

**Aging With HIV:
Allegheny County's Assisted Living Facilities Preparedness for HIV-Positive Older Adults**

by

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Abstract

HIV is no longer a death sentence, but a chronic illness that can be maintained over decades. An HIV-positive individual can live into his or her 60's and 70's. Currently, over 50% of people living with HIV (PLWH) are over the age of 50. As a result, there will be an imminent influx of HIV-positive individuals entering long-term care facilities that are not prepared to care for their unique needs. Aging with HIV is linked with co-morbidities such as multiple chronic conditions and concurrent viral infections, substance abuse, mental health concerns, and polypharmacology. This qualitative study reached out to 57 long-term care facilities in Allegheny County, Pennsylvania, to assess their level of readiness in appropriately caring for HIV-positive older adults. No respondent (n=9) felt that training their staff in caring for PLWH was extremely important, though many wished that their staff did know best practices in the HIV field. Furthermore, long-term care facilities in the county are not very familiar with local HIV training, healthcare, and referral organizations. Overall, more research needs to be conducted to conclude if long-term care facilities in Allegheny County are adequately prepared to care the imminent influx of HIV-positive residents. It is of great public health importance that long-term care facilities be prepared to care for HIV-positive older adults.

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1.0 Literature Review

1.1 Introduction

In the two decades since the creation of medical intervention, HIV has progressed from a terminal disease to a manageable chronic illness (Chambers et al., 2014). In 1996 highly active antiretroviral therapy (HAART) was released on the American pharmaceuticals market. Before then, HIV was a death sentence, with no medication to keep the virus in the body in check. As a result of HAART, people are aging with HIV in a way that we have never seen before. Researchers have known for years that by 2015, more than 50% of people living with HIV (PLWH) would be over 50 years old, and some estimates say that by 2030 nearly 75% of PLWH will be over 50 (Chambers et al., 2014; Friedman & Duffus, 2016; Moore et al., 2018; Singh, Del Carmen, Freeman, Glesby, & Siegler, 2017; Ware et al., 2018) (Figure 1). Furthermore, “approximately 10 per cent of individuals infected with HIV are considered to be older adults” in the United States, and that number continues to grow (Lane, Hirst, & Reed, 2013, p. 56). As a result, researchers are fighting to quickly understand the unique needs that older HIV-positive adults have so that they can treat PLWH using evidence-based methods.

Overall trends show that aging with HIV is linked with co-morbidities such as “multiple chronic conditions, numerous treatments, concurrent viral infections, substance abuse, mental health concerns, and polypharmacology” (Chambers et al., 2014, p. 662). However, there is very little research regarding HIV-positive older adults entering skilled nursing facilities, independent living facilities, or receiving home-based care. It’s unknown if these facilities are prepared for the imminent influx of HIV-positive older adults.

Research on older HIV-positive populations is in the beginning stages (Chambers et al., 2014). Much of the current research focuses on the physical health of PLWH as they age, with very little focus on the policies and practices at long-term care facilities that care for this population. Learning about the lived experiences of HIV-positive adults would be beneficial to educating staff at these facilities, such as nursing homes.

This thesis has two goals: first to identify the main health issues facing HIV-positive adults over the age of 50, and then to assess the number of long-term care facilities in Allegheny County that have healthcare staff educated on the health effects of aging with HIV and are prepared to care for older HIV-positive adults.

According to 55 Pa. Code § 2800.65¹ and 55 Pa. Code § 2600.65² in the *Pennsylvania Code*³, assisted living residences and personal care homes in the Commonwealth are not required to educate staff about caring for people living with HIV/AIDS (Commonwealth of Pennsylvania, 2018). The regulations merely state that direct care staff persons must be trained in the “care and needs of residents with special emphasis on the residents being served in the residence.” 55 Pa. Code § 2600.65 states nearly the exact same requirement, substituting “home” for “residence.” The phrasing of this statute allows for a loophole: staff members are not required to have HIV training prior to an HIV-positive individual moving into the facility. Furthermore, there is no central database that collects information regarding the HIV education that long-term care facilities require of their healthcare staff.

¹ “Staff orientation and direct care staff person training and orientation” in an assisted living residence

² “Direct care staff person training and orientation” in a personal care home

³ Last updated 1 December 2018

The only HIV training required of assisted living residences and personal care homes in Pennsylvania is universal precautions. State code requires that only administrators and initial direct care staff receive this training. Universal precautions is the practice of avoiding a person's bodily fluids by utilizing gloves, goggles, and face masks made of nonporous materials. It is meant to protect staff from coming into contact with bloodborne pathogens and microorganisms, such as HIV.

There is an unfortunate dearth of information regarding the readiness of nursing homes, independent living facilities, and home-based care organizations to adequately care for this population. However, knowing what affects older people with HIV will help policymakers, healthcare organizations, and long-term care facilities in creating appropriate policies and programming for these facilities. It's important that we take the information researchers have published and use it as a means of implementing evidence-based interventions to better the health outcomes of older adults living with HIV.

Peer review academic journal articles were examined to learn what are the biggest health problems facing HIV-positive older adults. The following literature review provides a brief overview of the consensus of current research on HIV and aging. There are no major disagreements regarding the health issues that this population faces, and new research continues to reinforce and review past research. Within their published research, very few researchers consider what their research might mean for long-term care facilities.

Thanks to current medicines on the market, PLWH are living longer than ever. It's imperative that we understand their unique health needs as they age so that we can provide evidence-based interventions for this population as they enter care facilities and begin receiving home-based care.

1.2 Life Expectancy

Advances in HIV treatment has extended the longevity of life for PLWH, resulting in a growing number of HIV-positive individuals living into their 60s and older (Chambers et al., 2014). In America and Canada, a 20-year old HIV-positive adult who is on Antiretroviral therapy (ART) is expected to live into his or her early 70's (Allavena et al., 2018). However, there is a large discrepancy in life expectancy between certain HIV-positive population sub-groups depending on sex, race, and lifestyle (which can include diet, exercise, and drug use). The “graying” of HIV means that we need to adapt our treatment of HIV-positive people to consider what happens to their bodies as they age. This is a concern because there are physical, mental, and psychosocial health issues that are linked with HIV and aging (Allavena et al., 2018).

Aging itself comes with unique health issues that affect the mind and body. When an aging person also has HIV, the health effects from both can create a “synergistic effect,” which can ultimately lead to changes “in T cell functioning, increased immunosuppression, diminished functional performance, muscle loss and a decrease in bone density” (Allavena et al., 2018). If social workers, doctors, nurses, and carers of elderly HIV-positive patients are unaware of the role HIV and old age together have on the body, they will be unable to provide the best care for their patients.

1.3 Cognitive Aging

A study published in 2018 outlined the ways in which aging with HIV can impact successful cognitive aging (SCA) in a way that HIV-negative persons don't experience (Moore et al., 2018). This cross-sectional study served as preliminary data for a longitudinal study that is currently being conducted. It focused on HIV-positive and HIV-negative community-dwelling individuals aged 50 and over in San Diego County, California, comparing successful cognitive aging between the two groups and determining "associations with positive psychological factors and health-related quality of life (HRQoL)⁴." The researchers discovered that HIV-associated neurocognitive disorders (HAND) were observed in just over half of those who were HIV-positive, with this population being at a three-times risk of HAND compared to their younger counterparts.

This population also faces more psychosocial challenges, such as social isolation and stigmatization, than their HIV-negative counterparts (Johnson Shen et al., 2019) (Siegler & Brennan-Ing, 2017). Many of these social networks are informal, and as a result are fragile and often incapable of meeting the caregiving and support needs a person living with HIV might have (Siegler & Brennan-Ing, 2017). It's important to combat this social isolation by creating communities of HIV-positive older adults and educating their caretakers so that the burden of knowing this information does not fall exclusively on the HIV-positive individual.

