People ageing with HIV face an uncertain future

As an increasing number of people age with HIV, social and health services could struggle to adapt to their complex needs. Talha Burki investigates.

UNAIDS estimates that 7.5 million people over the age of 50 years are now living with HIV. With the current generation of antiretroviral therapies (ARTs) offering patients a life expectancy roughly in line with that of the general population, HIV is well on its way to becoming an epidemic of the middle-aged and elderly. The shift is particularly pronounced in the USA and western Europe.

In the UK, around 40% of people accessing HIV care are more than 50 years old and in the next few years over 50s are likely to form the majority of cases of HIV in the USA. It will take considerably longer for this to happen in sub-Saharan Africa, but the region is already home to more than 2 million people infected with HIV in this age group.

“The epidemiological picture is changing”, said Giovanni Guaraldi (University of Modena and Reggio Emilia, Modena, Italy). “You see it when you sit in your clinic and you watch the patients walking in”, he told The Lancet HIV.

A 2015 modelling study concluded that by 2030, three-quarters of Dutch patients infected with HIV will be aged 50 years and over. “We believe that our results can be generalised to other high-income countries with mature epidemics predominantly in male populations and a history of good access to HIV care”, noted the authors. Health-care systems and caregivers will have to adapt to the greying epidemic.

People infected with HIV are more vulnerable to conditions such as cardiovascular disease, type 2 diabetes, kidney disease, liver disease, osteoporosis, and several cancers.

“Many of the diseases we normally associate with the ageing process are increased in patients with HIV; this is especially noticeable in those who started treatment late in the disease course, which really means the vast majority of patients around the world”, explains Peter Hunt (University of California, San Francisco, CA, USA).

“As people get older, we are going to see much more of these age-related complications.”

The relative contributions of lifestyle, inflammation, and the virus itself to such complications have yet to be defined. The biggest risk factor in non-AIDS cancers in people living with HIV is smoking. Avoiding the habit could prevent 37% of these malignancies. Moreover, people infected with HIV are only more likely to develop certain specific conditions; there are plenty of diseases for which risk levels are not elevated.

The investigators in the Dutch study predict that by 2030, 84% of people with HIV will have at least one non-communicable disease, 29% will have at least three comorbidities, and more than half will be prescribed medications alongside their ART, with a fifth of patients expected to receive at least three other medications. If the current tranche of antiretroviral drugs is still in use, the scenario outlined in the modelling study would result in up to 40% of patients facing complications as a result of drug-drug interactions and contraindications.

As with ageing among the general population, it is impossible to predict exactly how old age will look for any given patient.

“If I get HIV now, in 10 years’ time my clinical picture will not be the same as a person who acquired the virus 20 years ago; ageing with HIV and contracting HIV at an old age are totally different issues”, points out Guaraldi. “When we talk about ageing, we are really talking about a geriatric syndrome and for patients with HIV, the nature of the syndrome will depend on how many years they have spent with the virus, rather than how old they are.”

There are very few data on elderly women with HIV or on how the virus affects the menopause.

Patients diagnosed before the introduction of ART in 1996 are likely to experience the greatest difficulties. Clive Blowes is HIV and Ageing Lead at the Terrence Higgins Trust, a non-governmental organisation based in the UK. He sees increasing numbers of HIV-positive patients with other conditions such as chronic pulmonary obstructive disease, neuropathy, and frozen shoulders, all of which are related to the early treatments. Frailty is also an issue for this cohort.

“People who were diagnosed in the era before ART were told that HIV was a death sentence”, said Blowes. “Their clinicians probably said to them ‘look, you’ve got 6–12 months to live, get out there and make the most of it.’”
Large numbers of Britons with HIV made the understandable decision to live for today. They quit their jobs, ran down their savings, sold their houses, and cashed in their pensions. The advent of medication saved their lives, but the virus had left them debilitated. Those who were not up to returning to work were placed on disability benefit.

“It was not everyone, but there was a pretty big group of people living with HIV in the 1990s who were moved into the welfare system and left there”, said Blowes. These individuals came to rely on benefit payments, but recent reforms have meant that their eligibility has been reassessed.

“It has been an incredibly stressful time, people who have been out of the job market for 20-plus years have been told that their benefits are being withdrawn. People are scraping by on limited finances at a time when the cost of living is rising; it leads to a creeping loneliness and isolation, they are concerned about their housing and how they will be able to afford nutritious food,” said Blowes.

Uncharted Territory, a 2017 report by the Terrence Higgins Trust on people living with HIV aged over 50 years, found that a third were reliant on benefits and the vast majority were worried about their future financial security. 58% of those aged 55 years and older lived on or below the poverty line, double the rate for the general population. 82% of those surveyed reported moderate-to-high levels of loneliness.

“This is a huge problem for people living with HIV as they move into their 50s and beyond”, said Guaraldi. “We need to concentrate on how to measure loneliness and start programmes that can engage people in old age.”

Gay men, especially those from older generations, may be estranged from their families. Social circles may have been depleted, perhaps even wiped out, by the HIV/AIDS epidemic. Many people will have been grieving for years; some may be experiencing survivor guilt.

“There is a certain amount of stigma in the gay community to do with ageing; people put value on being young and fit”, adds Guaraldi. All of which contributes to the elevated rates of depression among those who are ageing with HIV.

Guaraldi notes that the Italian health-care system implicitly expects youngsters to take care of their parents. “Many of my patients do not have children; they were advised not to because of the infection, or they are gay men”, he told The Lancet HIV. “Who is going to look after them?”

“ Those who require social care can find themselves encountering the same kind of stigma that characterised the early days of the epidemic”

The situation is similar in the UK. “A lot of people living with HIV live alone; they do not have partners or children, and they are worried about what will happen to them if they get sick. I think the health-care system does make an assumption that families and children will help out,” Blowes explained.

Those who require social care can find themselves encountering the same kind of stigma that characterised the early days of the epidemic. Uncharted Territory recounts the story of an elderly man in Wales who was turned away from two residential care homes because of his HIV status, whereas a third home agreed to accept him only on the condition that he paid double the standard rate.

A woman with HIV living in a care home in London was discouraged from associating with the other residents and had the television remote control taken away from her and disinfected.

Blowes visits care homes to apprise staff of the realities of HIV. “Health and social care professionals have not been updated on where the science is today; the massage about ‘undetectable equals untransmittable’ is not getting picked up”, said Blowes.

“We have not had a public awareness campaign in the UK since the 1980s, so people are still carrying around outdated views.” He urges services, particularly those related to social care, to ensure that staff are adequately trained in dealing with individuals who are infected with HIV.

Hunt points out that there are two key issues. “The first is about the science to understand the ageing process for those with HIV, and to develop interventions to prevent all those multimorbidities; researchers are spending a lot of time looking at this”, he said.

“The second is about what we do about people living with HIV who have already developed multimorbidities and are frail; that has to be addressed by health-care systems.”

He recommends establishing multi-disciplinary teams to treat people living with HIV. “We need a coordinated network that addresses the heart disease, the bone disease, the mental health issues, and so on”, Hunt told The Lancet HIV.

“We could take a cue from the geriatric field in terms of establishing a holistic approach, focusing on function.”

Guaraldi agrees. “The principles of geriatrics are good for people living with HIV; we need to teach these principles and move beyond viral load and management of co-morbidities”, he said.

“We should be concentrating on overall health and the intrinsic capacity of an individual; look at what they are able to do, rather than the diseases that they have.”

Talha Burki