable Care Act (ACA) has expanded health coverage for millions of people nationwide, including OPWH, by eliminating insurance exclusions for pre-existing conditions such as HIV and expanding Medicaid eligibility for those with low incomes. The ACA offers protections such as not having being charged higher premiums because of an HIV diagnosis. People with HIV rely heavily on Medicaid – much more than the general population, ‘due to high disability rates, multiple chronic conditions, and the low-income realities that qualify many people with HIV for Medicaid’ [2]. Unfortunately, not all 50 states have expanded Medicaid under ACA.

Social Supportive Services

Social supportive services in this chapter will refer to assistance coming from non-medical providers that are frequently provided through governmental agencies or community-based organizations. Social and supportive services are numerous and address the needs of OPWH. Such services include transportation, support groups, nutritional support (prepared meals, food vouchers, and food pantries), recreational activities, socialization, personal hygiene assistance, harm reduction, mental health and substance use treatment, educational workshops, emergency cash assistance, financial and entitlement assistance, alternative therapies, housing services, budget management, legal services, HIV prevention and education, and so on. Therefore, when it comes to assessing the needs of HIV-infected older adults, helping professionals require knowledge of a person’s bio-psycho-social well-being and supportive and social services that exist in a given community.

These services often supplement or supplant assistance from informal caregivers who provide emotional and practical support to friends and relatives living with HIV in line with Cantor’s Hierarchical Compensatory Model [33]. For many OPWH, this

type of non-medical assistance and supportive services are essential for maintaining social participation and remaining independent in the community. The lack of necessary support services can place extraordinary demands on primary informal caregivers (spouse/partners or family members) and can prevent both the OPWH and their informal helpers from becoming economically productive and socially involved. Globally, OPWH have significant unmet needs for supportive services, yet multiple policy and service gaps exist in low resource settings. Realistically, no one model of supportive services will work in all instances and meet everyone's needs and such assistance needs to be tailored to the specific context of OPWH.

Brennan-Ing et al. [3] examined service utilization among OPWH in New York City, a high resource setting that offers a wide variety of social services. This study classified supportive services into 4 main groups: (1) government agencies and programs; (2) HIV/AIDS programs; (3) health and long-term care services; and (4) senior services. Government agencies included offices for federal entitlement programs (e.g., Social Security, Medicaid) and city government agencies (New York City Housing Authority, Police Department). HIV/AIDS services comprised of entities such as ASOs, HIV Day Programs, the New York City Department of HIV/AIDS services, and non-medical case management. The last group of senior services included senior centers, nutritional support, and legal advice. Given the high level of need factors affecting OPWH, it is not surprising that they use a high volume of services. Brennan-Ing et al. [3] found that OPWH used 3 times as many non-HIV services on average as compared to community-dwelling older adults aged 65 and older.

The health and long-term care services domain has considerable overlap with the medical supportive services previously discussed. However, some services in this domain are provided by non-medical providers, for example, social work counseling. There can also be considerable overlap in the types of services provided in this sector. For example, mental health services such as counseling may be provided by general social service agencies, ASOs, or even faith-based settings. While multiple service venues are not necessarily undesirable, as they allow for multiple points of entry into the social service system, they do point to a need for service coordination and referral, as articulated in care coordination models.

One point of coordination and referral in the existing system are non-medical case management services provided through programs such as the Ryan White CARE Act. Case management has been called a metaservice that increases access to all manner of community-based service providers [75], and has been identified as a critical positive enabling factor with regard to service utilization among OPWH [3, 66]. Case management for those with HIV is largely focused on promoting medical care engagement and HAART adherence, by helping clients to navigate social services and facilitating resources, such as housing or mental healthcare, that support engagement and adherence goals [66]. Case management requires nonjudgmental assessments, thoughtful care plans and effective advocacy and monitoring on the part of case managers. When fragile social networks are evident, referrals to social services may be

required. Referrals may also include clinical provider referrals, mental health and substance use treatment, housing assistance, legal services, food, transportation, home care, emergency assistance, patient education support groups, and other programs such as ADAP and prevention services. One study found that clients who received comprehensive case management evidenced significantly greater care engagement, and achieved parity in average CD4 T-cell counts with a non-case management comparator group [66].

One area where care coordination is problematic is between HIV/AIDS and senior service sectors who have not historically shared clients and are just beginning to develop collaborative relationships [76]. There are cultural barriers between these 2 service sectors. HIV services developed in a culture of activism and militant politics that was evidenced by groups such as Act Up [77], a results-oriented worldview that was fostered in the early days of the AIDS crisis. In contrast, the culture of senior service providers reflects many of the values of social work, with an emphasis on process, human dignity, and social justice [78]. Thus, the first step in coordinating services for OPWH is to have both HIV and senior service providers being able to communicate and work together effectively. A second barrier is the age of the 'older' person with HIV. At present, the vast majority of this population (75%) is 59 years or younger [14]. However, to be eligible for senior services funded through the Older Americans Act (e.g., senior center meals), clients must be aged 60 or older [79]. Thus, a large sector of senior services is presently unavailable to most OPWH due to this age restriction, although they present with many of the same service needs as those in older cohort of 60 years and above. While tying senior program eligibility requirements to chronological age seems objectively fair and simplifies intake, it fails to recognize that age in and of itself is not the best determinant of service needs and artificially proscribes valuable services from a population who would benefit by being able to access a variety of senior services.

Conclusions and Future Directions

Growth in the population of OPWH, and their rates of disability influence supply and demand for medical and supportive services from the formal sector. Such supply and demand is also influenced by informal network composition, such as changes in family structure and friend-centered networks, and how such changes impact the ability of informal network members to be available, willing, and competent to provide the level of caregiving and assistance needed. The aging of OPWH, and their friends and family members, point to a greatly increased demand for supportive services provided through government or community sources. As the number of OPWH continues to increase in the US and worldwide, it is uncertain if existing supportive resources will be able to cope with this demographic shift in the HIV epidemic. However, given the prevalence of multimorbidity and numerous service needs, supportive services of

all types will be needed, and the capacity of the system to provide such services must increase. While the current focus on preventing and curing HIV is essential to ending this epidemic, advocacy, policy and program planners must better address the needs for care in an aging HIV population, in a variety of high- and low-resource settings.

To best help OPWH gain access to these services, formal and informal caregivers must be skilled in negotiating and navigating formal supportive services and systems, modeling a person-centered perspective, and maintaining effective communication. Care managers and providers can best help OPWH when they exhibit the qualities of an affirming attitude, authenticity, integrity and honesty, a nonjudgmental attitude, and patience. Providers should also work to educate, inform, and empower the OPWH to become an active advocate and agent for their own service needs, for without the voice of the client in care decisions and planning, we are unlikely to provide the support necessary to promote healthy aging in this population.

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