⁴ The Office of Disease Prevention and Health Promotion define Health-Related Quality of Life (HRQoL) as a multi-dimensional concept that looks at a person's perceived and actual physical, mental, emotional, and social functioning. Clinicians and public health officials use HRQoL to measure the effects of chronic illness, treatments, and short- and long-term disabilities ("Health-Related Quality of Life and Well-Being," n.d.).

Depressive disorders are common among HIV-positive individuals, with observed lifetime rates as high as 48% (Buchanan, Wang, & Huang, 2002). PLWH were also twice as likely to have had a recent episode of a major depressive disorder than those who are HIV-negative, according to the same study. Overall rates of depression are five times greater in the older HIV-positive population than the older HIV-negative population (Siegler & Brennan-Ing, 2017).

Buchanan and colleagues (2002) a Minimum Data Set⁵ (MDS) and looked at HIV-positive people living in nursing homes, upon admission, more than 20% of the residents also had been diagnosed with depression (Buchanan, Wang, & Huang, 2002). They compared two groups of HIV-positive people living in nursing homes: those who are HIV-positive *and* have diagnosed depression upon admittance to the nursing home, and those who are HIV-positive but *not* diagnosed with depression upon admittance to the nursing home. The study concluded that HIV-positive women are more likely to be diagnosed with depression, and African Americans with HIV are less likely to be diagnosed with depression. They conclude that depression might go undetected among HIV-positive African Americans due to the difference in proportion of HIV-positive and depressed African Americans in nursing homes (42.1%) and those who are just diagnosed with HIV (63.8%). Moreover, they found that older, white, HIV-positive women were most at risk for being diagnosed with depression upon admittance to a nursing facility.

Those who are HIV-positive and have a diagnosis of depression received interventions for reorientation more frequently than those who were just HIV-positive. Reorientation is a therapeutic

⁵ The MDS is part of the federally mandated process for clinical assessment of all residents in Medicare and Medicaid certified nursing homes. The MDS provides a comprehensive assessment of each resident's functional capabilities and helps nursing home staff identify current health problems. ("Minimum Data Set 3.0 Public Reports Overview," 2012)

technique where individual or group sessions are aimed at lowering disorientation in confused residents. Last, many HIV-positive residents diagnosed with depression are not receiving antidepressant medications or mental health services in their nursing homes. The reason behind this is unknown and was not considered by the researchers. However, another researcher concluded that older PLWH were less likely than their younger counterparts to receive mental health care (Siegler & Brennan-Ing, 2017).

It is unknown if they are not receiving mental health services because the facilities lack the ability to provide them, or if clients are refusing them. Further studies must be done to understand why HIV-positive older adults are not receiving the mental health support that they need in order to have successful cognitive aging.

As HIV-positive individuals age, they often find that their social participation diminishes as their informal social networks including intimate partners, families, and friends can dramatically shift as a result of retirement, illness, relocation, or death (Chambers et al., 2014). Ageism plays a big role in isolation, too. As people age, regardless of their HIV-status, their social participation decreases (Johnson Shen et al., 2019). However, coupled with an HIV-positive status and possibly identifying as LGBTQ, there is a heightened stigma that individuals must grapple with and fight against when working to build up new social supports (Johnson Shen et al., 2019). PLWH often experience anticipated stigma, fearing they will be socially stigmatized by revealing their identity as HIV-positive. Furthermore, gay and bisexual men who are HIV-positive feel even higher levels of demoralization in accessing support systems and social networks because of the compounding stigmas associated to their HIV-status and sexual orientation (Johnson Shen et al., 2019) (Earnshaw, Bogart, Dovidio, & Williams, 2013).

One cross-sectional study of HIV-positive adults aged 50 and older ($n = 356$) determined that 58% of participants reported a symptom of loneliness (Greene et al., 2017). They concluded that participants who were lonely were more likely to report depression, alcohol and tobacco use, and have fewer relationships than those who did not report symptoms of loneliness. Loneliness was associated with lower HRQoL. Having steady and reliable social supports is associated with better physical and emotional health for the HIV-positive population (Poindexter & Shippy, 2008).

Another study found similar results. When examining social networks and social isolation among two different groups of HIV-positive adults (older adults aged 50+ compared to younger adults ages 20 to 39), older adults living with HIV were at higher risk of social isolation (Emlet, 2006). More than 38% of older HIV-positive adults were at risk for social isolation, compared to 25% of younger HIV-positive adults. Older HIV-positive adults of color risk of social isolation was 54%. Having someone to confide in and receiving support were significantly correlated to reduced HIV stigma.

Many studies examine the physical support systems that older PLWH have in place, but it is only recently becoming more common to research the perception of such physical supports (Carmo Filho et al., 2013); (Greene et al., 2017); (Karpiak, Shippy, & Cantor, 2006). For example, studies may fail to learn if the individual perceives the presence of friends and family to be a positive or negative influence on their QoL.

One study looked at the experiences of 34 older PLWH in New York City over the course of two months in 2005, focusing on how they perceive their social network. Five focus groups were conducted with men and women ranging in age from 50 to 73. Most participants had social networks made up of other HIV-positive individuals (Poindexter & Shippy, 2008). Participants discussed the positive and negative factors of having a social network consisting of other PLWH;

a major disadvantage is experiencing the illness and death of friends, where an advantage is feeling empowered and supported. Having other friends who are living with HIV is a form of disclosure management and stigma management. However, the fragility of their networks and how quickly they can lose a support system to death or illness was a fun.

Several studies have suggested that there are possible benefits of creating and implementing interventions to improve resilience, social networks, and optimism among HIV-positive older adults as a way of improving HIV outcomes (Moore et al., 2018) (Emlet, 2006) (Fang et al., 2015). These interventions could be the next step in improving successful cognitive aging, daily functioning, and quality of life within this population.

1.4 Current Available Services in Long Term Care Facilities

While we know a lot about the different physical and mental ailments that HIV-positive older adults face, we know very little about the services they receive in care facilities or with home-based care professionals. Further, few studies have investigated the quality of care provided to this population.

One such study, published in 2004, looked at the treatment of HIV/AIDS in nursing homes, comparing the care given in rural facilities to the care given in urban facilities. This cross-sectional study reviewed 1,423 nursing homes using the 1999 National Nursing Home Survey (NNHS). They found that most nursing homes in the United States do not provide any specialty spaces for HIV/AIDS care (Pearson & Hueston, 2004). Only 0.7% of nursing homes surveyed provided specialty treatment. While there was no difference between rural and urban care facilities in providing specialty treatment to HIV-positive older adults, rural nursing homes were more likely

to be dependent on patients funded only by Medicaid. The availability of specialized HIV/AIDS care was based solely on the size of the facility, and not its funding sources or urban/rural location.

A limitation of this survey is that it did not include facilities that specialized in HIV/AIDS, and many PLWH may have been receiving care at a specialty facility during the time of this study. Furthermore, the study took place with data that is nearly twenty years old, and yet it is still the most recent data this field of study has. Another limitation to this study is that the NNHS did not have a question asking if there were patients with HIV/AIDS living in their facility, only if there was a specialized HIV/AIDS treatment area designed specifically for those who are HIV-positive. Some of the nursing homes surveyed may have provided HIV/AIDS care, just not in a specialized treatment area.

Because there is little recent data regarding nursing homes providing best practice and evidence-based care to HIV-positive older adults, many elderly clients may face challenges when trying to find the best facility to enter. The burden falls on the client to do their own research, as there is no database of nursing facilities that provide specialty HIV/AIDS care, or that promises to educate their staff on best practices.

1.5 Housing First for HIV-Positive Older Adults

The inability for an HIV-positive older adult to find safe and suitable housing can lead to unsuitable housing choices, “which can have significant deleterious impacts upon the health of older adults with HIV/AIDS” (Lane, Hirst, & Reed, 2013, p. 55). Stable housing leads to better health choices, allowing PLWH to have safe storage methods for medications and adhere to often times complex drug regimens and get better quality sleep. Stable housing also reduces the risk of

engaging in risky behaviors, such as unprotected sex and IV drug usage, which can affect one's HIV health outcome (Aidala et al., 2005). Furthermore, it is known that “those who lack stable housing face multiple barriers to service utilization, including limited access to services that might provide risk reduction resources.”

