LIVING WITH HIV OVER THE LONG-TERM:
COMMUNITY REPORT

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Jessica S. Cattaneo[1], Soo Chan Carusone[2,3], Lydia Makoroka[1], Stephanie Karapita[2], Kenneth King[2], Kate Murzin[4], Winston Husbands[1,5]

[1]AIDS Committee of Toronto, [2]Casey House, [3]McMaster University, [4]Canadian Working Group on HIV and Rehabilitation, [5]University of Toronto,

AIDS Committee of Toronto (ACT)
www.actoronto.org
E: info@actoronto.org
T: 416-340-2437

Casey House
www.caseyhouse.com
E: info@caseyhouse.on.ca
T: 416-962-7600

CASEY HOUSE

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REPORT SUMMARY

This report presents the results of *Living with HIV over the Long Term*, a qualitative study led by community-based researchers at the AIDS Committee of Toronto (ACT) and Casey House. The project developed in response to feedback from community stakeholders in Toronto that people living long term with HIV – sometimes referred to as *long-term survivors* – were not well supported within the HIV service landscape. Since the introduction of Highly Active Antiretroviral Therapy (HAART) in 1996, the medications available to treat HIV have been effective at managing the replication of the virus in the body, improving the health of people living with HIV. Today, a person diagnosed with HIV able to access and adhere to HIV medications can anticipate a life expectancy similar to that of uninfected populations.[1] Even though living long term with HIV is the reality for most people living with the virus, the long-term experience of HIV is poorly understood. This study was designed to address this knowledge gap and build our understanding of the priorities and experiences of people living long term with HIV in Toronto.

We carried out 4 focus groups with 31 people who identified as living long term with HIV and key informant interviews with 17 service providers and administrators who work within the HIV-sector. Our focus group discussions and interviews centred on the following questions:

1) How is the concept or term *long-term survivor* used and understood in community and social service contexts?
2) What are the care and service needs, challenges and priorities for people living long term with HIV?
3) How does the long-term use of health and social services shape experiences of living with HIV over time?

Participants' descriptions of living long term with HIV shared much in common with general depictions of living with chronic illness. Research participants described: fluctuating periods of health and illness; uncertainty related to disease progression; the reworking of life expectations and identity; the burden of care falling largely on the individual living with HIV and their family/social network; and stigma associated with illness and dependence on government supports. Two

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[1] Nakagawa et al. 2013

features emerge as central to the experience of living long term with HIV: holistic healthwork and accumulated impacts.

Holistic healthwork refers to "the active, purposeful work that people living with HIV do to look after their health".[2] People living with HIV long term described a broad range of activities, programs, and services that they engage in or access to manage their health over time. While this healthwork could enable long periods where their HIV felt managed or contained, our focus group participants emphasized that regardless of the state of their physical health, they needed to commit considerable time and energy to healthwork. *Accumulated impacts* refer to the ways in which the impact or effects of living with HIV accumulate over time. For instance, episodes of illness were described as having a cumulative effect on physical, mental, and financial health, as well as social networks. Key informants explained that individuals did not always return to their previous state of health following an episode of acute illness, and that managing these episodes required one to draw on financial or social supports, which could strain or even exhaust these resources. Research participants also drew attention to more positive or productive impacts, particularly in relation to patient/service user knowledge and expertise, relationship building, and community development. For instance, research participants described the connections that develop over time between people living with HIV and service providers or organizations as a significant outcome of their long-term engagement with HIV-related services. We feel it is important to frame HIV as a chronic illness, as this understanding may enable us to develop programs and services that can better acknowledge and respond to the burden of care associated with HIV and the ways in which its effects accumulate over time.

We asked focus group participants and key informants to talk about the needs, priorities, and challenges that people living long term with HIV may experience. Participants described a broad range of issues which we have grouped in terms of three key themes: growing older, income and practical supports, and social and community engagement. Participants also spoke about their experiences accessing programs and services over the long term. Their feedback suggested that the way in which services are delivered is perhaps more significant than the content of any particular program. Research participants highlighted the importance of flexible services that can respond to an individual's strengths, needs, and social context.

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[2] Mykhalovskiy 2008: 137

Lastly, we asked research participants to reflect on their understanding and use of the term *long-term survivor*. There was no consensus across individuals or groups on the value or definition of the term. In fact, several participants changed their opinions and ideas about the term through the process of discussion and reflection. Despite this, individuals diagnosed with HIV pre-HAART were included in all participants' definitions of *long-term survivor*. Participants were also clear that there were important distinctions or differences between someone who had been living with HIV long term and someone more recently or newly diagnosed.

Reflecting on our research findings, we end the report with a number of considerations or recommendations for care and support services appropriate for HIV as a chronic illness. These include: a focus on relationship building for long-term engagement, person-centred care, continuity of care across sectors, and integration *and* specialization of HIV care. We also recommend policy change that would recognize HIV as a chronic illness, as well as research focused on the effects and implications of HIV-related stigma. If the integration of HIV care is to succeed at more effectively responding to the needs of people living with HIV over time, HIV-related stigma needs to be addressed across health and social service sectors.

STUDY BACKGROUND – WHY ASK QUESTIONS ABOUT LIVING LONG TERM WITH HIV?

Living with HIV Over the Long Term developed in response to feedback from community stakeholders in Toronto that people living long term with HIV – sometimes referred to as *long-term survivors* – were not well supported within the HIV service landscape. Although there has recently been an increased focus on issues related to aging and HIV, it is difficult to find research or programming focused more specifically on the durational aspects of living with HIV – work that considers the impact of time (not only age) on the experience of health and wellness for people living with HIV. Since the introduction of Highly Active Antiretroviral Therapy (HAART) in 1996, the medications available to treat HIV have been effective at managing the replication of the virus in the body, improving the health of people living with HIV. Today, a person diagnosed with HIV able to access and adhere to HIV medications can anticipate a life expectancy similar to that of uninfected populations.[3] The impact of these medical advances can be seen in the shifting demographic profile related to the disease: in Canada the number of older people living with HIV has doubled in the past 20 years, and in the United States more than half of the HIV-positive population will be 50 years or older by 2015.[4] Even though living long term with HIV is the reality for most people living with the virus, the long-term experience of HIV is poorly understood. This study was designed to address this knowledge gap and build our understanding of the priorities and experiences of people living long term with HIV in Toronto by asking the following questions:

1) How is the concept or term *long-term survivor* used and understood in community and social service contexts?
2) What are the care and service needs, challenges and priorities for people living long term with HIV?
3) How does the long-term use of health and social services shape experiences of living with HIV over the long term?
4) What can the experiences of people who have lived long term with HIV tell us about developing programs and services for HIV as a chronic illness?

There are three key intersecting themes that informed this study: the concept of long-term survivor, the shifting demographic profile of people living with HIV, and HIV as a chronic illness. Originally, the objectives of this study focused on addressing ambiguities and knowledge gaps related to long-term survivors specifically. The long-term survivor identity emerged before the advent of HAART but its definition and use has evolved with the

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[3] Nakagawa et al. 2013
[4] Chambers et al. 2013

improvements in the understanding and treatment of the virus.[5] We quickly found however, that this focus was too narrow; the identity remained ambiguous for many of our research participants, and although most of the people we spoke to saw value in the concept, they were often ambivalent about its use in relation to HIV. Instead, we found that paying attention more broadly to the durational aspects of HIV better enabled us to address our research questions and capture the current context of HIV care.

Research focused on aging and HIV has been important in developing knowledge related to living long term with the disease. There is a growing body of research aimed at understanding the intersection of HIV and aging for older people living with HIV, both in terms of their physical health and the social contexts in which they live.[6] However, aging and living long term are different, though overlapping, issues[7]. A Vancouver study comparing the experience of aging between gay men diagnosed pre-HAART and older gay men diagnosed in their 40s and 50s, identified important differences between the two groups. Those who had lived long term with HIV were more likely to live in poverty because of years on disability support, to have experienced AIDS-related multiple losses, and to experience challenging and painful side effects from long-term use of HIV medications.[8] Research has also pointed to the strength and resiliency of long-term survivors to meet adversity and to advocate for themselves and their communities.[9]

We hope this report will contribute to our knowledge of and ability to respond to issues related to living with HIV, while offering a broader frame for considering the impact of time on the experience of illness.

Methods and Participants

Living with HIV over the long term was a qualitative study involving focus groups with people living with HIV and key informant interviews with service providers and administrators working within the HIV-sector in Toronto. Both focus groups and key informant interviews took place in the spring and early summer of 2011. Most of our discussions with research participants focused on issues related to health and social services. We were interested in knowing if the priorities or needs of people living long term with HIV were addressed in the current service landscape. As this study was the project of two community-based organizations, we wanted to understand the experience of living long term with HIV in terms that we could directly apply within our organizations.

