Introduction

According to the CDC, nearly half of the people with HIV (PWH) are 50 years of age and older. This number includes people who are newly infected which the CDC reported as approximately 1 in 8 HIV diagnoses in 2017 were among this group. People aging with HIV face challenges associated both with the normal process of aging and managing HIV disease. They also have an increased likelihood of experiencing comorbidities, and unique social needs that require more attention to care. As a result, care coordination can be challenging and important to the ongoing care needs of those aging with HIV.

To increase our understanding of HIV in people over 50, HealthHIV developed the “Positively Aging” program. The program seeks to improve access to quality services and care coordination for PWH over 50. While medical providers are often adept at addressing HIV or addressing people as they age, there is a greater need for enhanced training and medical education on how to treat comorbid conditions associated with aging with HIV. “Positively Aging” offers consumer and medical education to enhance care coordination/access, health literacy, and the management of conditions associated with aging. The Positively Aging program uses multidisciplinary strategies that can be applied in practice to improve care coordination for people aging with HIV.

Methods and Activities

HealthHIV’s Inaugural State of Aging with HIV™ national survey was conducted to assess the state of care coordination for people with HIV (PWH) aged 50 and older. The survey instrument consisted of 76 questions, both qualitative and quantitative. The survey was distributed online using Survey Monkey™ and covered six key areas: care coordination; HIV management; provider interaction; healthcare expenses; pharmacy usage; and aspects of living with HIV.

HealthHIV’s Inaugural State of Aging with HIV™ National Survey was fielded from July 17 through August 14. 2018. Respondents were recruited through open invitations using targeted email lists and social media postings. Respondents also had the option of printing the survey and returning it via fax. The survey generated 1,090 unique responses and 831 full responses that were analyzed for the report. See figure 1 for the respondent demographics. The survey findings informed medical education activities for clinicians. The Inaugural State of Aging with HIV™ Survey Report was finalized in March 2020. (Figure 1)

Results

The national survey focused in six categories, see Figure 4:

Care Coordination

The most frequently cited barriers to care are cost of care, lack of transportation, lack of providers knowledgeable about HIV, lack of convenient appointment times, and not being able to find a provider who accepts their insurance. Thirty-six percent (36%) of respondents were never connected to government or community resources by their provider and were significantly more likely to be dissatisfied or very dissatisfied with their care coordination.

HIV Management

Provider Interactions

- People aging with HIV are engaged in routine care, with nearly all having seen a provider in the last year, and three quarters having seen an HIV care provider in the last six months.
- Ninety-two percent (92%) of respondents stated that their primary care provider and HIV care provider are the same person.
- Respondents were less likely to be prescribed medication for their comorbid conditions, with the most start differences found in type 2 diabetes, asthma, and kidney disease.
- Respondents report experiencing discrimination when seeking healthcare services. Over half report experiencing stigma and approximately a quarter of respondent’s report experiencing anger and homophobia.

Healthcare Expenses

Ninety-five percent (95%) of respondents have health insurance; though many report issues paying for services. Thirty-five percent (35%) access their HIV medications through their state’s AIDS Drugs Assistance Program (ADAP).

Pharmacy Usage

- The majority of respondents consider their pharmacist to be an important part of their care team and are likely to contact their pharmacist for medication counseling.

Aspects of Living with HIV

- Respondents struggle with lack of social support and isolation. Approximately half of respondents use at least one substance on a daily basis, with alcohol and tobacco as the most frequently used substances. A quarter of respondents also indicated they are or have been in recovery from substance use.

Challenges and Limitations

- A key challenge was generating representation of people aging with HIV from the southern region. A concerted effort was conducted to ensure representation from the Southern US.
- A limitation was an underrepresentation from geriatricians and other providers connected to aging issues working outside of the HIV field. Increased representation of this cohort will provide more information on the care coordination within health systems with people aging in contrast to people aging with HIV.

Lessons Learned

- There are significant issues surrounding improved care coordination for people with HIV and the need for follow-up activities.
- To improve care and health outcomes we must be intentional in connecting resources to non-clinical service providers who play a valuable role in engagement and care coordination.
- An enhanced systems approach is necessary to address the effects of discrimination, stigma and homophobia on service provision and outcomes.
- Increased patient engagement and provider relationship satisfaction positively impacts care coordination and patient mental health.
- Qualitative responses from patients in the survey showed that respondents who weresatiated with their healthcare providers and report decrease depression and isolation.

Next Steps: Care Coordination for PWH over 50

Recognizing these challenges, we have identified several focus areas as next steps.

- Launch the 2nd Annual State of Aging with HIV Survey designed for providers to address the navigation and care coordination within health systems.
- Engage AIDS Service Organizations (ASO) and Community Based Organizations (CBO) nationwide to assess gaps in services in different localities and jurisdictions.
- Create HealthHIV’s Care Coordination Center for People Aging with HIV as a repository for providers and consumers to access medical education and resources. This center will be a one-stop shop for providers looking for information on supporting patients aging with HIV and will include educational modules, webinar recordings, and the most current literature.
- Collaborate with organizations that address audiences and systems complementary to HIV focusing on the Black and Latinx community.
- Extend advisory committee engagement to assess existing care coordination for people aging with HIV and create partnerships for Positively Aging.
- Inform best practices related to care coordination for people aging with HIV by developing and distributing resources and key learnings for providers and the community to inform systems change.

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