Stable housing is an important determinant of health and wellbeing among PLWH. One study concluded that the effect of unmet basic needs like stable housing on physical health was greater among HIV-positive individuals aged 50+ than it was on younger groups of HIV-positive people (Sok et al., 2018). When basic needs such as housing were not met, more than one-third of PLWH in the United states did not keep their medical appointments (Cunningham et al., 1999). Unmet basic needs, such as food, clothing, and housing, was the most important prediction of poor physical and mental health in HIV-positive homeless men and women (Riley et al., 2011; Riley et al., 2012). In 2018, a cross-sectional study was published determining “the degree to which unmet basic needs are associated with physical and mental HRQoL; specifically, whether these associations vary with increasing age” (Sok et al., 2018, p. 2). Researchers categorized participants into three different age groups: young (20 – 24 years), middle-age (35 – 49 years), and old (50+ years). The study concluded that unmet basic needs had a greater impact on the physical and mental health of the middle-aged and older groups than it did on the young group. The clinical importance of this study shows that healthcare physicians, nurses, and carers need to be aware that HRQoL decreases more significantly as someone ages with HIV.

For over a decade, viral load of PLWH has been widely acknowledged as being the best predictor of clinical prognosis (Hawk & Davis, 2012). This was the basis of a small study published in 2012 which linked housing as a structural intervention for chronically unhoused PLWH to lower viral loads. 69% of HIV-positive study participants, provided with communal

housing in a housing first approach, were able to reach undetectable viral loads, rendering them unable to transmit HIV. While the sample size is small ($n=26$), it is an important topic that can be further researched.

1.6 Comorbidities Among HIV-Positive Older Adults

HIV is not the only thing that this population needs to be concerned about as they age. Dr. Kenneth Freedberg, a Harvard Medical School professor who directs the Medical Practice Evaluation Center at Massachusetts General Hospital, says that the great success of modern day HIV treatment is that “as people age, they now will survive long enough to have to deal with the complications of aging — hypertension, heart attacks, cancer, and all the other great things we develop” (Goldman, 2014, p. 359). Those with HIV who live over the age of 50 are likely to be burdened more by comorbidities and frailty than their HIV-negative counterparts (Siegler & Brennan-Ing, 2017). HIV management is only one of many concerns. Stephen Karpiak, a senior researcher at the AIDS Community Research Initiative of America (ACRIA) says that we can’t be treating HIV “in a silo.” As HIV-positive people age, we must look at more than their CD4 count and viral load. It’s not just HIV anymore, it’s all the other aspects and health problems that come with aging. This isn’t something the healthcare community has ever had to pay attention to before. We need to learn how to transfer patients from resources geared towards HIV to resources geared towards general aging.

In order to treat these patients in the best and most comprehensive way possible, we must embrace “the birth of geriatric-HIV medicine” (Guaraldi & Rockwood, 2017). We know that both life expectancy and mortality rates improve over time when healthcare coverage is improved, so

it's necessary that we continue adapting healthcare to better benefit the recipients (Allavena et al., 2018). As HIV-positive people are living longer, many are developing conditions that are commonly seen in older adults but are only loosely related to HIV (Guaraldi & Rockwood, 2017). Furthermore, HIV-positive older adults are developing “multiple comorbid illnesses associated with aging 10 to 20 years earlier than expected” (Seidel, Karpiak, & Brennan-Ing, 2017, p. 189). Structural and cultural changes in patient evaluation are needed so that people working in healthcare can transition from merely evaluating comorbidities present in HIV to actually implementing comprehensive geriatric assessments (Guaraldi & Rockwood, 2017). Much of the current research we have simply evaluates comorbidities, but very few create, implement, and evaluate interventions.

Furthermore, we need to either adapt current geriatric assessment tools, or create entirely new ones, to effectively assess HIV-positive individuals (Guaraldi & Rockwood, 2017). There are obstacles to care that are HIV-specific that need to be addressed, such as the interaction between the HIV and aging stigma. It's also important that we understand how polypharmacy plays a role in aging with HIV. Polypharmacy refers to the “concurrent use of 5 or more medications” (Ware et al., 2018). Most HIV-positive individuals are already on five or more medications, putting them at unique risk of harms such as decreased medication adherence, organ system injury, diabetes, and geriatric syndromes such as falls, fractures, and cognitive delays (Friedman & Duffus, 2016; Guaraldi & Rockwood, 2017; Singh et al., 2017; Karpiak & Brennan-Ing, 2016).

As this population ages, they may also be prescribed more medications to manage age-related symptoms. While geriatricians understand these syndromes and multi-morbidities are common in their aging patients, they may go unrecognized by HIV providers (Singh et al., 2017). This puts their clients at high-risk for serious medical problems. There is currently no formal

guidance on incorporating assessment and care for these comorbidities among older PLWH. By having a cemented partnership between infectious disease physicians and chronic disease physicians, patients will be receiving more appropriate medical management of their complex medication regimes (Friedman & Duffus, 2016). This is particularly necessary as not only is there a shortage of well-trained HIV providers, but also a diminishing number of geriatricians.

Still, it is necessary to not only connect physicians from different medical fields to one another. Integrating medical and social services is also important in providing older PLWH with adequate care. By merging of HIV medicine, subspecialty care, geriatric medicine, aging services, and HIV services, PLWH will be receiving truly informed and holistic treatment and care (Siegler & Brennan-Ing, 2017). While integration programs have mixed results in the general population, it may be incredibly beneficial to those who are older and more ill.

To promote geriatric-HIV medicine and care, ACRIA (formerly the AIDS Community Research Initiative of America) created its National Older Adults with HIV (NOAH) program. NOAH targets aging and HIV providers throughout the country that serve older adults who are living with or at-risk for HIV. Its program goals include “increasing knowledge, reducing stigma, and creating partnerships between senior service providers (SSPs) and HIV service providers” (Seidel et al., 2017). Outcome evaluation found that there was a significant increase in knowledge about HIV and aging among providers who collaborated with NOAH. However, NOAH faced issues with recruiting providers and receiving short- and long-term follow-up from participants.

ACRIA’s goals are also to raise awareness of the risk HIV among older adults, dispel the myth that older adults are not sexually active, promote discussions about sexual health among older adult populations, and to increase attention to older adult sexual activity in clinical settings

(Seidel et al., 2017). As a result, older adults will be receiving better care from more informed physicians, nurses, and social workers on geriatric-HIV medicine.

Many HIV studies are cross-sectional. However, one longitudinal study concerning aging with HIV studied polypharmacy among HIV-positive older adults. The prospective cohort study, which took place from 2004 to 2016 in four regions across America, discovered that “rates of aging-related comorbidities, which require targeted medications to treat, have been shown to be increased among persons living with HIV compared with uninfected counterparts” (Ware et al., 2018). While the number of drugs taken to manage HIV has diminished throughout the years, older PLWH increasingly require more medications to manage chronic age-related conditions that are not related to their HIV. The Multicenter AIDS Cohort Study (MACS) discovered that HIV-positive patients over the age of 50 have an enhanced risk of polypharmacy, making it even more important for those in the healthcare field to understand the unique needs of PLWH as they age (Ware et al., 2018).

MACS is not the only longitudinal study to look at aging while HIV-positive. A similar study has been taking place for many years in France.

The Dat’AIDS cohort has been following HIV-positive individuals and publishing research studies about their findings. Dat’AIDS cohort is a French multicentric prospective cohort that involves 19 HIV reference centers in France (Allavena et al., 2018). The primary focus of one of their recent studies was to compare within the cohort the HIV geriatric population, aged 75+, to the elderly population, aged 50 to 74 years. The reason behind this study was to introduce research into the HIV and aging field that included participants over the age of 75, as few HIV studies focus on this population. In December 2015 they were able to look at data from 16,436 HIV-positive subjects aged 50 to 74 (elderly participants), and 572 subjects aged 75 and over (geriatric

participants). This made up nearly 45% of the Dat' AIDS cohort. The majority of participants were born in France, with a smaller number born in African countries before emigrating to France.

