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Building a Focus on Healthy Aging for Older Adults Living With HIV: A Call to Action

The Imperative to Take Action

More than half of the 1.2 million people living with HIV in the United States are over the age of 50, according to the Centers for Disease Control and Prevention. It is estimated that by 2020, 70 percent of HIV patients will be 50 or older.[i,ii]

Advances in HIV treatment have turned what was once considered a death sentence into a manageable chronic disease. Many patients in the early days of the epidemic lived only a few years after diagnosis, but a person diagnosed today with HIV may experience a lifespan similar to that of the general population.[iii] There is a growing percentage of people with HIV who are living decades, not merely years, after their diagnosis.

While HIV therapy has created a turning point in the HIV epidemic, some advocates say that healthcare providers (HCPs), policymakers, caregivers, people working in AIDS service organizations, and others supporting people with HIV need to recognize that achieving a longer lifespan is not the end of the battle. In fact, it may be only the beginning of a more protracted struggle to ensure that people living with HIV are able to live healthier lives into their older years.

Some advocates contend that we have reached a transition point in aging for the population with HIV. To that end, advocates reason that there is a need to focus on building a more hopeful future for adults with HIV, where they and their providers are able to collectively address the whole health of people with HIV and to advance efforts to achieve optimal healthy aging.

The Impact of Comorbidities and Resulting Health-Related Challenges

Now that people with HIV are living longer, they are experiencing the impact of age-associated comorbidities, such as heart and liver disease and multiple cancers – conditions that have long affected the general population as they age. While these individuals have a higher risk for these age-associated conditions, they develop them at similar ages to those without HIV.[iv] Roundtable participants underscored that most older adults aging with HIV currently do not exhibit these comorbid conditions, but that as this population ages and grows in number, the incidence of these conditions will increase. What is different for the aging population with HIV now is that they are developing high rates of multimorbidity that is the result of multiple risk factors, of which HIV is one. (Multimorbidity refers to the co-occurrence of two or more medical or psychiatric conditions, which may or may not directly interact with each other within the same individual.)[v] They face a heavier burden of disease than those

This report provides a recap of a roundtable discussion supported by Theratechnologies that was convened March 2, 2016, focused on healthy aging for people with HIV and the impact of multimorbidity on this population. The report itself does not represent the opinions of Theratechnologies, but rather it reflects the opinions of participants listed on page three of this report.

at the same age.[vi]

Older adults who were diagnosed with HIV in the 1980s through the mid-1990s, who often refer to themselves as HIV long-term survivors, may face many other distinct challenges, including social stigma, which results in depression and social isolation. These factors are known to contribute to poor medication adherence and health management. Compounding those challenges, many of these older adults are on permanent disability, are Medicaid dependent, and have limited Social Security income. When these survivors want to re-enter the workforce, they often confront ageism, wide gaps in their resumés, and fatigue. Most of these older adults lost many of their friends and partners to HIV and do not have an adequate support system to help them deal with issues that arise with aging. Additionally, the powerful forces of HIV stigma are often exacerbated by body shape changes that can occur with HIV, such as facial wasting or the appearance of a distended stomach associated with excess visceral adipose tissue (VAT), a hard type of fat that may surround the internal organs, may increase risk for comorbidities, and may worsen a person's quality of life and body self-image. This stigma can affect this population's confidence and motivation needed to focus on health.

Advocates for people aging with HIV say more can and needs to be done to provide better support and appropriate care for long-term survivors of HIV. Advocates report that some medical professionals seem stuck in delivering an outdated message to patients that long-term survivors should feel "lucky" and satisfied to have lived this long. Although geriatricians and some other medical professionals are trained in assessing and actively treating multimorbidity, a major communication and knowledge gap exists between the typical HIV provider community and those who are optimally skilled at managing older adults as they age into and beyond their sixth decade of life. Additionally, these older adults with HIV may find barriers to accessing aging supports and health services. These barriers often are driven by HIV/AIDS stigma that has been internalized in staff and institutions. The person with HIV too often confronts a judgmental attitude that creates an immediate barrier to accessing care. The attitude can be driven by continued myths about HIV transmission and stigma around serving those living with HIV.