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[5] Epstein 2004
[6] Chambers et al. 2013, Husbands et al. 2012, Solomon et al. 2013
[7] Owen and Catalan 2012
[8] Robinson et al. 2008
[9] Leaver et al. 2008, Robinson et al. 2008

We asked focus group participants to talk about their current priorities and needs, and followed this discussion with questions about the type of care and support services that could or do enable them to meet their needs. More specifically, we asked focus group participants to talk about 1) the range of programs and services they currently use, 2) the differences between formal and informal supports, 3) their experiences accessing programs and services, and 4) how their use of services, and/or their connection to community-based organizations, has changed over time. We also asked focus group participants if they considered themselves to be long-term survivors, and how or if they used this term. (See Appendix I – Focus Group Discussion Guide)

Similarly, we asked key informants to share with us their ideas regarding the needs and priorities of people who have lived long term with HIV, and what gaps or barriers they felt these individuals may experience in terms of the services available to them. We also asked key informants how they understood the term long-term survivor, if their organizations had any care and support services designed for or used primarily by long-term survivors, and if they or their organizations experienced challenges in terms of understanding and meeting the needs of their service users who have lived long term with HIV. (See Appendix II – Key Informant Interview Guide)

What emerged was a picture of living long term with HIV framed around the particular experience of using health and social services. This picture is limited - understanding the lived experience of individuals through their use and experiences with institutionally-defined responses to health and illness is partial. Although we sought to understand the experience of long-term survivorship, in many ways the object of our study was our institutional response(s) to HIV and its suitability for people who have lived long term with this disease.

FOCUS GROUPS: INDIVIDUALS LIVING LONG TERM WITH HIV
A recruitment flyer was posted at AIDS Service Organizations (ASOs) in Toronto and circulated through the online networks of various HIV-related organizations and groups. Four focus groups were carried out with 31 individuals who self-identified as living long term with HIV. Focus group discussions were audio recorded, each lasting about 2 hours. Participants were also asked to complete a short socio-demographic questionnaire.

The average age of participants was 47 years (ranging from 20 to 68). Individuals had been living with HIV for an average of 18 years (ranging from 6 to 30 years). Twenty three (74%) of the participants were male, 7 (23%) were female and one identified as a transwoman. Fifteen (48%) participants identified as gay, 12 (39%) as heterosexual, 3 (10%) as bisexual and 1 as two-spirited.
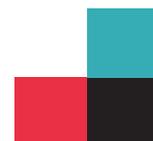
Twenty-six of the 31 focus group participants self-identified their ethno-racial background. Half (13/26) of these participants identified as Caucasian, four (15%) as Aboriginal and four (15%) as African (other categories included Caribbean, Middle Eastern, other).

Demographics	N (%) / Mean (range), n=31
Age	47 years (20 – 68)
Years living with HIV	18 years (6 – 30)
Gender	23 (74%) male 7 (23%) female 1 transgender person
Ethnicity **(self-identified)**	14 (45%) Caucasian 5 (16%) African/Caribbean/Black 4 (13%) Aboriginal
Annual income	23 (74%) < $20,000 4 (13%) $20,000 - $50,000 2 (6%) $50,000 - $69,000 2 (6%) Did not respond
Employment ***Individuals identified all that apply**	1 (3%) Working, full-time 3 (10%) Working, part-time 24 (77%) Accessing disability insurance

TABLE 1: FOCUS GROUP PARTICIPANT CHARACTERISTICS

KEY INFORMANT INTERVIEWS: SERVICE PROVIDERS AND ADMINISTRATORS
We carried out 14 key informant interviews with 17 service providers and administrators. Individuals were identified by the research team and invited to participate in an hour-long interview that was audio recorded. Seven front-line workers and 10 managers/directors from 11 different organizations participated. The participating organizations included ASOs and hospitals within the Toronto-area (see acknowledgements for a full list of participating organizations).

ANALYSIS
Each focus group discussion and key informant interview was transcribed. Three members of the research team read all the transcripts, developed the coding framework and coded the data. The full research team discussed the emerging themes and provided feedback on the analysis process.
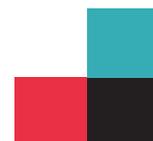
UNDERSTANDING HIV AS A CHRONIC ILLNESS

The descriptions of living long term with HIV offered by our research participants included a number of components common to general depictions of living with chronic illness. Framing HIV as a chronic illness is not novel; depictions of HIV as a chronic illness started as early as the late 1980's.[10] However, this depiction is often understood as *emerging* or as *in-process* – the shift in understanding HIV as predominately a chronic illness, rather than an acute and consistently fatal disease, is not universal. The ongoing characterization of HIV as emerging as a chronic illness relates in part to the slow and inequitable access to antiretroviral treatment (ART) in the Global South.[11] In addition, there are concerns that viewing HIV as a chronic illness contributes to notions of HIV as a mostly manageable and stable illness, contradicting the lived experiences of many people who are HIV-positive.[12] And in some cases, the mismatched distinction between infectious versus chronic diseases may have delayed the development of policy and healthcare strategies for HIV as a chronic illness. Currently HIV is classified as an infectious disease by the Public Health Agency of Canada, although its definition of chronic disease could mostly be applied to HIV: "chronic diseases, also known as noncommunicable diseases or NCDs, are diseases that are persistent and generally slow in progression which can be treated but not cured."[13] Many of our research participants drew comparisons between HIV and other chronic illnesses, and often expressed concerns that although defining HIV as a chronic illness could help normalize the disease, it could also reduce public concern or urgency around the disease.

> Male2: *Well today it's more treated like… the psychology of it all is treated more like, "well, he's got HIV. Well, he's basically like a diabetic", okay? It's not contagious if he does what he's supposed to and he's been treatable and the disease should be somewhat contained. Okay, it's not like it was years ago, you figure oh it was bed sheets, and the hospitals they were putting down disposable bed sheets. I mean, the whole thing was just bent out of shape, but now it's evolved.*

> Male4: *I think the dangerous part of that is that that mentality filters up to Government as saying, oh well everyone's living longer and everyone's taking their meds and everyone's being treated, and everyone's… So we*

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[10] Scandlyn 2000, Colvin 2011

[11] Deeks et al. 2013, Kendall and Hill 2010, Russell and Seely 2012, Swendeman et al. 2009, Wouters 2012

[12] Colvin 2011

[13] Public Health Agency of Canada 2014

> *kind of start pulling back on our funding because, you know, we want to give*
> *people $500 extra a year in the bank accounts from saved taxes.* (FG3)

Because research participants often described living long term with HIV using experiences that shared important similarities with general depictions of living with chronic illness, we found it useful to explore the literature on chronic illness. We see an opportunity to contribute to this literature by introducing common experiences shared by our research participants. By drawing on this literature, we seek to complicate ideas that stability and manageability are fundamental markers of HIV as a chronic illness.

Living with HIV Over the Long term and Chronic Illness Experience

Chronic diseases are rarely curable and often have a prolonged and lifelong course, with fluctuating periods of health and illness or episodic disability.[14] Ongoing or potential fluctuations in health are often depicted as requiring a constant reworking of identity, as one reorganizes their expectations or assessment of their life course.[15] Living with chronic illness also requires individuals to cope with uncertainty related to disease progression.[16] Much of the literature focuses on the concepts of self-care, self-management, and/or healthwork as the burden of managing chronic illness generally falls on the individual living with illness, and their families, friends, and/or communities.[17] Relatedly, doctor/patient roles fluctuate, as the individual living with chronic illness develops knowledge and expertise related to their illness. Also identified in the literature is some degree of tension or competing role/behaviour expectations for people living with chronic illness – not only will they fluctuate between periods of health and illness, they may simultaneously inhabit roles related to being sick and being healthy.[18] Stigma is identified as a feature of illness experiences generally. In the context of chronic illness, stigma is often linked to notions of illness as avoidable, the result of an individual's poor choices, lifestyle, and/or behaviour.[19]

Literature that highlights the structural dynamics that shape lived experience argue that, in the context of neoliberal economies, *health* is a commodity that individuals are expected to invest in by utilizing self-care and self-improvement strategies.[20] In this context, the ongoing use of government-funded support is interpreted as a moral failing, and the consequent loss of

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[14] O'Brien et al. 2008
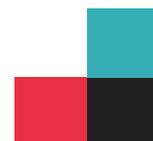[15] Bury 1991, Kelly and Field 1996, Kralik 2002
[16] Mishel 1990
[17] Corbin and Strauss 1985, Kralik et al. 2004, Gately et al. 2007, Clarke and Bennett 2012
[18] Galvin 2002, Higgs et al. 2009, Varul 2010
[19] Clarke and Bennett 2012, Varul 2010
[20] Clarke and Bennett 2012

autonomy is often experienced as a challenge to self-concept and identity.[21] Managing the visibility of illness is also a part of chronic disease experience as individuals work to make markers of illness visible in order to access resources, and in other contexts work to conceal illness in order to avoid stigma and discrimination.[22]