Their findings showed that life expectancy rates improve as linkage to coverage improves, but it is also affected by the quality and tolerability of ART regimens and HIV care (Allavena et al., 2018). Their fear is that “due to the increased risk of age-related co-morbidities among HIV-positive adults, it is possible that life expectancy may plateau or decrease in the future.” It is possible that the integration of geriatric care and HIV-care—known as geriatric-HIV care, as discussed earlier—could curb this effect and allow for longer and healthier quality of life. However, this study concludes that there is an emerging population of geriatric HIV-positive adults that needs specialized care due in part to more co-morbidities within this population.

1.7 Sexuality and Aging

Long term care facilities need to focus on more than maintaining HRQoL in the HIV-positive aging community. These facilities must also focus on HIV prevention among their residents. According to the Centers for Disease Control and Prevention (CDC), in 2016 people aged 50 and older accounted for 17% (nearly 7,000 individuals) of new HIV diagnoses in the United States (“HIV Among People Aged 50 and Older,” 2018; Oraka, Mason, & Xia, 2018). The CDC states that 841 of those cases were in people aged 65 and older (Figure 2).

A study conducted in 2001 found that with age and reduced sexual activity, older adults believe their likeliness of contracting HIV and other STIs declines (Davis, Turner, & Young). In 2004, researchers published an epidemiological and qualitative study conducted in Hartford, Connecticut, and Chicago, Illinois. Data were drawn from nine senior housing buildings,

examining demographic, sociobehavioral, and contextual factors that predict HIV/AIDS risk perception among low-income older adults (Ward, Disch, Levy, & Schensul, 2004). The sample included 398 residents aged 50 to 93; 45% of participants believed themselves to be at no risk for contracting HIV. Furthermore, 42% of participants reported being sexually active. Four individuals disclosed being HIV-positive at the time of the survey, and four new individuals tested positive for HIV after receiving an OraSure HIV test during the study (15% of participants chose not to be tested for HIV).

It is common for older, sexually active adults to not test for HIV, believing their risk for contracting HIV to be low or non-existent. While their sexual activity may reduce as they age, a national representative sample of 3,000 adults over age 57 concluded that many adults are having sex into their 80's (Seidel et al., 2017) (Figure 3). Another study on sexual activity and sexual satisfaction among older women determined that 32% of women over the age of 65 had engaged in sexual activity in the last four weeks (Trompeter, Bettencourt, & Barrett-Conor, 2012). A 2010 AARP study concluded from a sample of 1,670 older adults, only 20% used condoms on a regular basis (Seidel et al., 2017).

It is estimated that nearly 84% of sexually active older adults, independent of sexual orientation, never get tested for HIV (Oraka et al., 2018). This is alarming as older adults are the fastest growing segment of the population living with HIV⁶. Many older adults are unaware of their HIV status, and many providers are reluctant to ask them about their sexual histories or

⁶ Though they are the fastest growing segment of the population *living* with HIV, they are not the fastest growing segment of the population being *diagnosed* with HIV. In 2016, people aged 50+ made up around 20% of new HIV diagnoses. See: Figure 4 in Appendix A.

evaluate their risk factors for contracting HIV (GuoYuqi & Sims 2017; Seidel et al., 2017). It is currently unknown if the rate of HIV infection is higher in older adults living in long-term care facilities than it is in older adults living on their own.

Having an assisted living facility or nursing home filled with healthcare staff educated on geriatric-HIV care is essential to the health of older adults living with HIV. Promoting health behaviors such as “consistently taking medications and receiving regular monitoring and treatment from health care professionals” is uniquely tied to stable housing and is less likely to occur when housing arrangements are precarious (Lane, Hirst, & Reed, 2005, p. 57). Housing itself is a social determinant of health. In nursing home and assisted living settings, the responsibility of health maintenance shifts from being solely the burden of the individual to also being in the hands of the healthcare workers tasked with caring for that individual. Without a thorough education on the effects of aging with HIV, healthcare workers in these live-in facilities will be incapable of providing the best treatment to their patients.

1.8 HIV in Allegheny County

Annually the Pennsylvania Department of Health releases its HIV Surveillance Survey. The most current annual report is from information gathered throughout 2017 and includes cases of HIV/AIDS diagnosed before the end of 2017 but reported by March 31, 2018.

The report states that “the most common methods of HIV transmission are sex between men, heterosexual sex and injection drug use” (Watkins et al., 2018) (Table 2). Three times as many males have been diagnosed with HIV than females, with 49% of new HIV diagnoses being African Americans (despite African Americans only making up 11% of Pennsylvania’s

population). New HIV diagnoses in Hispanics is also disproportionately high, with new diagnoses being 13.6% despite making up only 6.6% of Pennsylvania's population. Lastly, while the majority of new HIV cases occur in people aged 20 to 49, 18% of new infections in 2017 occurred in people over the age of 49 (Table 3).

However, HIV diagnoses have been steadily declining since the mid-1990s, with only 1,000 new diagnoses reported in the state in 2017 (compared to 3,000 in the mid-1990s).

Allegheny County has had the second highest number of cumulative HIV cases in Pennsylvania since 1980 (4,956), second to only Philadelphia County (32,480). In 2016, the rate of HIV by county of residence was 10.3 per 100,000 in Allegheny County. Furthermore, Allegheny County and Philadelphia County are the only counties in Pennsylvania with ≥ 100 new diagnoses of HIV in 2016 (Figure 4).

According to the Jewish Healthcare Foundation's contribution to the HIV Surveillance Report, 76% of PLWH in Southwestern, PA (11 counties) are living in Allegheny County. 10% of PLWH are over the age of 49. A number that is growing as PLWH continue to age into older adulthood with the help of HAART.

1.9 Literature Review Conclusion and Further Research

It is known that HIV-positive older adults have unique needs. Research has discovered much about the mental health status of older HIV-positive adults, as well as the physical needs they have as they age. Research has also shown that it's important to combine the infectious disease and chronic illness fields so that physicians can be better informed when caring for their clients. However, there has been very little done in the way of creating, implementing, and evaluating

interventions that aim to better the lives of HIV-positive older adults. There is a gap in researching HIV-positive elderly people over the age of 75. There is hardly any research conducted with HIV-positive adults living in long-term care facilities, such as nursing home or independent living centers, or receiving home-based care from providers and carers.

The HIV and aging field is a relatively new area of study, but over 50% of the HIV-positive population is over the age of 50, and it is continuing to grow. It's imperative that we research the ways in which this community can thrive and age successfully.

As discussed, there are no major disagreements in this field regarding the current state of HIV-positive older adults. Researchers have come to similar, if not the same, conclusions in their independent research. PLWH are more likely to have experienced a recent depressive episode, are more likely to experience social isolation, more likely to be on 5 or more medications (polypharmacy), and are more likely to experience geriatric syndromes such as falls, fractures, and cognitive delays. What we don't know is how long-term care facilities and home-based care organizations are handling these needs, whether their professional staff is educated on geriatric-HIV care, or whether they have programming specifically meant to increase socialization among HIV-positive older adults.

Further research is needed to study the quality of life for HIV-positive older adults living in long-term care facilities and receiving home-based care, as there is very little information on this topic. It is also necessary to conduct research on how many long-term care facilities have policies and programming specifically meant for the HIV-positive population. There is no recent research identifying how common it is for facilities and home-based care organizations to have policies on educating their staff on geriatric-HIV care or provide specific programming.

It's important to continue studies such as Dat' AIDS and MACS which are longitudinal and follow HIV-positive adults into older age. We must continue to support such studies, as well as expand cross-sectional studies to areas such as programming and policy evaluation. There is a dearth of research that studies the effectiveness of HIV programs for older adults, whether they be community driven or implemented within long-term care facilities.