The Call to Action

Given the unique needs of people with HIV as they navigate a path toward healthy aging, advocates are calling for increased focus and purposeful action to develop a plan that will allow patients and providers to collectively improve the way that older people with HIV can expect to age. To further this conversation about needed actions, Theratechnologies, a specialty pharmaceutical company addressing unmet medical needs in metabolic disorders to promote healthy aging and improved quality of life, convened key national thought leaders in aging and HIV at a roundtable on March 2, 2016. The meeting's two-fold focus: discuss the current landscape for older adults with HIV and explore the perceptions and knowledge about what's needed to improve the ability of the older population with HIV to effectively manage multimorbidity and to focus on healthy aging. Roundtable participants (*see list on page three*) identified three core themes that they perceived as important next steps to advance actions that can improve healthy aging for people with HIV.

The key themes are:

- **Advance the Conversation Beyond Survivorship**: The current conversation around adults aging with HIV is focused on survivorship. Roundtable participants expressed a need to advance the conversation beyond survivorship and toward a focus on healthy living and aging well with HIV.

- **Re-engage Older Adults With HIV in Efforts to Improve Their Long-Term Health and Minimize the Complications of Multimorbidity**: Roundtable participants discussed the need to empower adults with HIV to re-engage in their health and to demand better integrated care that is calibrated to best address age-related health challenges. Attendees talked about a pervasive sentiment among the HCP community that older adults with HIV should simply be happy to be alive and how that has created a lack of motivation among the community to ask for better, more suitable care as they age. Attendees noted that part of this process will include empowering this population to actively take charge of their health, using established self-care models for multimorbidity and HIV.

- **Increase Education Among HCPs About Multimorbidity Management in the Older Population With HIV**: Roundtable participants noted the need for increased education among a wide range of health professionals on the impact of multimorbidity on adults with HIV. Although HCPs who treat patients with HIV are skilled at helping them to control HIV, roundtable participants said medical professionals must extend their focus beyond HIV care management to more effectively address age-associated multimorbidity, as well as other related conditions that can affect healthy aging.

Roundtable Participants Included:

- Tez Anderson, Let's Kick ASS (AIDS Survivor Syndrome)
- William Arnold, Community Access National Network (CANN)
- Jeff Bailey, AIDS Project of Los Angeles (APLA)
- Rick Guasco, Positively Aware
- Stephen Karpiak, PhD, ACRIA Center for HIV and Aging, New York University College of Nursing
- Alysa Krain, MD, American Academy of HIV Medicine
- Jeffrey Kwong, DNP, MPH, ANP-BC, FAANP, Association of Nurses in AIDS Care
- Jenetter Richburg, AID Atlanta
- Rick Siclari, MBA, Care Resource
- Marianne M. Swanson, RN, BSN, ACRN, Association of Nurses in AIDS Care
- Aaron Tax, JD, Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE)
- Nelson Vergel, Program for Wellness Restoration (PoWeR)

Participant feedback offered during the roundtable and included in this report reflects each participant's own opinions and not necessarily the opinion of the organizations they represent.

Advancing Communication and Action around Healthy Aging for Older Adults With HIV

Theme One: Advance the Conversation Beyond Survivorship

Advances in treatment regimens have had a profound impact on improving survivorship rates among people living with HIV. Many individuals diagnosed with HIV in the 1980s and 1990s had come to accept their condition as an inevitable death sentence, often after having been given a life expectancy of one-two years. As treatment for HIV improved in the late 1990s and lifespans began to increase, the accepted narrative was that simply surviving to age 50 and beyond was an achievement. Striving for a better quality of life and quality of care at a more advanced age was forgotten.

But more than half of all people with HIV in the United States are over the age of 50.[vii] That number is increasing. Roundtable participants said the lengthening of lifespan now demands a more complex conversation about not only surviving HIV, but also taking actions that can contribute to living a healthier life as one ages.

