Our Days Are Numbered

As I face open-heart surgery, I wonder how my elders in the HIV movement are best served, whether the elderly even need HIV services and what they might look like.

May 3, 2021 By Bob Leahy

I've now faced two life-threatening diagnoses. First out of the box was HIV, in those challenging pre-treatment days. Now, many years later, I need open-heart surgery for something called aortic stenosis, or I will die. Think heart valve replacement; the operation is currently awaiting scheduling. I'm coping OK. Wish me luck!

I've lived with HIV since 1993. Almost 30 years later and well into my 70s, I'm thinking about what the HIV community has to offer. I can't be alone in that. The population at the front lines of the epidemic in those early years is growing in size, joined by others. Many of us are not just aging, we are aged and all that entails. Slowing down, grumpy even and increasingly experiencing comorbidities. That describes me, at least.

It's bringing back memories. I remember an early interaction with the community, perhaps my first encounter with a roomful of people with HIV. It was a regional conference, a series of workshops and opportunities to mingle with our kin. I found family. First session on the agenda, though, was about palliative care. Compassionately handled but matter of fact. I remember asking if palliative care settings allowed your dog to be with you when you passed. (The answer was yes. I was glad about that.) We went on to talk about powers of attorney, living wills too. It seemed a natural topic, after all. We were all facing death then.

Later, I was a regular speaker at our local hospital talking to nurses in training about palliative care for people with HIV. Eventually the topic became less relevant, so we talked about care for those with HIV in a more general sense. Then that work dwindled too. People living with HIV more often than not were responding well to treatment and living normal lives. Nobody talked much about being old, yet alone dying. Conversations were always, always about living.

Now we die—and we are dying in more numbers than ever before because our aging contingent has grown—not dying as a result of HIV but from other causes, more often than not comorbidities like diabetes, cardiovascular disease, respiratory illnesses. We no longer talk much about palliative care though, or even being old or infirm. The HIV response is no longer geared to those of us approaching end of life. HIV and aging conversations are, in fact, often dominated by the middle-aged with totally different concerns to folks like myself.

Where are our elderly?

Should our elders be better served? I think so, but there are challenges to catering to the elderly. We are all but invisible, except to the general health care system, for which we tend to be high volume users. We retire, we get sick, we no longer visit HIV service providers. The advocates within our cohort go silent. There is no squeaky wheel, and few services recognize our precarious existence and declining quality of life. As for discussions around end of life, I have hardly heard the words “palliative care” muttered in decades.

But here’s the rub: Do the elderly even need HIV-related services? If so, what are they? The questions remain largely unanswered, at least at the local level. Organizations like the World Health Organization say HIV-related palliative care is important, though.“Palliative care is an essential component of a comprehensive package of care for people living with HIV/AIDS” they say, “because of the variety of symptoms they can experience—such as pain, diarrhea, cough, shortness of breath, nausea, weakness, fatigue, fever and confusion. Palliative care is an important means of relieving symptoms that result in undue suffering and frequent visits to the hospital or clinic. Lack of palliative care results in untreated symptoms that hamper an individual’s ability to continue his or her activities of daily life. At the community level, lack of palliative care places an unnecessary burden on hospital or clinic resources.”

So why do International AIDS Conferences largely ignore aging issues, yet alone the issues of our most elderly living with HIV?

Speaking with our feet

I don’t want to focus just on palliative care, though. The question is: Do the elderly living with HIV have special needs that service providers need to address, be they housing-related, home visits, food, workshops or various forms of practical assistance peculiar to the elderly? Or are HIV-related service providers largely irrelevant to the elderly? Have we spoken with our feet? I haven’t stepped inside the doors of my local AIDS service organization for years, for example. But then I’m privileged. I’m partnered and someone who copes fairly well with adversity. Others aren’t any of those things.

The reality is that many older people living with HIV are marginalized and live without the kind of home and community supports we take for granted. Says Kate Murzin of Realize, the Canadian agency with an agenda that includes HIV and aging issues, “Several of my own colleagues and friends who are older people living with HIV have had health crises over the last few months that have landed them in a hospital, increased their contact with the health care system, or just generally interrupted their lives. Thankfully they’ve had support—emotional, practical or both—from their family or partners, but my latest research project, PANACHE Ontario, confirmed that many older people living with HIV don’t have that. These situations remind me that we’re reaching a tipping point in the HIV community. We have to act now to make sure that formal supports are there for the oldest and least-resourced because they may be needed any day now.”

Kate says recent events have been illustrative. “The COVID-19 pandemic has revealed the undercurrent of ageism that persists in our society. I like to think it’s also created an opportunity in that more people are speaking out about the problems that plague our systems of care for seniors. From an advocacy perspective, more voices are more likely to affect change.”

It’s not that some service providers aren’t responding entirely. Realize is exploring Advanced Care Planning. Those are the buzzwords that describe “a time for you to reflect on your values and wishes, and to let people know what kind of health and personal care you would want in the future if you were unable to speak for yourself.” As well, a handful of organizations in Canada like ACT and others have conducted workshops addressing similar needs. But if there is an appetite for more to be done, elderly people living with HIV need to speak up.

So what of the future? As we move toward more holistic standards of care, where HIV services are better integrated with those of other health care providers and community services, HIV agencies probably have a place. We need frank discussions about what that place looks like. Not just a presence at our funerals and celebrations of life but the months and years leading up to them. We are family, after all.

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