HOLISTIC HEALTHWORK

All of these features or aspects of living with chronic illness emerged when research participants talked about living long term with HIV. Throughout this report you will find accounts of fluctuating periods of health and illness, uncertainty related to disease progression, and experiences of stigma. Because we asked focus group participants to talk about the different programs and services they've used, we also heard a lot about the ways in which they manage or take care of their health. Sometimes referred to as self-care or self-management, we prefer to use the concept of healthwork to refer to these activities, borrowing from Mykhalovskiy and McCoy who describe the term as referring to "the active, purposeful work that people living with HIV do to look after their health".[23] In the community-based research project, *Making Care Visible*, the concept of healthwork was used as a methodological tool to understand how people living with HIV make decisions related to HIV medications. They found the term useful as it enabled them to consider "the wide range of practices that people engage in around their health, without defining in advance what the work might or should involve".[24] Similarly, in talking about their use of programs and services and connection to community-based organizations, research participants in our study identified various activities as part of the work of taking care of one's self and community:

> *Well, I mean, I access my doctor every three months. I access the laboratories that do my blood work every three months, one more if necessary. I access the pharmacy in order to get my meds. I access [ASO] for food, for haircuts, for financial assistance. I access [ASO] for counseling, support groups. I volunteer at both those organizations.* (Male5, FG3)

> *Whenever I hear of [a research project] I try to do it because I feel that I don't have a job, I'm not doing anything else, I may as well contribute something to the data or at least to make something out of my experience that they can use for future use.* (Male2, FG3)
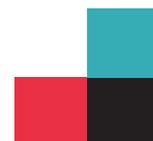
Focus group participants described a broad range of activities, programs, and services that they engage in or access, including counselling, support groups, food programs, social

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[21] Galvin 2002
[22] Hay 2010
[23] Mykhalovskiy 2008: 137
[24] Mykhalovskiy and McCoy 2002: 24

programs, income supports, case management, massage, respite care, and volunteering. Because our recruitment strategy relied on the networks and connections related to ASOs, the people who participated in our focus groups were likely overly representative of individuals who are significantly engaged in HIV-related programs and services (not all people living with HIV access ASOs, and may draw from other resources to support their healthwork). The individuals who participated in our focus groups describe relatively constant and significant engagement with healthcare systems, institutions, and professionals. While this healthwork may enable long periods where their HIV feels managed or contained, our focus group participants emphasized that regardless of the state of their physical health, they still needed to commit considerable time and energy to healthwork. Engaging in healthwork also provided participants some sense of control over the uncertainly related to fluctuations in health and wellness. This presented a challenge, as many participants needed to access external or government funded resources to maintain their health, yet sometimes found they were denied these resources precisely because their efforts were proving successful:

> *But you're also penalized, I mean, I've lived this long, I've worked really damn hard to be healthy, to take care so that I don't have to go to the dentist, so that I don't have … not that I don't when that happens, I have to. But the issue is that I'm working really hard, and then they're going to cut my special allowance for food off the menu kind of routine because you're too healthy.* (Male1, FG3)

Research participants described the healthwork necessary to manage HIV over the long term as requiring a holistic approach to health and illness, because these are states of being shaped by multiple and interacting factors. This is not an uncommon understanding of health and illness, as concepts/theoretical approaches including the social determinants of health[25], syndemics,[26] and intersectionality[27] seek to understand illness within the social, economic, cultural, political, and geographic contexts of lived experience. Research participants talked about the ways in which poverty, metal health issues, co-morbidities, discrimination, and social isolation amplify the experience of illness. One key informant explained, "when one piece goes often another piece goes, often another piece goes. And oftentimes we can see just a de-compensation in a person's depression can lead to poor sleeping habits, poor diet and eventually the meds go, right, that sort of investment in yourself"(KI-4). Healthwork therefore, required attending to these multiple dimensions or areas of life, which, depending on one's resources, could be difficult. As one focus group participant put it, "HIV is not my problem, it's everything else." (Female2, FG3)

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[25] Commission on Social Determinants of Health 2008, Hamilton and Bhatti 1996
[26] Singer and St. Clair 2003, Singer et al. 2006
[27] Rapid Response Service 2013
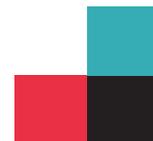
ACCUMULATED IMPACTS

In addition to the interconnection or interaction of multiple factors on health and well-being, participants described the experience of living with HIV as having an accumulated impact over time. Episodes of illness were described as having a cumulative effect on one's physical, mental, and financial health, as well as social networks. Key informants explained that individuals did not always return to their previous state of health following an episode of acute illness, and that managing these episodes required one to draw on financial and social supports, which could strain or even exhaust these resources.

In addition to episodes of acute illness, the ongoing healthwork that individuals engage in to manage their health was also described as having an accumulated impact over time. For instance, the impact of accessing disability-related income supports was described as producing financial insecurity and over time, could led to challenges related to self-esteem and social engagement:

> Male1: *… another problem with those groups is financial issues. There is a lot of assumptions on their part sometimes that you have the finances to be able to go to a restaurant. Do you know how much it costs to go to a restaurant just for dinner? Or if you want… there's certain fees involved. So, I mean, there's restrictions there in that regard, I mean, that's great, you can join these groups and I understand that. But if you're not financially prepared or have the funds to be able to keep up with the rest of these people- you know, and sometimes having been so long poor, and not having a lot of money, you're up against people who do … they talk about their latest trip to the Caribbean or, you know, it's just- I can't relate.*
>
> Interviewer: *You feel left out?*
>
> Male1: *Well you do and you become more isolated and then you go home and you stay home because you don't want to go back again.* (FG3)

Research participants also drew attention to more positive impacts that accumulate over time, particularly in relation to patient/service user knowledge and expertise, relationship building, and community development. For instance, research participants described the connections that develop among people living with HIV over time as a significant outcome of long-term engagement with HIV-related services:

> *First of all I think they're a bit of a brethren. That's funny but, at least around here, they often know of one another. They've had long contact with one another in the community. And they're ... they track one another in terms of how folks are doing. And they often recall times when they weren't unwell.* (KI-12)

Relationship building was also identified by focus group participants and key informants as an important consideration related to service engagement over the long term. As one focus group participant explained, "because I see this person on a weekly basis, that's enormously helpful for me … when I think of my future and all the uncertainties, it suddenly seems very important to me because there's a continuous consistency there." (Male1, FG2) This was important in terms of the relationship between service user and service provider or organization, where the personal connection developed over time could impact service use and outcome:

> *Because you see a client from giving birth, I mean, none of us have been here eighteen years, but you see people pretty long term and then to stop a service is hard. But for positive kids they can go onto other services, but that is not an easy transition to make … those kids are seen from birth. The people in that clinic have seen them from birth to eighteen. That's a really hard transition for them to make.* (KI-8)

And similar to accounts of living with other chronic illnesses, research participants also discussed how people living with HIV develop knowledge and expertise related to their illness and the services available to them:

> *I think clearly one of the things that we do see well, long-term survivors are also – many have incredible assets and skills and strengths in terms of the ability, because they've been HIV-positive for so long that they've seen all of the multiple layers of the evolutions of this disease and the different interventions and treatments and all that, so some of them are better educated than some of their doctors.* (KI-4)

Examples of the accumulated impact of living with HIV can be found throughout this report as research participants consistently drew attention to the importance of understanding and addressing accumulated impacts in terms of both the content and delivery of care and support services.

DEFINING AND UNDERSTANDING THE TERM *LONG-TERM SURVIVOR*

The term *long-term survivor* emerged early in the HIV epidemic to refer to individuals who were living beyond clinical expectations. This term is sometimes used inter-changeably with the term "long-term non-progressor", referring specifically to individuals who maintained a relatively high CD4 count in the absence of anti-retroviral therapy.[28] The term has evolved and was not universally applied or understood by our research participants. In order to contextualize the voices and experiences of individual participants in this study, and increase our understanding of current definitions and use of the term long-term survivor, we explored the meaning of the term directly. In the focus groups, participants who identified as living long term with HIV were asked to describe how they understood the concept of long-term survivor and whether or not they identified as long-term survivors. Key informants (service providers and administrators) were asked how they would define the term and whether or not they used it in their work.

Individuals who were diagnosed at the start of the HIV epidemic, before the advent of HAART, were the only individuals included in all descriptions of long-term survivors (regardless of medication history). For some of our research participants, these were the only individuals for whom this term applied. This group was referred to by one participant as "the pioneers" who continue to be "the thin edge of a wedge that tills the soil that hasn't been tilled yet". (KI-5)

Individuals diagnosed pre-HAART were felt to be united by a collective community experience. Participants identified shared experiences of stigma, trauma and loss as common to individuals in this group. These experiences, even if they occurred decades ago, were felt to strongly influence their current experiences and ways in which they seek support. Our research participants identified receiving a diagnosis with a very short life expectancy as a universal and defining experience for individuals who were diagnosed pre-HAART. For example, one participant explained how his diagnosis immediately affected his family: "I was told six months and I had four children and they took away the kids and everything and that was 30 years ago. And nothing happened in six months." (Male3, FG1) One service provider reflected on how this diagnosis experience also relates to early activism, and still influences the needs and experiences of the cohort today:

> ... *for a lot of people being told, you know, having the sense that they are not going to live very long and all of the stories of the 80s and look at the ways people were diagnosed, the kind of horrific bigotry and contempt that they encountered in the medical system, the lack of support on many, many levels. Potential positives*

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[28] Pogash 2005, Sáez-Cirión et al. 2005, Tremblay and Bernard 2009

around community development and activism, anger and the way that mobilizes people and the way it also plays out defences, so for some people they are re-exploring what drove them for so many years, you know, kind of finding new ways of being. So, loss of work, loss of health, loss of friends, stigma, development of new identities around that, trying to cope with that, the way stigma can reignite developmental issues related to shame. (KI-7)

Participants felt that the experience and impact of diagnosis is quite different today. As one key informant said:

I think with recently diagnosed people, they don't carry the weight or they don't have the history of a lot of the brutality I think that people living with HIV over a longer period have seen. They're almost invariably more hopeful, knowing that treatments are available, know that some of the long-term side effects may be able to be avoided. They may have very minimal disruptions in their work. They're often employed people. So there's a vast difference between long-term survivors and newly diagnosed I would say, yeah. (KI-3)

This account of what it might be like to be newly diagnosed in the present day can be contrasted to the experience of individuals in the focus groups. One focus group participant explained his experience of diagnosis:

Back in the 80s there wasn't even a test to even discover that you were HIV positive because for me it's going on to 26 years and I went through no testing, no - then testing, then false testing, then the health board coming down on you, then it being declared that you've got two to three years to live, get your affairs in order and then through the procedure of experimental drugs...