Those conversations are slowly taking place in communities nationwide. However, the increase in life expectancy for individuals aging with HIV has not been accompanied, in large part, by a change in attitudes toward survival and expectations for a continued full life. Several roundtable participants stated that the pace and breadth of those conversations needs to change now. In their view, surviving is not thriving.

"Survivorship equates to living just to live – almost subsistence," noted one roundtable participant. "There is no growth. Just because a person has HIV and is aging, does not mean that they cannot continue to thrive and live to their full potential."

But, as roundtable participants underscored, people aging with HIV face considerable challenges if they are to have fuller lives. Too many instances of rejection by potential partners, changes in physical appearance, lack of meaningful work and community engagement, limited financial assets, and insufficient systems of support diminishes expectations of thriving. Moreover, the need for a shift in attitude has not been widely embraced or promoted by many of the medical professionals caring for older adults aging with HIV. One roundtable participant noted, "We have a great deal of data on survival, but it's almost like there is this shame to even bringing up all of the other issues that come with aging. There is this attitude that people with HIV should be happy to be alive. That's what medical providers often tell people with HIV."

Despite the obstacles, advocates say that the time has come to move conversations and expectations about aging with HIV beyond survivorship to resilience – not only among people living with HIV but also among medical and social support professionals helping these individuals. "I always thought resilience was one of those things that was inborn," said one roundtable attendee. "But my experience is the opposite. After falling down many ways – health-wise, psychosocial-wise and all other things – I started focusing less on how I fell down and more on how I got back up again."

Roundtable participants said too many people aging with HIV seclude themselves at home watching television, wasting away. “Their minds aren’t engaged, and those are the ones I worry about the most because they’re the ones who have not taken the first step to getting involved,” said one attendee. Meeting participants embraced the need to greatly broaden engagement and a sense of hope among people aging with HIV. Reflective of that position, “No matter your HIV status, you can participate in a program where you learn to foster, build, and strengthen your resiliencies and to see your life as valuable.” This is termed “generativity.”

Advocates suggested that an increase in programs that promote resilience and engagement – not simply surviving – will bolster an individual’s ability to seek more effective care for comorbidities affecting this population, such as cancers and diabetes, as well as frailty-related issues. Such a change in attitude and engagement could help empower patients aging with HIV to advocate more forcefully for access to interventions that can promote healthier aging. Roundtable participants pointed out that such learnings about resiliency may well be transferable to the larger aging community.

Theme Two: Re-engage Older Adults With HIV in Efforts to Improve Their Long-Term Health and Minimize the Complications of Multimorbidity

The incidence of multimorbidity increases with age, regardless of whether an individual is aging with HIV. But as noted earlier, for those living with HIV who have a constellation of other risk factors (smoking, poor diet, high stress, lack of exercise, social isolation, and substance use histories), evidence shows they develop multimorbidity at higher frequencies that significantly impact their quality of life.

In light of advances in treatment options and the burden of multimorbidity, advocates say that people aging with HIV need to become more active in their engagement with HCPs and other support service professionals.

However, fear remains a key element in too many patient-physician conversations, participants noted. “Even in my young patients, they are asking ‘Is my body going to change?’ They are so concerned over that and that poses a problem. They don’t want to go on treatment because they’re afraid of the body changes,” said the roundtable member, an HCP. “They want to look in the mirror and see that same face and body that they’ve seen for years.”

Not surprisingly, efforts to increase the engagement of older adults aging with HIV in their care and to reduce fear-based responses require more education. “When we talk about education, it needs to be very simple, very instructive. We want people to understand what they need to do about healthy aging and what they should ask their healthcare providers,” said one roundtable participant.

Part of that educational effort is to confront myths within the HIV community. For example, some roundtable members stated that excess VAT is seen by many individuals as merely a cosmetic issue rather than a medical condition that may negatively affect comorbid conditions. “We need to stress the broader health impacts of addressing excess VAT,” said one attendee. “If clinicians and educators don’t know the downstream benefits of addressing such conditions, the patients are not going to know it either,” added another participant.