Our HIV-positive population is aging, yet the geriatric healthcare world is unprepared to effectively care for them once they enter long-term care facilities and receive home-based care. It's imperative that we take the step from researching ailments that affect HIV-positive older adults and start creating and implementing programming and policies in the arenas that this population frequently inhabits. Public health research has done well in preparing the geriatric-HIV community for what ailments this population faces, but we now need to step into the programming realm so that we can effectively help this community.

2.0 Assisted Living Facilities HIV Preparedness Study

2.1 Methods

The aim of this study was to assess current practices and policies of long-term care facilities in Allegheny County regarding their preparedness to adequately care for HIV-positive individuals in their care. Surveys were administered to directors of local long-term care facilities ($n=57$) through an online form. Only non-profit and for-profit facilities were included. Government facilities were excluded. As the survey questions were not considered to be human subjects research, no IRB/HRPO protocol was submitted.

Medicare.gov's Nursing Home Compare website was used to locate Medicare- and Medicaid-certified long-term care facilities within Allegheny County. Facilities included independent living, skilled nursing, and personal care. Eligibility criteria included being either a Not for Profit or a For Profit long-term care facility. Original findings using the Medicare.gov tool concluded there were 62 long-term care facilities in Allegheny County that were Medicare- and Medicaid-certified. Five were excluded for being government run.

Long-term care facilities were broken up into non-profit and for-profit, and ≥ 100 beds and < 100 beds (Table 1). This was to assess the general size of each facility.

Table 1 Long Term Care Facilities Analyzed

	<i>n</i> ≥100 beds	<i>n</i> <100 beds	Total
Not for Profit	13	13	26
For Profit	24	7	31
	37	20	57

Furthermore, each long-term care facility was assessed as being a part of a Continuing Care Retirement Community (CCRC). CCRCs offer a tiered approach to the aging process, with residents' needs being accommodated as they age. They often offer independent living, nursing, and skilled nursing facilities so residents can stay in the same community as they require more assistance. Eighteen of the long-term care facilities were CCRCs.

Nursing Home Compare was chosen as it is a centralized database run by the government through their Medicare.gov website. No information was available to determine the traffic the website gets, making it difficult to compare the popularity of this website to other popular long-term care facility databases.

After a brief introductory phone call to each long-term care facility, an online survey link was emailed to those who agreed to participate. No reward, financial or otherwise, was offered to respondents.

During these phone calls the purpose of the survey was explained, and often a short conversation was had in which the respondent gave information on whether staff was trained on how to care for an HIV-positive person. This qualitative information is included in this thesis.

Results were compiled and analyzed using Qualtrics and Excel.

Survey-derived measures included: (1) professional information (name of facility employed at, duration of employment); (2) availability of training (presence/absence of training, required/not required, frequency of training, creator of training); (3) perceived need of training; (4) knowledge on local HIV organizations.

The six local HIV organizations that were chosen were AIDS Free Pittsburgh, Allies for Health + Wellbeing, MidAtlantic AIDS Education Training Center, Central Outreach Research and Referral Center, Pittsburgh AIDS Center for Treatment, and the Positive Health Clinic. They were chosen as they include training organizations, referral organizations, and healthcare organizations.

2.2 Results

All 57 long-term care facilities were contacted via phone with sixteen agreeing to be sent the link. On average, 1.1 phone calls were made, and 1.2 emails were sent over the course of four weeks to each facility.

Upon starting the survey, no Executive Director said they had the information necessary to complete the survey, instead transferring the survey to the Director of Nursing or the Nurse Administrator. As a result, the surveys were all completed by Directors of Nursing and Nurse Administrators. Sixteen email links were sent out, two were sent to Executive Directors before being abandoned, and fourteen of which were to Directors of Nursing and Nurse Educators.

Emails were sent using a personal link so that those who started the survey but did not complete it could be contacted again for follow-up.

Of the sixteen long-term care facilities that were sent the survey, fourteen began the survey and eleven completed the survey. There was a 64% survey completion rate.

Of those that completed the survey, four (36.36%) stated that their facility does not provide HIV training to their staff. Only one of those four facilities required that HIV training be completed by employees, while two responded that it depends on one's position in the facility as to whether they receive HIV training. They did not further explain which employees received the training. The last responder chose to skip this question.

Seven respondents (63.64%) stated that their facility does provide training on how to care for older PLWH. Four of these facilities provide HIV training once a year and one facility offers it more than once a year. Six facilities chose not to answer this question. Two facilities stated the position of the person who runs their trainings (Infection Control specialist and the Nurse Educator respectively), whereas nine facilities chose not to answer this question. Lastly, three of these facilities offer HIV training during new employee training/orientation, three stated that it is not offered during new employee orientation, and five chose not to answer whether this training was available at that time.

When speaking with Directors of Nursing and Nurse Administrator's (DN/NA) about their HIV training policies over the phone, prior to them agreeing to be sent the survey, most assumed they were being asked if their facility provided the mandatory Universal Precautions training. At times it took multiple tries to explain to a DN/NA that they were being asked about the healthcare that PLWH in their facility receive, not whether they were protecting their employees from contracting HIV. Several stated that HIV training isn't necessary unless a resident who is HIV-positive moves into their facility. One facility that does require HIV training requires it of "CNA, nurses, office [*sic*]." Furthermore, five facilities stated it was very important that their staff be up to date on the best practices of caring for PLWH, while four said it was slightly important (Figure 1).

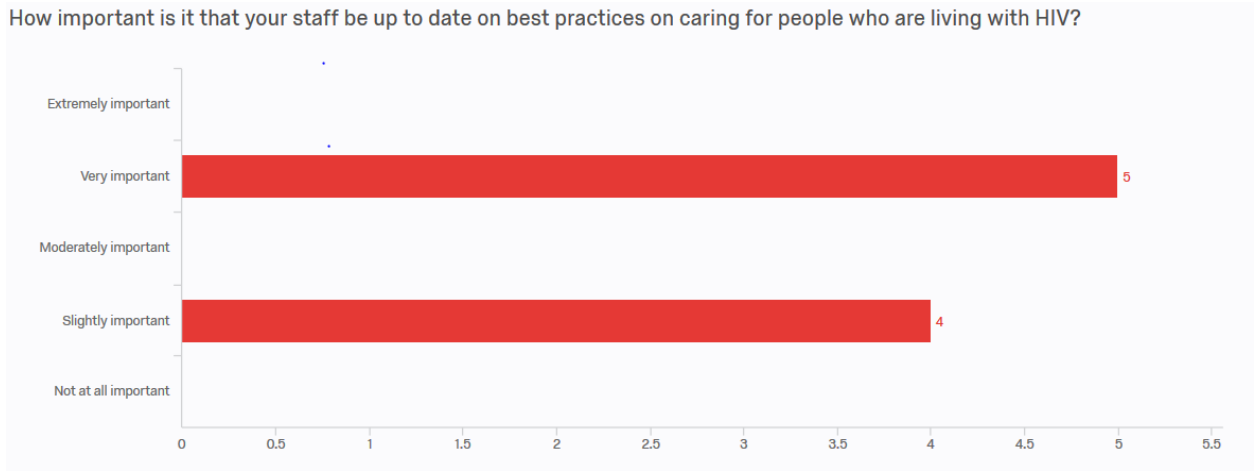


Figure 1 Importance of staff being up to date on best practice for caring for PLWH (n = 11)

Table 2 Availability of HIV Training at Long-Term Care Facilities In Allegheny County Survey Results

Variable	n=11
Respondent's length at current position	
1 – 3 years	4 (36.36%)
4 – 6 years	1 (9.09%)
7+ years	6 (54.55%)
Does facility provide training on how to care for PLWH	
No	4 (36.36%)
Yes	7 (63.64%)
Is this training required?	
No	1 (9.09%)
Maybe, depending on position	2 (18.18%)
Yes, for every employee	3 (27.27%)
No Answer	5 (45.45%)
How frequently is this training offered?	
Once a year	4 (36.36%)
Twice a year	0
More than twice a year	1 (9.09%)
No Answer	6 (54.55%)
Is this training offered during new employee training?	
No	3 (27.27%)
Yes	3 (27.27%)
No Answer	5 (45.45%)

No long-term care facility felt that it was extremely important to train their employees on how to care for PLWH (Figure 2). When the four facilities who stated there was no HIV training in place were asked why there was no training, one respondent stated it was “unknown,” while two others stated that if an HIV-positive person were to move in, then training would happen. The fourth did not answer the question. Furthermore, one of the facilities that does not require any HIV training of staff stated that if it were available it would only be available to clinicians.