He talked about his medical struggles but then how this experience has influenced how he lives much more broadly:

Trying to now... having to deal with trying to validate your life or your existence is the hardest thing for me right now. (Male3, FG3)

Discussion of the early epidemic often involved reference to the political and social norms at the time. "Because the investment in the cause was different then, it was because everyone was dying and we all had to get together and look after everybody that was dying and it galvanised all of us. I don't know anybody my age that didn't sit on a care team."(KI-4). One key informant referred to HIV as not just a disease but a "politic" (KI-3). For those diagnosed before HAART, participants frequently expressed the interconnectedness of the medical diagnosis of HIV and the socio-political experience of living through that period of time. Both focus group participants and key informants emphasized the importance of respecting these

experiences and activities of long-term survivors "looking to the future, I mean, I would hope that that would be respected for the huge impact it has on people's lives." (KI-14)

Although the experiences of this pioneering cohort are unique, there may be important similarities to the experiences of individuals diagnosed with HIV after the introduction of HAART. This may be more apparent in circumstances where individuals are coming from countries, for example, where HIV medications are not readily available or where trauma and loss related to socio-political conflict are common. This cohort of pioneers offers important opportunities for understanding medical, psychiatric and psychosocial issues related to living with HIV, and the associated medications and complications. Insight on these issues could inform not only the care of the cohort members themselves but also the current and future care and support of all others living with HIV.

Although those diagnosed pre-HAART were included in all participants' definitions of *long-term survivor*, there was no consensus across individuals or groups on the value or definition of the term. Individuals themselves changed their opinions and understanding of the term through the process of discussion and reflection.

Some focus group participants immediately identified with the term and acknowledged it as something they were proud of, viewing it positively. Others seemed somewhat indifferent about the term ("I never thought about it until now. I'm just thinking, you know" [Male2, FG2]). Some tentatively agreed that they were a 'long-term survivor' but felt it was not something they owned or was a part of their identity. One focus group participant responded to the question of whether the term was meaningful to them by saying "I just don't know what else to call it" (Male7, FG1) another said "It's okay, but I don't use it personally" (Male1, FG2).

Although not a common view, a few focus group participants explicitly resisted the term because either they did not want to use a disease specific identifier ("why do I have to name myself after a disease, it's just an illness" [Female2, FG1]) or they did not agree with some implications of the word "survivor" ("I have a problem with the word 'survivor' because I don't feel like a victim" [Female2, FG2]).

In addition to the issues raised by those living with HIV, there were additional concerns from service providers and administrators. Although key informants might have a definition of this term they did not feel that this was consistent with how individuals living with HIV might identify.

> ... I have a definition in my mind, I'm not sure they have the same definition, so if they do say, 'I'm a long-term survivor', I say, and 'when were you diagnosed?' and 'when did you go on medication?'. So I can fill in the blanks in my own head. And I try not to... I would never say to somebody, 'well then you're not, strictly

speaking, a long-term survivor'. I just leave it at that and I just need to understand what the situation really is. (KI-13)

There were no external criteria that could be set or that were felt to be appropriate for using the term *long-term survivor*, unless the individual also chose to identify with the term. Definitions proposed and discussed varied from living five years with HIV to including individuals who had "survived" the start of the epidemic and the community experience, regardless of their HIV status. The question was also posed as to whether a youth who had been living with HIV their entire life but did not know their status should be considered a long-term survivor. A few key informants described the term as having always been fluid, changing meaning as the experience of living with HIV changed.

> *So even the term long-term survivor I see shifting over time because the long term won't mean anything anymore … because long term is like 20 years, five years, ten years, are we going to have debates about this?* (KI-5)

However, the lack of clarity in defining the term was not felt to preclude the utility and importance of the identity. As one key informant explained, "...there is a certain segment of the [people living with HIV] population that clearly identifies that way and owns that as an identity, and I think that identity is incredibly important in terms of the multiple layers of what that means for people..." (KI-4).

The identity of long-term survivor was felt to be important for some individuals to allow individuals with potentially similar experiences to come together. "So, if you don't have a name for something then people don't even know how to find you." (KI-5). One focus group participant described how he uses the term to help educate others:

> *I personally do use the term long-term survivor when referencing myself. Usually I'll say "I'm living with HIV" as opposed to "dying of AIDS" or something like that, in a positive context. But I'll use the term sometimes in conversation as "long-term survivor"' because I find it an easier reference point for some of the people that I'm talking to, for them to get their head around what I'm trying to say... and if I can show somebody that I'm living with it 24 years and if they've just been newly diagnosed, then that doesn't necessarily hopefully mean that it's, as it once was regarded, a death sentence or the negativity they're experiencing about their own future prognosis. They realize that it has to be put in context.* (Male3, FG2)

There was a clear sense that long-term survivors, however they were defined, were a discrete group from those who were newly diagnosed. This distinction usually came up in the context of services and their target audiences. A dichotomy often emerged from services designed for "younger, newer people" (Male3, FG3) versus others who were identified in one focus group as

"the bulk of PHAs who have been living with it for say three, four, five years or more" (Female2, FG1) or "people that's 20, 25 years diagnosed" (Male2, FG3).

LIVING WITH HIV OVER THE LONG TERM – PRIORITY ISSUES

We asked focus group participants and key informants to talk about the needs, priorities, and challenges that people living long term with HIV may experience. Participants described a broad range of issues which we have grouped in terms of three key themes: growing older, income and practical supports, and social and community engagement.

Growing Older with HIV

All research participants identified aging with HIV as an emerging and pressing issue that requires immediate attention. Although the length of time a person had lived with HIV was described as having accumulated impacts that were distinct from their age, research participants also stressed the ways in which growing older could accelerate or increase accumulated impacts. While they acknowledged that aging was a normal and universal experience, they were concerned that for people living with HIV, physical decline could occur earlier, and would be complicated by a lack of adequate infrastructure and resources. In the context of aging, the accumulated impact and amplification of illness related to living long term with HIV were described as real challenges for maintaining health and wellbeing:

> *I think there's anxiety around sort of long-term care, if you will. So, living with HIV for 20 years I'm now getting to an age where I'm starting to experience age-related problems as well. My medication and my HIV status is exacerbating some of those problems. Like how will my needs be met as this … because it's only going to get worse, not better as I get older.* (KI-10.2)

Key informants and focus group participants used terms like "premature aging", "rapid aging" or "accelerated aging" to describe a concern they saw as applying to people living with HIV, and more challenging for older adults who had been HIV-positive for many years. Accelerated aging was explained as the appearance of various health issues associated with older age, but developing 10 to 20 years earlier in people living with HIV. These health challenges were described as occurring rapidly and in succession:

> *Now that's the spectrum with which we deal with. But you know, "oh my god I've got osteomyelitis in my knee - oh I have to have my knee removed" … "They're going to fuse my leg", okay. So that gets done and you think you're doing okay and "oh my god, I've got an abscess in my foot now and..." And for many of them, as hard as they try to overcome, it seems like they often are just facing a new illness and with greater frequency as they age.* (KI-12)

Health complications were sometimes attributed to long-term exposure to HIV medication and/or a long-term exposure to HIV, and participants were often unclear if these age-related issues could be treated or cured. Key informants described doubt as to whether they had acquired enough knowledge to quickly respond to these health problems. Uncertainty related to HIV and aging was expressed as a challenge for service providers as well as people living with HIV. Key informants in particular expressed frustration for being unable to anticipate the health-related needs of their services users:

> *I am thinking about what's next and I can't anticipate it because the folks I'm hanging out with, I'm kind of behind them. And as they live their experiences I'm going, "Oh, my God, we do need to be thinking about dementia, we do need to be thinking about physical abilities, we do need to be thinking about…" I can't even imagine social connections for people. And I hadn't anticipated thinking of those things. So I'm always half a step behind, going "are our current [programs] actually relevant?" And I have to listen really hard to what the issues are that these folks are bringing forward and respond well.* (KI-5)