Part of the educational effort includes providing tools, such as an iPhone or Android app, to help patients prepare for and guide conversations with their HCPs on a host of issues that arise as patients are aging with HIV, according to roundtable participants. Among the ideas proposed: an easily accessible checklist of specific tests to ask about and specific questions to raise with medical professionals regarding care options.

Roundtable participants suggested other education-focused initiatives to help re-engage patients in care, including:

- Re-establishing peer-driven education programs (online and face-to-face) to teach patients the skills to proactively discuss health issues with their physicians and, in doing so, to improve their resilience.
- Bolstering the capacity of key community advocacy non-profit groups to create supportive environments for open discussions on barriers to healthy living while aging with HIV.
- Establishing conversations and initiatives that will allow individuals to mitigate the impact of stigma and isolation within the community and empower them to engage more forcefully and fully in health-seeking behaviors.

Theme Three: Increase Education Among HCPs About Multimorbidity Management in the Older Population With HIV

HCPs who treat patients with HIV are very skilled at helping patients to sustain control of their HIV. They do not always have the training necessary to focus on the "whole HIV patient," including needs related to aging. As patients with HIV age, many providers who began their careers as HIV-specific treating providers have had to expand their skill set to encompass care more traditionally associated with primary care providers and geriatricians. "Many HIV-specialty providers are now operating as geriatricians by default and have had to pick up that skill set as they go, even though they weren't necessarily trained in that discipline," one roundtable participant observed.

As a consequence, many roundtable participants underscored the need to discuss with the healthcare community the ongoing needs of older adults aging with HIV and the need to address healthy aging. Participants called for HCPs to purposefully engage their patients in conversations that focus on "their next decade of healthy living with HIV." Those conversations need to go beyond management of the virus and discuss effective management of multimorbidity and other related conditions that the aging population with HIV is increasingly facing.

Roundtable participants discussed several strategies to help providers incorporate support and treatment for comorbidities and healthy aging. These included:

- Increasing training on how to treat older patients, including learning core competencies from geriatrics that can be applied to the treatment of this population.
- Developing efforts to create additional synergy between the providers focused on the general aging community and those specifically focused on the HIV community, so that they may learn models of care that could be applicable to both populations.

- Providing more Continuing Education (CE) for a range of health professionals on caring for people with HIV, comorbidities and other related conditions, such as excess VAT.
- Creating treatment recommendations specific to the older HIV population or providing education on existing guidelines that can be used to focus treatment on older adults with HIV.

The Lessons of Geriatrics Can Be Applied to Treating Older Adults With HIV

Attendees discussed the need to ensure that not only physicians, but also nurses, physician assistants, pharmacists, social workers, case managers, the aging network, and community liaisons who provide wrap-around care receive additional information about how to best manage an aging population with HIV. A common refrain among roundtable participants was the lack of training in the tenants of geriatric care. What's needed? More consistent training for the broad range of medical professionals who care for people aging with HIV, according to attendees.

As one attendee noted, "We are having trouble teaching patients how to handle comorbidities for a variety of reasons. We are short staffed, and patients are reluctant to go to specialty centers out fear of cost, among other reasons. But, we need more resources to be dedicated to educating healthcare providers about geriatric training, because I don't feel that many of us are adequately trained in (multimorbidity) management or geriatrics."

Attendees said one way to bridge this knowledge gap would be to create more synergies between the traditional aging community and the community treating older adults with HIV. "What is the community treating the general population doing to promote wellness among older adults, and how can that be replicated in the population with HIV?" one attendee asked. In short, participants called for assessing models of care that are being used both for treatment and for the promotion of wellness within the general aging community and what modifications, if any, are needed to make them applicable to older adults aging with HIV.

Increasing the Availability of CE Focused on Treating Older Adults With HIV, Multimorbidity and Other Related Conditions

Attendees said that it is crucial to provide more Continuing Education (CE) for health professionals treating older adults living with HIV who evidence multimorbidity. CE programs hold the potential to ensure that an array of health professionals treating this population have current information about more effectively treating patients with HIV who also may face numerous other age-related challenges. Attendees suggested that working with AIDS Treatment Centers (ATCs) could be an effective way to ensure that more providers receive the education they need.