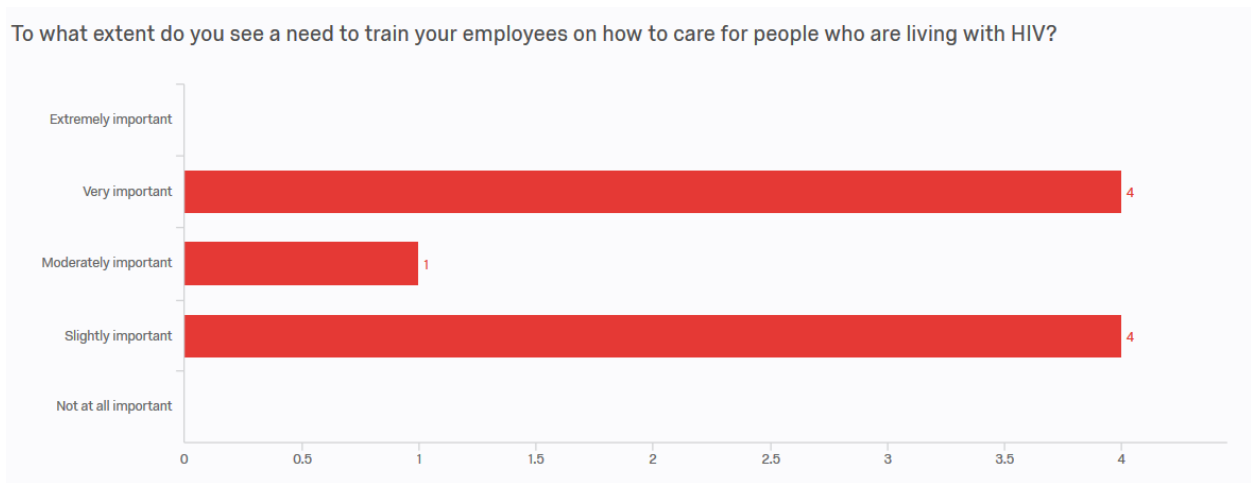


Figure 2 Importance of training employees on how to care for people who are living with HIV? (n = 11)

Lastly, the seven respondent’s knowledge of Allegheny County HIV organizations was minimal. When asked to what extent they were familiar with six HIV organizations in Allegheny County (AIDS Free Pittsburgh, Allies for Health + Wellbeing, MidAtlantic AIDS Education Training Center, Central Outreach Research and Referral Center, Pittsburgh AIDS Center for Treatment, and the Positive Health Clinic), every facility stated they were Not at all Familiar or only Slightly Familiar with the organizations.

One respondent stated that if one of her employees had questions about caring for an HIV-positive resident, she would not know where to reach out to for assistance, but would first try the

“CDC [*and*] department of health.” Two others stated that they did know where to reach out for assistance, but also stated that they were not at all familiar or only slightly familiar with the six local organizations named in the survey.

Table 3 Long-Term Care Facilities Familiarity with Local HIV Organizations

n=9

To what extent are you familiar with the following:	Not at all familiar	Slightly Familiar	Moderately Familiar	Very Familiar	Extremely Familiar
AIDS Free Pittsburgh	8 (88.9%)	1 (11.1%)	0	0	0
Allies for Health + Wellbeing	8 (88.9%)	1 (11.1%)	0	0	0
MidAtlantic AIDS Education and Training Center (MAAETC)	9 (100%)	0	0	0	0
Central Outreach Research and Referral Center	8 (88.9%)	1 (11.1%)	0	0	0
Pittsburgh AIDS Center for Treatment (PACT)	7 (77.8%)	2 (22.2%)	0	0	0
Positive Health Clinic	8 (88.9%)	1 (11.1%)	0	0	0

2.3 Discussion

More than half of respondents felt that it was very important that their staff be up to date on best practices for caring for PLWH. Half of respondents also stated that it is very important that they train their employees on how to care for PLWH. However, due to several questions being unanswered, it's impossible to determine if these facilities currently offer training to the part of or the entirety of their staff.

There was not a question asking if the long-term care facility ever had or currently has an HIV-positive resident. The decision to exclude this question was made as it was discussed that a respondent might assume at some point their facility had an HIV-positive resident and therefore say they have without checking records. Furthermore, this survey was designed to be completed in under five minutes and not require the respondent to do any research of their own.

What was rather alarming was how few local HIV organizations these long-term care facilities were familiar with. Not a single facility was moderately familiar to extremely familiar with any of the six organizations listed. These six organizations provide treatment and referrals, perform HIV training courses, conduct HIV research, raise awareness and build collaboration to end the AIDS epidemic in Allegheny County, or provide resources to PLWH and those who care for them. These HIV organizations are not adequately reaching long-term care facilities, leading to these facilities being siloed.

Furthermore, every Executive Director that was spoken to stated they did not have information regarding HIV trainings that take place at their facility. Two Executive Directors, upon starting the survey, contacted the researcher stating that they did not have adequate

knowledge to answer these questions and asked if they could have the survey sent to a DN/NA. Executive Directors at Allegheny County long-term care facilities seemingly do not have much information on whether staff at their facilities are provided with, or required to complete, HIV training sessions (apart from Universal Precautions training).

One respondent stated that it was “unknown” as to why HIV training was not a part of mandatory training modules at their facility. That same facility only saw a slight need in having their staff trained in best practices for caring for PLWH, and was not at all familiar with any of the six community HIV organizations. Not every facility knows why certain topics are included in their training modules while others are not. This requires looking more in depth as to who makes the training requirements at certain facilities.

Only two of the seven respondents who do provide HIV training to their staff answered the follow-up question asking who on their staff (ex. Physicians, RNs, non-RNs, social workers, kitchen staff, program staff etc.) is able to take the HIV training. Only clinical staff and clinical and office staff were said to have received training at the two facilities respectively. No facility reported providing training to social workers, kitchen staff, or cleaning staff. This leaves a large number of non-clinical staff not receiving HIV training beyond Universal Precautions training, which benefits the safety of the employee and not the health of an HIV-positive resident.

During the preliminary phone calls, one DN/NA mentioned that it was not included in their training modules as it was not a part of the University of Pittsburgh Medical Center’s (UPMC) training courses that they “provide” to the facility. As many of the long-term care facilities are overseen by UPMC, it’s likely that they receive the same or similar trainings. Therefore, HIV-training might not be included in any of their trainings that are overseen by UPMC.

2.3.1 Limitations

A major limitation of this survey was that Executive Directors were not able to answer the survey questions, and therefore asked that it be sent to DNs and NAs. Furthermore, there was no question asking what the respondent's position at the facility is, as it was originally expected to be only Executive Director's completing the survey. Furthermore, at least one Assistant Director of Nursing and one interim Director of Nursing completed the survey, confirming with the researcher over the phone that they were able to complete the survey despite not being either an Executive Director or the permanent head DN/NA.

Furthermore, four of the open-ended questions were not accepting written responses upon being sent and were not fixed until late in the process after six respondents had already completed the survey. This meant several respondents did not have the opportunity to answer several open-ended questions which would have given more detail on the policies at their facility.

Not all of the survey questions were mandatory to answer, which resulted in each respondent skipping over at least one question. This made it hard to examine individual facilities in depth for their current policies and practices. For example, if one facility said that it was important for them to train employees on caring for PLWH, they may not have answered the question asking whether this training already exists and whether it is required. Therefore, individual facilities were not able to be examined, but rather all of the facilities broadly.

Lastly, time was a major barrier. There was not ample enough time to reach out to each facility multiple times and follow up with each possible respondent.

