Supplement. HIV, Aging, and The Patient's Perspective

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I have been living with HIV for 35 years and am a long-standing advocate for people living with HIV (PLWH), as founder and executive director of the National AIDS Treatment Advocacy Project. I am greatly concerned regarding the rising and inadequately addressed aging-related issues among people with HIV, including chronic disease morbidity and poor social support, among others. Without an effort to address these needs, our older aging generation is slated for great sickness, disability, and mortality.

The current generation of older aging PLWH consists of the first surviving people with HIV to become elderly. But the entire population with HIV is aging, with the most striking statistic being 75% are over 45 in many large major metropolitan areas where the HIV epidemic is older. As well, 50% are over 50 years old and 25% over 65, in these cities and areas. Aging with HIV is a very serious problem, and it differs greatly from the aging issues facing the general population. Aging older PLWH suffer from more comorbidities and at much earlier ages compared to people without HIV. They suffer higher rates of frailty with onset earlier in age and its onset among the community occurs with a steeper curve of onset than among people without HIV. Studies show as PLWH reach around 65, the slope of onset for heart disease, bone disease, and frailty steepens compared to people without HIV. Rates for cancers are higher among PLWH. Kidney disease rates among older PLWH are much higher compared to people without HIV, as are rates for many key morbidities. On average, PLWH over 60 years old have 3-7 comorbid medical conditions. Polypharmacy with 12-15 medications taken daily is common. This polypharmacy may increase with therapies added to prevent cardiovascular disease (e.g. statins), underscoring the need to consider the benefits vs. risks of therapies with PLWH in a shared patient-clinician decision-making framework. This is particularly true in elderly patients for whom the risks of drug-drug interactions and off-target side effects may be greater. Increasingly, older aging PLWH face worsening disability with a more premature onset than aging HIV-negatives. The risk for heart disease and heart failure may pose the greatest risk, as studies report on average 50% higher rates up to as much as 75% greater compared to people without HIV.

People living with HIV are more vulnerable, and as they age are often alone and disabled, unable to receive the attention they need and deserve. The inequity of this is dramatic. The Ryan White Care Act (RWCA) and annual domestic HIV government spending is $5-10 Billion a year, yet there are no formal programs funded to provide for these needs. We need special support services for older aging PLWH who need them, and for their clinics and clinicians. This program should be part of the domestic funding for HIV in the USA, and could be included in the RWCA, as part of the National HIV/AIDS Strategy, and championed by the Office of AIDS Research, Centers for Disease Control and Prevention, and National Institute of Allergy and Infectious Diseases. Currently, the problem of care for people aging with HIV gets inadequate attention or substantive discussion that could lead to a solution. I worry that, as a result, these patients suffer in silence and will decline further, in the absence of the assistance and support they need.

Why is this not a great focus? There is no entity dedicated specifically to addressing HIV-related

aging. There is no national advocacy effort and little federal leadership to address this issue. Clearly, this group of older aging PLWH needs special support services for themselves as well as their clinics and clinicians. Yet this need remains largely unmet. In a large city like New York, there are aging services for meals, housing, social support, home healthcare. Yet all too often, even in New York City, linkage and use of these services remain low. I am afraid as time goes by and these individuals become increasingly disabled and sick there will be no programs for them, and inadequate care, as they fall between the cracks. Our field remains consumed by HIV prevention and cure research, yet the possibility of a cure remains very difficult to achieve and even if possible, years away. Older aging PLWH suffering the devastating ravages of premature aging, senescence, and disability are suffering NOW and need help NOW. The comorbidities they are suffering from – including but not limited to cardiovascular diseases – need to be addressed NOW. Already, many aging PLWH are emotionally homebound due to depression, and are socially isolated; as well, they often suffer from lack of mobility and an impaired ability to perform normal daily functions. Do we not owe the first aging generation of PLWH to become elderly with more dignity and respect?

Ultimately, if we are to curb the oncoming epidemic of HIV and aging, we will need better awareness and more patient-focused research and care efforts. We owe better to the aging population of people living with HIV, without whose years of advocacy and engagement in research and care we would undoubtedly be in a worse position than we are today.