Additional CE could help physicians develop skills necessary to more effectively balance the competing needs of patients with multiple conditions. Continuing Education also could provide strategies for incorporating other members of the care team, including medical and non-medical professionals, into managing care for these individuals.

Guidelines for Treating Older Patients With HIV and Multimorbidity

Roundtable participants were split over the need for standalone guidelines for treating multimorbidity in the population with HIV. Some said that there is a need for treatment guidelines that differentiate between best practices in caring for people with HIV and caring for the general population. Other attendees noted that the population of people with HIV and multimorbidity is not large enough to generate the needed evidence base that underlies typical standards of care. Attendees pointed out that while there are HIV primary care guidelines available, there is little variance between these guidelines and guidelines for treating the general population. Other participants reported that there are a handful of existing guidelines that could be useful in advancing improved care for the older population with HIV, but that they are underutilized due to a lack of widespread knowledge of their availability and utility. One effort to address this issue is the recommendations provided by the expert team that established the www.HIV-AGE.org website. That effort is a collaboration between the American Academy of HIV Medicine (AAHIVM), the American Geriatrics Society (AGS), and the ACRIA Center on HIV and Aging. That group will soon publish a handbook guide for older adults with HIV that will assist them in their healthcare management and interactions with medical providers.

"Inciting a more concerted effort to use and implement best practices and guidance is the challenge," one participant summed up. "Unless healthcare professionals and patients are committed to using guidelines and tracking tools to improve treatment, even improved guidelines will not make a difference in the quality and comprehensiveness of care and improvement in outcomes."

In Summary

With the tremendous growth in the population of people aging with HIV, education at every level, from the patient to the medical provider to those who provide wrap-around social support services, is paramount.

National and local thought leaders who attended the aging and HIV roundtable discussion were united in their conviction that such enhanced and robust educational efforts will enable the older adult with HIV to better embrace aging and achieve a quality of life that reflects the historic challenges that have been overcome by those who battle the complications of the enduring HIV epidemic.

[i] Centers for Disease Control and Prevention. (2015). HIV Among People Aged 50 and Over. Retrieved from : www.cdc.gov/hiv/group/age/olderamericans/index.html.

[ii] Centers for Disease Control and Prevention. (2008). HIV/AIDS Among Persons Aged 50 and Older. Retrieved from: http://www.cdc.gov/hiv/pdf/library_factsheet_HIV_among_personsaged50andolder.pdf.

[iii] NAM aidsmap. (2014). Life expectancy now considerably exceeds the average in some people with HIV in the US. Retrieved from: http://www.aidsmap.com/Life-expectancy-now-considerably-exceeds-the-average-in-some-people-with-HIV-in-the-US/page/2816267/.

[iv] Althoff K, McGinnis K, Wyatt C, Freiberg M, Gilbert C, Oursler K, Rimland D, Rodriquez-Barradas M, Dubrow R, Park L, Skanderson M, Shiels M, Gange S, Gebo K, Justice C, Veterans Aging Cohort Study. Comparison of risk and age at diagnosis of myocardial infraction, end-stage renal disease, and non-AIDS-defining cancer in HIV-infected versus unaffected adults. HIV/AIDS. 2015:60. 15 February.

[v] HIV-Age.org. Multi-Morbidity. Accessed 4.15.2016 from http://hiv-age.org/multi-morbidity/.

[vi] Hasse B, Ledergerber B, Furrer H, Battegay M, Hirschel B, Cavassini M, Bertisch B, Bernasconi E, Weber R, Swiss HIV Cohort Study. Morbidity and Aging in HIV-Infected Persons: The Swiss HIV Cohort Study. HIV/AIDS. 2011:53 1 December.

[vii] Centers for Disease Control and Prevention. (2015). HIV Among People Aged 50 and Over. Retrieved from : www.cdc.gov/hiv/group/age/olderamericans/index.html.