3.0 Conclusion

Further research needs to be conducted with long-term care facilities both in Allegheny County and in the United States. The last National Nursing Home Survey (NNHS) that looked at the care people with HIV/AIDS care was receiving at nursing homes happened in 1999. While outdated, it came to some very important conclusions. However, much has changed in twenty years as new and better medications have extended the lives of PLWH and changed the type of care they need.

Furthermore, more of an effort needs to be made to put long-term care facilities in contact with local HIV organizations. Dozens of research studies have confirmed that as PLWH age, they face unique health problems that require physicians skilled in geriatrics and HIV to increase HIV health outcomes. Creating a network of long-term care facilities and HIV organizations within the county will allow for quicker and easier access to resources for long-term care facilities in the event they have an HIV-positive person move into their facility. Furthermore, the spread of knowledge to these long-term care facilities will help prepare them for the imminent influx of older PLWH that will happen within the next decade.

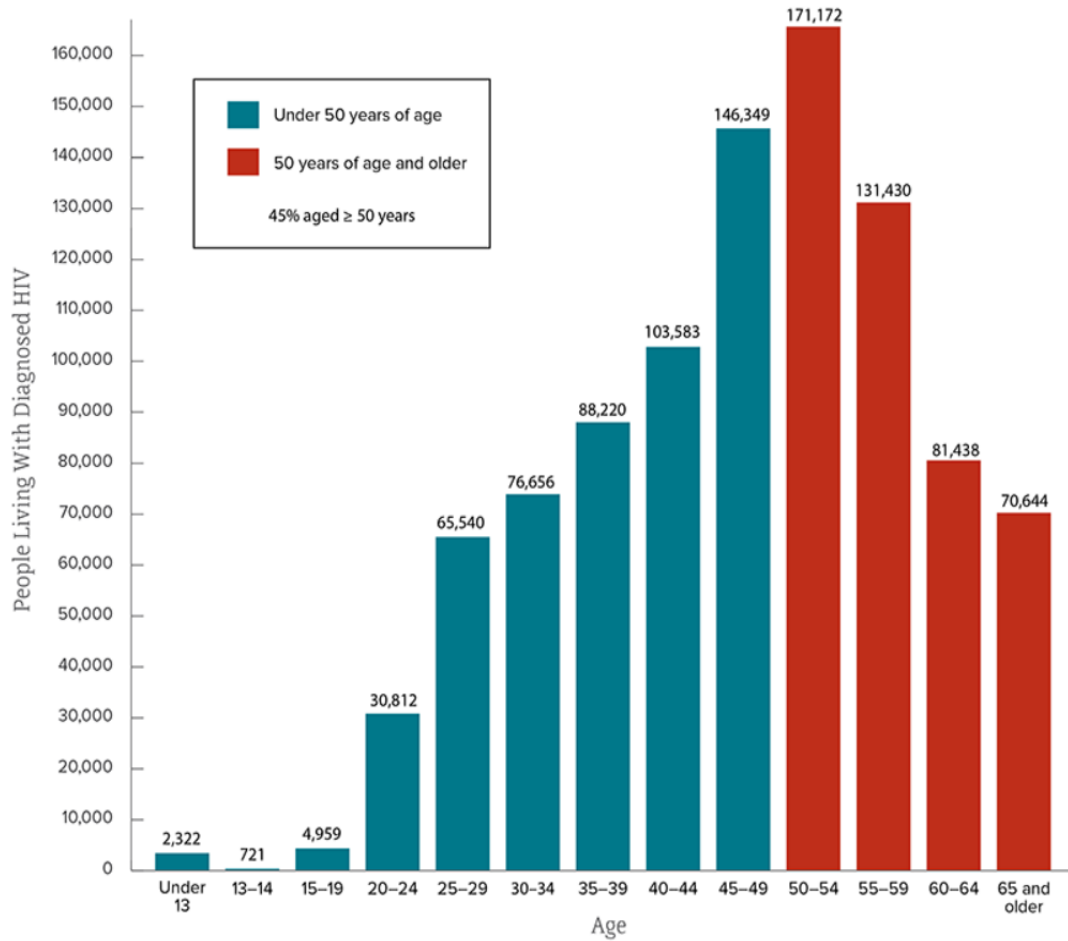
The question now becomes whether long-term care facilities wish to be proactive or reactive. Receiving training prior to an influx of PLWH rather than as a reaction to it may lead to better health outcomes for this population, though there is no current research looking particularly at time of employee HIV training in relation to admittance of an HIV-positive resident. PLWH can and do lead long and fulfilling lives, with a life expectancy similar to those who are HIV-negative. They are able to experience the illnesses that come along with old age, and therefore it's important

that they have physicians, nurses, and care staff that understand the unique ways in which their HIV and age-related illnesses may interact.

Overall, more research needs to be conducted to discover the preparedness of Allegheny County long-term care facilities to adequately care for PLWH.

Appendix A Charts and Graphs

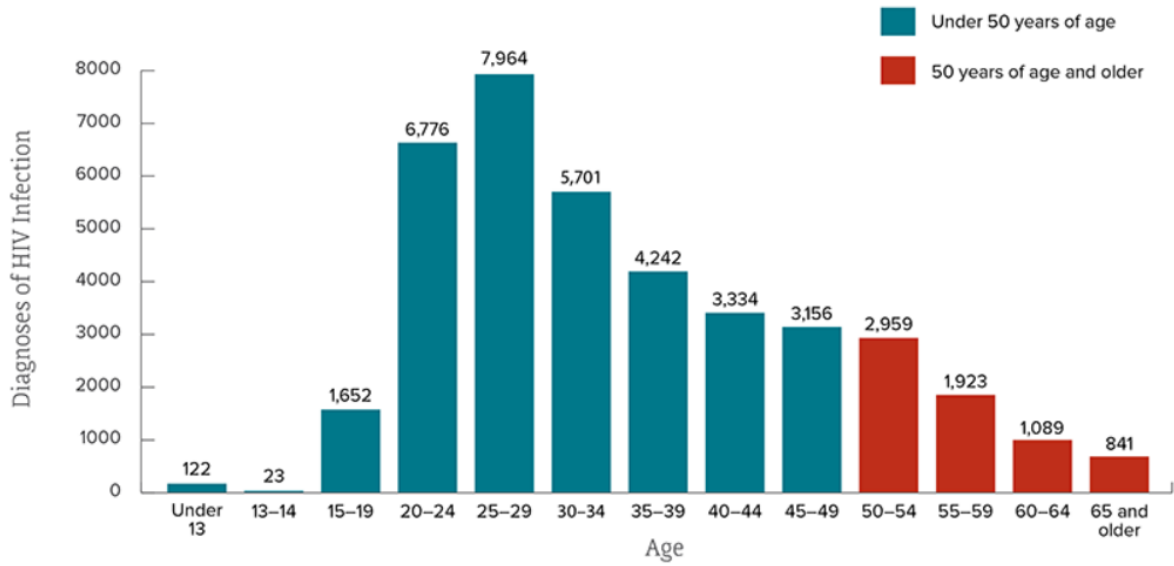
People Living With Diagnosed HIV by Age, 2015, United States



Source: CDC. [Diagnoses of HIV infection in the United States and dependent areas, 2016](#). HIV Surveillance Report 2016;28.

Figure 3 People Living With Diagnosed HIV by Age, 2015, United States

HIV Diagnoses by Age, 2016, United States



Source: CDC. [Diagnoses of HIV infection in the United States and dependent areas, 2016](#). HIV Surveillance Report 2016;28.