Key informants and focus group participants spoke specifically about cognitive health issues related to aging, with several focus group participants indicating that they had begun to experience health challenges in this area. Participants wondered how inevitable cognitive decline would be for them, and how cognitive impairments would impact their ability to care for themselves and manage their health. They also expressed concerns about the dearth of services related to cognitive health, and wanting to access supports to help prevent, treat, or live with cognitive health issues:

> *I guess a big issue for me is that I did testing for cognitive, but I was disappointed. After I got the report it said you have some issues, but they don't tell you where to go to get help with that issue. And my doctor got the report, he just looked at it, he didn't say "we can send you there". So I was very … because cognitive issues are exploding in the community, it's a big issue. But I was never told where to go. So I always have to, which I'm doing now, I'm going to try to find a place that can say, well, "here's what we got on paper, and here's how you can deal with it, you can improve your brain". But I was very disappointed, you get tested but you're not told, if you get results, where to go to get help … I was like, I've got three reports saying that I can't live independently, I need help. Finance has to be taken care of, you know, I have to be assisted. And they left me there. I got a nice printout, but where do you go? And every time we called somewhere, "no we can't help you", "no we can't help you".* (Male6, FG1)

Similarly, many key informants expressed concerns related to the impact that cognitive impairments would have on one's capacity to manage their healthcare needs. As one key informant explained: "…about 30% of our clients have a significant cognitive impairment. To the point where they, you know, can't live on their own, require a substitute decision maker. Or lack the capacity to engage in caring for themselves." (KI-12)

Research participants also shared concerns related to social isolation for people as they age with HIV, both in terms of the negative impact of isolation on people's mental health, and the challenge of managing one's health and well-being independently as needs increase. Many described declines in the informal supports they could draw from, a decline that may have begun in the early 80s as people lost friends and family to the epidemic and the stigma that surrounded HIV/AIDS.

> *As you get older, especially coming through the AIDS era, a lot of the peer groups that I probably would've grown up with or still have around, etc, have died. They're not there. I have one person left that I know from that era. So and through, you know, other issues, medical issues and so on and so forth, you have a tendency of not involving yourself socially as much as you used to. But as you get older it gets harder … Right. I have, you know, difficulties in regards to dealing with somebody who's younger sometimes because I can't talk to them about something that I felt good about, you know, years ago, or had a good time years ago, or I can't, you know, in that regard. Maybe it's just my lack of social skills. But it's like sometimes it's kind of difficult.* (Male1, FG3)

With increased health needs and fewer informal supports to draw from, most of our research participants talked about concerns related to the institutional care and support services that older people living with HIV will be able to access. Although research participants described living long term with HIV as leading to skills in terms of navigating health and social services – as one focus group participant put it, "all of us can advocate for ourselves and coordinate ourselves out of a paper bag" (Female2, FG1) - many suggested that the complex care issues that emerge as one grows older could lead to more challenging experiences related to navigating and finding services. And while ASOs were often described as a useful and easy starting point to access HIV-related services, they were not described as being well connected to aging-related services:

> *I think one of the things that I am noticing is that some of those … the complex care issues that seem to be occurring … seem to have created circumstances where they are less able to do that navigation piece. Our systems have become more complicated too, right, and our systems are changing, you know, the LHIN [Local Health Integration Networks] and how our health systems are intersecting*

with the social service systems and the housing systems, they're shifting and changing and so that skills set, right, also. And so it speaks to that whole navigation piece. (KI-4)

Both service users and service providers described a steep learning curve as they began to navigate long-term care and gerontological services. Some key informants discussed age-related access barriers, "inherently that's one of the very big challenges we face, is they have a body that presents with those physical needs, and they need access to those kinds of services, but they're not old enough to get those kinds of services, which are often age-specific" (KI-12). A second key informant went on to explain that disclosing the individual's HIV status was often the only way to ensure access to needed services:

If I don't say, you know, "HIV positive with family history of osteoporosis", or somehow make it clear that … even like, most of the criteria for that particular tests are … mostly it's in women, not in men, who get that test and mostly it's women of a certain age, so you know, when they get a requisition for a young man and you don't specify this person has, you know… you could say a long-standing chronic medical disease, but even if you said long-standing chronic medical disease, they'd e-mail you back or call you back and say, what? What disease? Right, like … I don't, you know, MS [multiple sclerosis], that won't cut it for you, right? So yeah, you do have to disclose the status. (KI-13)

However, stigma related to HIV and sexual orientation was a huge concern for research participants when discussing services for older adults, many sharing stories of people living with HIV who received subpar care, or were denied care entirely, by long-term care facilities. Research participants feared that long-term care facilities do not have the capacity to support people living with HIV, and several key informants had begun to work with various long-term care facilities with the aim of improving the kind of support people living with HIV could receive from these institutions. Several of our key informants expressed concern that older long-term survivors would again experience discrimination and trauma when accessing geriatric or long-term care facilities:

So what happens is a schism is created where the HIV, again, becomes a politic so many years later because on the forefront of appropriate resources for people who are older, again, it's not available much the same way it was in the 80s in health care, not available for people … so the same sort of thing is happening just, you know, 30, 35 years later for the people who are still [pause] had to fight the first fight are now continuing to fight another fight. (KI-14)
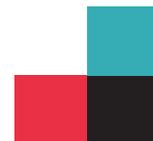
Income and Practical Supports

Research participants identified needs related to income and practical supports as an ongoing and significant concern for many people living with HIV. When these needs were unaddressed or poorly addressed for long periods of time, the consequences accumulated and extended into all aspects of a person's life. Research participants consistently identified income, housing, and food as priorities for people living long term with HIV. Disability-related income supports were described as inadequate, although some research participants distinguished between private long-term disability supports and the government disability supports, the former providing greater financial stability and health coverage. However, once individuals reach 65, they can no longer access private or government income support programs, and must rely on the Canada Pension Plan (CPP), Old Age Security (AOS) and any savings or private pension plans they invested in. Research participants described this as a challenge, particularly for those diagnosed before the advent of HAART. Many stopped working when they were first diagnosed and have been accessing income supports for much of their adult life. Because it is often difficult to save money when living on a fixed income, they feared entering older age with great financial insecurity:

> *Well the problem is that when you live longer you're starting to chew into your savings. You're looking in your mind short term five years, ten years. Well, if you're living 15, 20, whatever years after that, all of a sudden you look at your savings account, it's not there. So what do I do? I'm forced into a whole other realm of need, okay. So the Government doesn't give a shit about that, they want you to save, save, save. But if you live longer and you're not working how the hell can you save, you know, where the hell is the savings? You've lived off of that to survive.* (Male2, FG3)

Focus group participants, most of whom were accessing disability supports, described consistent challenges meeting their needs related to housing, food, and health-related expenses that are not covered by provincial health insurance (dental care, psychologists, mobility supports, homecare). Some challenges were related to bureaucratic mistakes that left individuals without income support or drug coverage. Other challenges related to being ineligible for many support services because they were too healthy or made too much money.

> *I just went with my friend to the, like, you mentioned the [food bank]. And I went with my friend to help him carry groceries back. And I showed them [my] ODSP [Ontario Disability Support Program] thing and he said, "well, you can only come once a month and you can only get so much because you make too much". How can anybody on ODSP make too much?* (Male4, FG1)
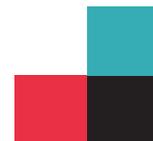
The issue of housekeeping or housecleaning came up in two of our focus groups. Several participants explained that they were physically unable to regularly and properly clean their home. They framed housecleaning as an important support to maintaining comfort and dignity – however they were unable to find a subsidized service they could afford. One older participant explained,

> *I've tried, to get some sort of a subsidized housecleaning. Somebody comes in and helps, because there's certain tasks I can no longer do. I can't scrub the floor; I cannot scrub the sinks or the basins or the rest of it or the bathtub, okay. I physically cannot do it. I break into a cold sweat, you know, it's exhausting. So I'm saying, is there a housekeeping facility that I can go to and access. And they say, "oh yeah, oh yeah, at $20 to $28 an hour." Well, for Christ sake, if I had that kind of money I wouldn't be bothering you to say "Is there…" you know, I'd just go hire someone. I know it's going to get worse because my health is not always going to be as good as it is today. And who the hell is going to do all this housekeeping if I want to maintain a roof over my head? I don't want to live in a pigsty.* (Male2, FG3)

Focus group participants did describe practical support services designed for people living with HIV as much more accessible. For example, this focus group participant described accessing a food bank at an ASO, "I know I can rely on them when I don't have money … I can see that there is in our community, they know what we need. Yes and we go there, they don't ask me for how much income you have, because whatever income you can get, it's easy to spend the money." (Female1, FG2)

Participants also described serious limitations in terms of the income and practical supports available. One focus group participant explained "With the money you can't live like a normal person anyway. You can never go on vacation, you can never have a Christmas"; she later added, in relation to subsidized housing, "I didn't like it at all because you have a room, you can't have pets, you can't have your friends over really and you just can't have a life, right. Can't have a life at all." (Female2, FG1). Many focus group participants also described the experience of accessing and being dependent of practical supports demoralizing, "it's just like, now I'm in the [supportive housing] situation, again, and I hate it. I feel like I'm three years old." (Female1, FG1)

All of our research participants described these challenges as having a negative impact on their health and overall well-being. Challenges related to accessing supports were linked to stress and anxiety "trying to get coverage, it can be a bit weird. It can be taxing, it can be stressful" (Male4, FG3). And living within the means of available supports was described as isolating and as possibly leading to depression and other mental health issues. Both focus

group participants and key informants identified employment supports and rehabilitation as priorities for the HIV-sector to meet the needs of people who have lived long term with HIV. Research participants often connected employment as an avenue to regain dignity, validation, autonomy, and break isolation.