Figure 4 HIV Diagnoses by Age, 2016, United States

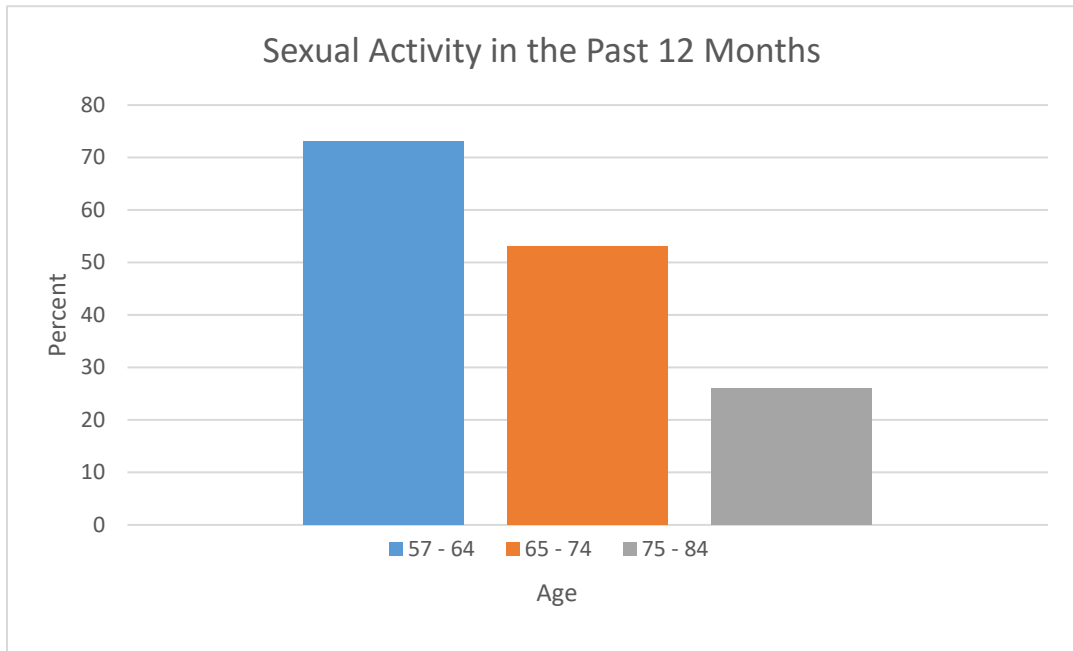


Figure 5 Sexual Activity by Age Group in the Last 12 Months, 2007

Information was gathered from Seidel, Karpiak, & Brennan-Ing, 2017

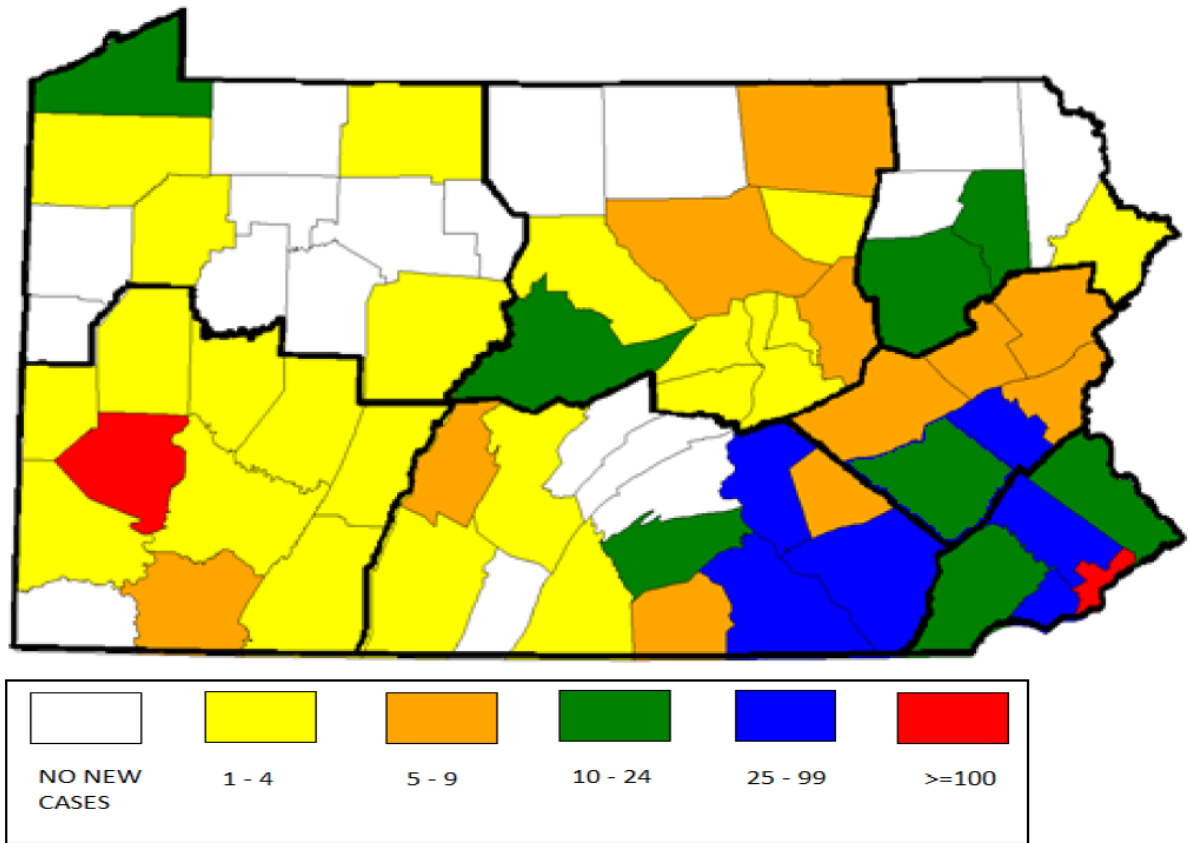


Figure 6 New Diagnoses of HIV Disease by County in Pa., 2016

Source: Annual HIV Surveillance Summary Report

Appendix B Tables

Table 4 Number of Cases of HIV Disease by Mode of Transportation and Year of Diagnosis, PA, 2012 - 2017

	2012		2013		2014		2015		2016		2017*		TOTAL TO DATE 1980-2017	
	Number	percent	number	percent	number	Percent	number	percent	number	percent	number	percent	number	percent
ALL MODES	1,465	100	1,331	100	1,217	100	1,191	100	1,103	100	966	100	61,664	100
Men sex w/ men (MSM)	651	44	649	49	615	51	632	53	583	53	479	50	23,329	38
Injection drug use (IDU)	124	8	92	7	67	6	68	6	58	5	65	7	15,573	25
MSM and IDU	34	2	31	2	28	2	26	2	24	2	23	2	2,969	5
Coagulation disorder	0	0	0	0	0	0	0	0	0	0	0	0	262	0
Heterosexual contact	482	33	445	33	436	36	338	28	304	28	150	16	15,210	25
Transfusion received	0	0	0	0	0	0	0	0	0	0	0	0	222	0
Undetermined/other	164	11	104	8	66	5	120	10	130	12	247	26	3,329	5
All pediatric modes**	10	1	10	1	5	0	7	1	4	0	2	0	770	1

* Counts may be incomplete due to lag in reporting.

** Includes adult cases that had pediatric modes of transmission (e.g., perinatal exposure)

Note: Percentage may not add to 100% due to rounding.

Source: Annual HIV Surveillance Summary Report

Table 5 Number of Cases of HIV Disease by Age at Diagnosis and Year of Diagnosis in PA., 2012 - 2017

	2012		2013		2014		2015		2016		2017*		TOTAL TO DATE 1980-2017	
	number	percent	number	percent	number	percent	Number	percent	number	percent	number	percent	number	percent
ALL AGES	1,465	100	1,331	100	1,217	100	1,191	100	1,103	100	966	100	61,664	100
0-12	10	1	8	1	5	0	6	1	3	0	1	0	753	1
13-19	71	5	72	5	62	5	59	5	48	4	56	6	1,970	3
20-29	460	31	406	31	395	32	426	36	412	37	336	35	15,216	25
30-39	306	21	303	23	272	22	263	22	274	25	257	27	21,249	34
40-49	330	23	267	20	230	19	198	17	162	15	138	14	14,537	24
OVER 49	288	20	275	21	253	21	239	20	204	18	178	18	7,939	13

* Count may be incomplete due to lag in reporting.

Source: Annual HIV Surveillance Summary Report

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