> *I think for a lot of people, especially if we're looking at guys who could of course be as young as in their 30s, sometimes in their 40s and 50s, is that they've been on disability for a long period of time. And it's a huge, huge question for people about whether or not they can go back to work. They may have been on ODSP [Ontario Disability Support Program] for extended periods of time, finding themselves bored or anxious or motivated to look for work … I think is a really critical part of what long-term survivors are looking for because they've survived beyond what they had anticipated and that's a huge element of course that we're looking at here. So it applies to rehabilitation and enabling people and facilitating people going back into the work force.* (KI-3)

Research participants described challenges in re-entering the workforce after a long gap, and were thankful for programs that enabled them to learn necessary skills ("I am very computer illiterate") or return to school. However, not all focus group participants knew about the existence of these supports and there was a sense that employment-related programming and rehabilitation should be better promoted. At the same time, many research participants shared concerns about potential employment experiences. People may be able to return to work, but the employment opportunities available to them may not be ideal. As one key informant explained, "And so a big challenge for us is how do you work with the client to successfully get them to return to work and also be able to get some satisfaction of what they do and be able to retain employment." (KI-10.3) Focus group participants were particularly concerned about being able to engage in the healthwork they needed to, while employed. They worried about having to disclose their HIV status in order to obtain accommodations from their employers, and having to work in an environment where they experienced stigma related to HIV and requiring workplace accommodations:

> *It's good the school that I go to, there is accommodations, all open, the disability program. But after that program I would like to have an employment where people understand my situation. I'm doing this for the placement now, but people are wondering if what they say is true. Today I had two appointments and I had a meeting at work, but arriving today at 12:00, the person [I] had the meeting [with] … was saying it was like it was my mistake. But I called that I had two appointments in the morning, so they don't know. At school, I've been there for two years, the Faculty Coordinator is aware of everything. Exposing myself in placement, it can be something else, so I'm really frustrated there. And I'm*

thinking about problems of employment; so I want to have employment where they understand. (Female3, FG2)

## Social and Community Engagement

Our research participants identified isolation as an issue that many people who have lived long term with HIV struggle with. Research participants attributed isolation to a number of causes including: side effects of medications, lipodystrophy, poverty, multiple losses, stigma, mental health issues, and mobility issues. They also frequently discussed the broad impacts of isolation, including ongoing dependence on income supports, depression, decreased social skills, boredom, and increased or deepening isolation. Programming that enables or increases social engagement was favoured by both focus group participants and key informants. This included employment programs, support groups, and social programs and drop-ins. In this respect, ASOs were often positioned as an important companion or support in the healthwork of people living long term with HIV:

> *What I was going to say with regard to support services, for me it hasn't always just been what the agencies are designed to give you in the way of counselling or the essentials, market, the food bank or the meals program or whatever you will. For me over the years what it's become is it has given me structure to my week and it has given me a reason to live and bring myself out of my depression. Because again, coming downtown, like no family and friends either chuck me onto the garbage heap or didn't want to know me anymore; I hadn't worked in a number of years, so when I came downtown it was a chance to reacquaint with who I want to be, who I am.* (Male3, FG2)

Several research participants discussed volunteering as a way to keep busy, be social, and engage in community issues. However, one key informant raised a concern related to volunteer work when people are living on limited income support:

> *A lot of them, you know, get caught up in all these activities and volunteer work, but at the end of the day, a lot of them … a lot of our clients feel that they're not doing anything for themselves. It's like a kind of burn-out; they give, give, give, they want something back too … In terms of something for their own life, for their own future, because they're on a very limited income.* (KI-2)

Both focus group participants and key informants talked about the value of social programming that allows them to have fun, socialize and "just get your mind off things" (Male3, FG3). This included outings and trips to a play, amusement park, or zoo – activities that were not focused on HIV, but where "you would physically go somewhere with a group that were all in the same boat so no one was judging anyone. And we'd have for a couple of hours a good time,
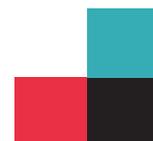
socialize and the rest of it". (Male3, FG3) Some key informants also recommended drop-in style programming with some facilitated activities, like cooking or art therapy. One key informant explained:

> *A lot of people need contained environments. Like being alone at home isn't doing it but they have a hard time tolerating a group or learning a task. But to have a situation where they are with other people and they are doing things that help them, that might be helpful … a place where people can go and they are doing something and there is food shared and it is very meaningful and there is not this weird construct of mental health being placed on top of it.* (KI-7)

Support groups were often described as important and impactful programs, "those support groups, you know, they push you higher and higher and you get yourself established from one point to another" (Male7, FG3). In particular, the peer element of these groups was highlighted by key informants as an essential feature of the HIV-sector:

> *I think that the support that people can get from other long-term survivors is we can't [pause] it's so hard to estimate the value of that because what happens when people come back to me and their inner group that's connected and is going well, no amount of what I could say or do could replicate or contribute to what they get from being with other people in a well facilitated group. So I think we need more of those groups.* (KI-3)

In addition to particular programs and services, some of our research participants suggested ASOs look beyond programmatic or institutional responses related to isolation. Instead they argued that ASOs could also play a role in broader community development efforts by prioritizing relationship building and community mobilization that was not attached to a particular program, service, or need:

> *I think we need different questions, and it's not about "what are your needs here?", it's about "who are you?" and "what are your big questions?" and can we help each other with these big questions ... "need" is too small. Identity questions are right because then they're about belonging and relationship to - ASOs are one part of it … like, we're a means to an end, right; we help people find each other. We help people sit together and ask good questions and think long thoughts and that's actually helpful for them, and they don't just see themselves as having needs that an agency is supposed to fill. It creates a different relationship as participants in [their] own experience.* (KI-5)

ACCESSING CARE AND SUPPORT SERVICES OVER THE LONG TERM

> *You see when they designed the programs they didn't think people were going to live that long anyway. So how can you build up a program where you don't even think it will be needed?* (Male3, FG3)

Throughout our focus groups and interviews, research participants described ASOs as an important and/or potential source of support for people living long term with HIV. Support with the ongoing healthwork that is often part of the chronic illness experience, as well as support during episodes of illness and periods of transition. However, as the quote above indicates, many of our focus group participants felt that the programs and services available at most ASOs weren't designed for people who have lived long term with HIV. Our research participants offered insights and recommendations in this regard. Many of their suggestions were related to the content of programs and services, wanting to see more programming related to aging, social and peer engagement, as well as income supports and employment. Research participants also shared concerns that the current system of health and social supports could not support people's ongoing efforts to maintain a state of health and wellness when living with a chronic illness like HIV. This emerged consistently when focus group participants described challenges related to accessing income and other practical supports. It also emerged when key informants described the range of services necessary to prevent and recover from episodes of acute illness. One key informant reflected on her own experience to illustrate her concern:

> *So I use the example, I had my knee replaced last year. So I got 12 sessions of physio, secondary to having my knee replaced, right? I had to get myself to the hospital. I had to get myself to the physio clinic. And get myself back home again every day. For 12 sessions. Which I ended up doing every other day because it was just a nightmare … and I'm well-resourced. I have a car, I have a family, I have money, I can actually pay. But can you imagine if you didn't? So these guys don't have the money or the access to services. I think people don't see everything that surrounds medical care, like housing and food and issues like that as part of their health.* (KI-12)

Research participants also had a lot to say about how services were delivered. In many ways, service delivery emerged in our interviews and discussions as more significant than the content of any particular program. Both key informants and focus group participants described the importance of services that were flexible or individualized. Key informants who work one-

on-one with people living with HIV described tailoring their style or approach to their clients. Most key informants highlighted the current range of services available as important, even highlighting how participation in other programs positively impacts the outcome of their own work with clients. One key informant explained that a range of services was important because "it is not one size fits all" after expressing concerns related to the consequences of providing too little or too much support, "If you give too much to someone they get deskilled. So some people need to be out in a place where they are cooking or they are shopping or they lose those skills. You are doing them a disservice if you are supplying all of that". (KI-7)

Participants highlighted the importance of care that considered the whole person. As one key informant explained, "I think it is our job to actually take into consideration their whole lives even if I can't respond to their whole lives." (KI-5) Many focus group participants described this in terms of being defined by their illness:

> *Don't look at me and say "Oh, you are living with HIV and everybody else having AIDS, all of those needs are the same." No, each one of us inside here has different needs and different criteria … So look at each individual differently. So that is one of the first things that the organizations need to do, but "Oh, that doesn't fit this HIV patient." We are not an HIV patient*. (Male4, FG2)

Focus group participants also described challenges when they felt patronized by service providers who provided support they didn't need. While some participants indicated they were happy to have service providers advocate on their behalf, others found this demeaning or unnecessary, as this participant explains, "they wanted me to set time to fill out a [Canadian Pension Program] form. I'm like, 'I have a degree, what's wrong with you? You think I can't read?' I was horrified." (Female2, FG1) What we heard throughout most of our focus groups and interviews was the value of service providers who ask questions and listen to what their clients tell them:

> *I think one of the areas that concerned me is that if people have been positive for so long, assumptions are made that everything is fine. Oh yes, they're taking their medications. Yes, they seem to be happy and so on. So that I think there's a risk of assuming that people are fine until there's a kind of crisis thing that happens that they end up coming to me for … just checking in with long-term survivors about, "hey it's been a long time that you've been on disability and you've been really feeling well. How's that going?" Without pressuring people, but asking questions so that people feel they can be brought up or, "it's been a long time since you've been in a relationship, are you okay with that or are you feeling like you're looking for other possibilities or where are you at?" Because I think people can be, in a*

medical setting particularly like this, if the numbers look good, they're adherent, they seem to be fine, then they're rushed in and out, and that concerns me. (KI-3)

In general, understanding the key features of living long term with HIV – holistic healthwork and accumulated impacts – determined participants' experiences in accessing or providing services. Systems and programs that could support the healthwork necessary to manage HIV over time, and respond to the accumulated impacts of living with this disease (in terms of both positive and negative effects) were described as useful by our research participants.

HIV OVER THE LONG TERM: CONSIDERATIONS AND RECOMMENDATIONS

Our recommendations are grounded in the voices of those living with HIV over the long term and the service providers who support them. Understanding HIV over the long term requires that we consider the durational aspects of living with the disease, the historical context that shapes individuals' experiences with HIV, and the ways in which illness experience changes both over time and across the lifespan. By focusing on the HIV over time, our research participants described HIV with all of the features common to chronic illness experience. In particular, ongoing holistic healthwork and the accumulation of impacts emerged as fundamental aspects of living with HIV over the long term. By understanding HIV as a chronic illness, we may better acknowledge and respond to the burden of care associated with HIV and the way in which its effects accumulate over time. The recommendations emerging from this study are focused on this understanding of HIV. We offer 7 recommendation grouped under 3 categories: programs, services, and systems; research; and policy.

PROGRAMS, SERVICES, AND SYSTEMS

Our research suggests that understanding the burden of care associated with HIV is fundamental to the development and provision of health and social services that support people living with HIV and their communities. Ensuring that people living with HIV have access to HIV medications is one critical component of adequate treatment. Supporting long-term adherence to these medications in the context of the social determinants of health and individual's informed choice is perhaps a more significant aspect of HIV treatment. Programming that asks the question, "what do you need to manage you illness?" and asks this question consistently taps into the expertise of people living with HIV and considers the changing experience of illness over the life course. With this in mind, we have four programming-related recommendations:

Relationship building for long-term engagement: The potential for long-term relationship building is important in terms of providing or accessing care related to chronic illness. Our focus group participants described the relationships they had developed with service providers and organizations as fundamental to their healthwork. We recommend relationship building be considered an important component of care that can sustain long-term engagement with organizations. Over time, relationships may need to shift or grow in order to accommodate changing roles or levels of engagement.

Person-centred care and support: All of our research participants described the importance of tailoring services to individuals. Their feedback highlighted the range and variation of support

needs among people living with HIV, and how these needs may change over time. They also emphasized the importance of considering the whole person, including their social networks and contexts, when addressing health-related issues. In many ways, their feedback points to the concept of *person-centred* or *patient-centred care*, "care that asserts that patients are persons and partners in care and should not be reduced to their disease alone."[29] Participant feedback suggests that many ASOs provide care that is person-centred – a commitment to the greater involvement of people living with HIV (GIPA) provides this foundation to service delivery and engagement. However, accessing services outside of the HIV-sector was consistently described as frustrating, often as a result of narrow eligibility requirements that limited access. Our research findings suggest that people living with HIV will benefit from services and systems that are person-centred across sectors.

Continuity of care: The concept of *continuity of care* is related to the quality of care over time, and refers to the extent to which services are delivered as part of a coordinated and uninterrupted succession of events consistent with the medical care needs of patients.[30] Our research suggests a need for greater continuity in the delivery of care across sectors. This was true for participants accessing aging-related services, but also emerged in their discussions of experiences with income supports, housing services, and practical assistance.

Integration and specialization: The medical and community response to the HIV epidemic resulted in the creation and then expansion of HIV-specific services and supports. Our research findings suggest, building on our recommendation for greater continuity of care, that services developed for people living with HIV should be better integrated into broader health and social service systems. However, our research participants also indicated that some specialized services for people living with HIV, as well as community development efforts, are essential for appropriate and person-centred care. Greater integration does not necessitate the dismantling of the HIV service sector, but may require some shifts related to service provision, along with greater communication and coordination between sectors. In order for integration to meet the needs of people living long term with HIV, systemic changes toward person-centred care and the elimination of HIV-related sigma must occur across sectors.

RESEARCH

In order to implement our recommendation related to programs, services, and systems, we feel need to strengthen or develop knowledge in the following areas:

Develop knowledge about how to work collaboratively, across systems and sectors: Health services research that examines the relationship that ASOs have with other sectors, and their

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[29] Olsson et al. 2012: 457
[30] Guilliford et al. 2006

role or capacity to connect people living with HIV to other services, may help to support greater continuity of care. Research that examines the way in which other sectors work together, for instance mental health and long-term care, may also support knowledge development on this topic.

Develop an understanding about HIV-related stigma in the context of service integration: Our plans for the future must be informed by the effects and implications of HIV stigma and also continue to work to identify interventions and measures to address this barrier. Given the complexity of HIV and the history of stigma within the healthcare system, we recommend that various care models, HIV-specific and not, be rigorously evaluated before major changes are made. Evaluations must consider not only outcomes of those that engage in the care model but also accessibility, retention and the client experience. Stigma remains an important barrier to promoting health in those living with HIV.

POLICY

Recognize HIV as a chronic illness in public policy: Although HIV is described as a "chronic, progressive illness" by the Public Health Agency of Canada, it remains classified only as an infectious disease. HIV is included in the provincial chronic disease management policies/strategies in only three provinces (Newfoundland, New Brunswick, and Saskatchewan). Our research findings suggest that HIV over the long term is indeed experienced as a chronic illness, and we recommend policy change to reflect this. We would like to see supports related to the ongoing management of HIV illness - supports related to income and employment, housing, medical adherence - be clearly prioritized as part of HIV treatment. Perhaps the influence of emerging approaches to HIV – treatment as prevention[31] and the treatment cascade[32] – will support a more holistic approach in terms of HIV care. However, we feel that classifying HIV as a chronic illness can strengthen arguments for HIV treatment that is grounded in the tenets of health promotion.

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[31] Montaner 2011
[32] Wilton and Broeckaert 2013
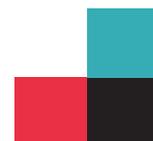
APPENDICES

Appendix I – Focus Group Discussion Guide

1) Do you consider yourself to be a long-term survivor?
   a. What does the term mean to you?

2) What kinds of health and support services do you use in Toronto?
   a. How have the services you use changed since you were first diagnosed with HIV?

3) Imagine you were speaking to a PHA who was new to Toronto, and this individual wanted to know how to connect to a range of services.
   a. How would you recommend he or she find services? [probe: go online, connect with an ASO, connect with a case manager]
   b. Do you think it will be easy for this individual to connect to services?
   c. Are some services easy to find and access and others more difficult? Which ones are easy? Which ones are difficult?

4) Where else do you get support? [probe: family, friends, work]
   a. How do informal supports like family and friends differ from the kinds of support services you might get at an ASO?

5) What are the priority issues or concerns in your life? [Probe: education, employment, income, relationships, physical or mental health, etc.]
   a. What kinds of supports or services could help you with these priorities/concerns?
   b. Are you aware of whether there are services in place that can support you with these priorities?
   c. Where are there gaps or challenges for you in finding the support or care you need to achieve your goals?

6) How are you connected to the work of community-based AIDS organizations (CBAOs)? [Probe: as a volunteer, employee, donor, etc.]
   a. If you are not connected, any reason why not?
   b. Has your connection to CBAOs changed over time? How so?

7) What do you think people living with HIV, and the organizations that support them, should know about living with HIV over the long term?

8) Have you been involved with research in the past? How so? [Probe: as a research participant, research assistant, community advisory committee member, etc.]
   a. What do you think researchers should know about the needs, priorities, and challenges of research participants and/or research assistants who are also living with HIV?
   b. Are there research questions about living with HIV over the long term that you would like to see addressed.

9) We are planning on releasing the results of this study as a report and summary online and in print. Are there other ways you would like to learn about the results of this study?

Appendix II – Key Informant Interview Guide

1) Before we talk about long-term survivorship, could you briefly tell us about your job – what kind of work does it entail?

2) A key part of this research project is to understand how the term *long-term survivor* is used in our work, and what it signifies in terms of the populations we work with. We would like to know if you and/or your organization use the term and in what context.
   a. Do you, or your organization, have a working definition of the term *long-term survivor*? What is it?
   b. Do your clients/service users ever refer to themselves or to other PHAs as long-term survivors? What do you think they mean by *long-term survivor*?
   c. What do you think of the term? Is it useful or meaningful? Should we continue to use it within the HIV sector?

3) What kinds of needs and/or challenges do you think people who have lived long term with HIV experience? [Probe: could you provide examples of what you have seen in your work?]
   a. What do you think their priorities are? How are these priorities different (if at all) from people who were more recently diagnosed with HIV?

4) (using an agreed upon definition) What care or support services do long-term survivors access at your organization?
   a. Are those different from the programs and services other clients use?
   b. Are there programs or services currently in place specifically designed to meet the needs of long-term survivors?
   c. Are long-term survivors involved in other ways? (if applicable) Are many of your volunteers long-term survivors?
   d. If you are unable to answer this question, is there anyone else within your organization that we should talk to? (the volunteer coordinator for instance)

5) Do you think there are gaps or barriers in terms of the services available to people living long term with HIV? How so?

6) What challenges do you face in understanding and meeting the needs of people living long term with HIV?
   a. How do you currently manage those challenges?
   b. What would better enable you to meet the needs of long-term survivors in your work?
   c. What questions emerge for you or your organization about long-term survivorship and HIV?

7) We are planning on releasing the results of this study as a report and summary online and in print. Are there other ways you would like to learn about the results of this study?

REFERENCES

Bury, M. 1991. The sociology of chronic illness: a review of research and prospects. *Sociology of Health & Illness*, 13(4): 451-468

Chambers, L., Wilson, M., Rueda, S., Gogolishvili, D., Shi, Q., Rourke, S., and the Positive Aging review team. 2013. *Evidence Informing the intersection of HIV, aging and health: a scoping review*. Toronto, ON: Ontario HIV Treatment Network

Clarke, L., Bennett, E. 2012. Constructing the moral body: self-care among older adults with multiple chronic conditions. *Health*, 7(3): 211-228

Colvin, C. 2011. HIV/AIDS, chronic disease and globalisation. *Globalization & Health*, 7: 31-37

Commission on Social Determinants of Health (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health.* Geneva, World Health Organization.

Corbin, J., Strauss, A. 1985. Managing Chronic Illness at Home. *Qualitative Sociology*, 8(3): 224 – 247

Deeks, S., Lewin, S., Havlir, D. 2013. The end of AIDS: HIV infection as a chronic disease. *The Lancet*, 382 (9903): 1525-1533

Epstein, S. 2004. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.

Galvin, R. 2002. Disturbing notions of chronic illness and individual responsibility: towards a genealogy of morals. *Health*, 6(2): 107-137

Gately, C., Rogers, A., Sanders, C. 2007. Re-thinking the relationship between long-term condition self-management education and the utilization of health services. *Social Science & Medicine*, 65: 934-945

Guilliford, M., Naithani, S., Morgan, M. 2006. "What is 'continuity of care'?" *Journal of Health Services Research & Policy*, 11(4): 248-250

Hamilton, N., Bhatti, T. 1996. *Population health promotion: an integrated model of population health and health promotion.* Retrieved from Public Health Agency of Canada website: http://www.phac-aspc.gc.ca/ph-sp/php-psp/index-eng.php

Hay, C. 2010. Suffering in a productive world: Chronic illness, visibility, and the space beyond agency. *American Ethnologist*, 57(2): 249-274

Higgs, P., Leontowtisch, M., Stevenson, F., Jones, I. R. 2009. Not just old and sick – the 'will to health' in later life. *Aging and Society*, 29: 687-707

Husbands, W., Cattaneo, J., Makoroka, L., Pires, R., Watchorn, J., Whitbread, J. 2012. *HIV Across the Lifespan*. Toronto: AIDS Committee of Toronto

Kelly, M., Field, D. 1996. Medical sociology, chronic illness and the body. *Sociology of Health & Wellness*, 18(2): 241-257

Kendall, C., Hill, Z. 2010. "Chronicity and AIDS in Three South African Communities" in *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*. Eds. L. Manderson and C. Smith-Morris. New Brunswick, New Jersey: Rutgers University Press: 175-194

Kralik, D. 2002. The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, 39(2):146-154

Kralik, D., Koch, T., Prince, K., Howard, N. 2004. Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing*, 13: 259-267

Leaver, C. A., Perreault, Y., Demetrapooulus, A. 2008. Understanding AIDS-related bereavement and multiple loss among long-term survivors of HIV in Ontario. *The Canadian Journal of Human Sexuality*, 17(1 – 2): 37-52

Mykhalovskiy, E. 2008. Beyond rational decision making: class, community organizations, and the healthwork of people living with HIV/AIDS. Contributions from institutional ethnographic research. *Medical Anthropology*, 27(2): 136-163

Mykhalovskiy, E., and McCoy, L. 2002. Troubling ruling discourses of health: using institutional ethnography in community-based research. *Critical Public Health,* 12: 17-37

Mishel, M. 1990. Reconceptualization of uncertainty in illness theory. *The Journal of Nursing Scholarship*, 22(4): 256-262

Montaner, J. 2011. Treatment as prevention – a double hat-trick. *The Lancet*, 378 (9787): 208-209

Nakagawa, F., Nay, M., Phillips, A. 2013. Life expectancy living with HIV: recent estimates and future implications. *Current Opinion in Infectious Disease*, 26: 17-25

O'Brien, K., Bayoumi, A. M., Strike, C., Young, N. L., Davis, A. 2008. Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework. *Health and Quality of Life Outcomes*, 6: 76
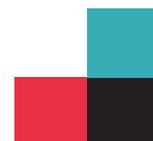
Olsson, L., Ung, J., Swedberg, K., Ekman, I. 2012. Efficacy of person-centred care as an intervention in controlled trails – a systematic review. *Journal of Clinical Nursing*, 22: 456-465

Owen, G., Catalan, J. 2012. "We never expected this to happen": narrative of ageing with HIV among gay men living in London, UK. *Culture, Health & Sexuality*, 14(1): 59-72

Pogash, C. 2005. AIDS and the secret of long-term survivor. (May 5). *The New York Times.*

Public Health Agency of Canada. "Chronic Diseases." Last modified October 2013. http://cbpp-pcpe.phac-aspc.gc.ca/chronic-diseases/

Rapid Response Service. 2013. *Rapid Response: Intersectionality in HIV and Other Health-Related Research*. Toronto, ON: Ontario Treatment Network

Robinson, W., Petty, M., Patton, C., King, H. 2008. Aging with HIV: historical and intra-community difference in experience of aging with HIV. *Journal of Gay & Lesbian Social Service*s, 20 (1/2): 111-128

Russell, S., Steeley, J. 2010. The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy. *Social Science & Medicine*, 70: 375-382

Sáez-Cirión, A., Pancino, G., Sinet, M., Venet, A., Lambotte, O. 2007. HIV controllers: how do they TAME the virus? *Trends in Immunology*, 28(12): 1471-1479

Scandlyn, J. 2000. When AIDS became a chronic disease. *West J Med.*, 172(2): 130-133

Singer, M., Clair, S. 2003. Syndemics and public health: reconceptualizing disease in bio-social context. *Medical Anthropology Quarterly,* 17(4): 423-441

Singer, M., Erickson, P., Badiane, L., Diaz, R., Ortiz, D., Abraham, T., Nicolaysen, A. 2006. Syndemics, sex and the city: understanding sexually transmitted disease in social and cultural context. *Social Science and Medicine*, 63(8): 2010-2021

Solomon, P., O'Brien, K. Wilkins, S., Gervais, N. 2013. Aging with HIV and disability: The role of uncertainty. *AIDS Care*, 26(2): 240-245

Swendeman, D., Ingram, B., Rotherram-Borus, MJ. 2009. Common elements in self-management of HIV and other chronic illnesses: an integrative framework. *AIDS Care*, 21(10): 1321-1334

Tremblay, C. Bernard, N. 2009. Long-term non-progressors: what helps them keep HIV at bay? *Relay*, 4(1): 4-6

Varul, M. 2010. Talcott Parsons, the Sick Role and Chronic Illness. *Body and Society*, 16(2): 72-94

Wilton, J., Broeckaert, L. 2012. The HIV treatment cascade – patching the leaks to improve HIV prevention. *Prevention in Focus*. Accessed January 2014: http://www.catie.ca/en/pif/spring-2013/hiv-treatment-cascade-patching-leaks-improve-hiv-prevention

Wouters, Edwin. 2012. Life with HIV as a chronic illness: A theoretical and methodological framework for antiretroviral treatment studies in resource-limited settings. *Social Theory and Health*, 10(4): 368-391