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## 17 Ageing with HIV

*Dana Rosenfeld, Damien Ridge and Jose Catalan, on behalf of the HIV and Later Life (HALL) Team<sup>1</sup>*

You haven't had old HIV people. We're technically the guinea pigs and first generation of old HIV people . . . up till now, no one discussed it because no one thought it would happen, that we'd be old HIV people. You know, give them six months and that's them out the door.

(P43, gay White man in his 60s)

### Introduction

That this chapter appears in a section entitled 'Ageing with a long-term condition or disability' rather than, for example, 'End of life' speaks to the radical changes that the HIV community has undergone over the past three decades (Deeks, Lewin and Havlir, 2013). From the first reports, in 1981, of young gay men suffering from diseases typically associated with compromised immune systems (later recognised as 'the first official harbingers of AIDS' – Altman, 2011) until 1996, when effective antiretroviral medications were developed, HIV typically led to AIDS, which caused high rates of premature death from opportunistic infections. Now, assuming early diagnosis and good access and appropriate adherence to medication, people living with HIV (PLWH) can survive into later life (Nakagawa, May and Phillips, 2013) and even reach normal life expectancy (May, Gompels and Sabin, 2012). The HIV population is now experiencing good health and ageing that neither the HIV sector nor medical science could have imagined only a few decades ago.

Consequently, in the United Kingdom, almost 30,000 PLWH aged 50+ access HIV specialist care, with the median age of PLWH accessing this care rising from 39 to 45 between 2006 and 2015 (Kirwan et al., 2016). If current trends continue, over half of the UK HIV cohort will be aged 50+ by 2028 (Yin, Kall, Skingsley and Delpech, 2015). The situation is similar in the United States, where the number of older PLWH (OPLWH) 'increased from 301,647 to 428,724 – an increase of nearly 40%' between 2010 and 2014 (Harris et al., 2018, 3), and worldwide: 'For the first time since the start of the HIV epidemic', 10% of adult PLWH in low and middle-income countries are aged 50+, making the estimated OPLWH population in these countries 2.9 million, and 'in

high-income countries, approximately 30% of adult PLWH are aged 50+ (UNAIDS, 2013, 3). OPLWH are members of the first generation to age with HIV – an historical fact introducing a mix of unique challenges, as detailed in this chapter.

In its early years, AIDS decimated the gay male community, in which it was primarily found (Halkitis, 2013; Tester, 2017). The HIV epidemic is now embedded across multiple groups and geographical regions, with, in the UK and in descending order, prevalence highest among White men who have sex with men (MSM), heterosexual men and women of Black African origin, and White heterosexual men and women. Thus, the older HIV population, like its younger counterparts, varies by gender, sexuality and ethnicity, each of which introduce their own circumstances, challenges and resources. Further bisecting these differences are age at, and time since, diagnosis. Older age at diagnosis has consequences: physical (e.g. age-related comorbidities or frailties), social (e.g. in terms of having or raising children, and romantic relationships or prospects) and economic (e.g. ability to work), both immediately and in the long term (hence time since diagnosis) as they accumulate over the life course (Willson, Shuey and Elder, 2007). Finally, both age at and time since diagnosis overlap with historical dimensions of illness: here, for example, OPLWH diagnosed pre-1996 are typically ageing after long periods of ill health, relatively high levels of stigma and un/under-employment.

Compared to their HIV-negative peers, OPLWH experience higher rates of frailty, and at younger ages (Kooij et al., 2016); higher rates of mental ill health, particularly anxiety and depression (Kall et al., 2015); and more comorbidities, again, at younger ages (Smit et al., 2015) within social support systems that, while often strong, are also disproportionately ‘fragile’ (Shippy and Karpiak, 2005). OPLWH are far likelier to live alone, and many, especially longer-term diagnosed MSM, are ageing in networks depleted by multiple AIDS-related deaths (Rosenfeld, Bartlam and Smith, 2012). As a result, OPLWH are lonelier than are their HIV-negative peers (Terrence Higgins Trust, 2017). Significant numbers of OPLWH depend on social networks primarily composed of friends whose own disabilities (Siegler and Brennan-Ing, 2017) and/or HIV status (Karpiak and Brennan-Ing, 2016) limit their ability to provide care.

OPLWH share HIV-related stressors with younger PLWH (e.g. stigma, challenges of disclosure, uncertainties of living with a chronic condition, impacts on romantic and sexual relationships, work and financial security and managing medical treatment). But they also face challenges that younger PLWH do not. For example, our study’s participants experienced uncertainty about how HIV affects ‘normal’ ageing (Rosenfeld, Ridge and Von Lob, 2014), and their experience of living with HIV was shaped by ageism, the development of frailty and comorbidities with age, retirement and the availability of pensions, parenting and grandparenting, caring for older parents, approaching dating and romantic relationships as a parent and/or older person, coming to terms with the past, imagining the future as an older person and concerns over independence and long-term care (see Rosenfeld et al., 2015).

No study to date has considered these challenges through the lens of Fraser's framework of social justice, which contests the 'false antithesis' between socio-economic and cultural oppression, each of which has, in traditional models, its own solution (economic restructuring and 'cultural or symbolic change' – Fraser, 2003, 7 – respectively). Fraser (2003) 'posit[s] a type of collectivity' whose core experiences and social position are equally shaped by 'the economic structure and the status order of society' (ibid., 15), where '*neither of these injustices is an indirect effect of the other, but both are primary and co-original*' (ibid., 15, emphasis in original), and who are thus 'bivalent' (also important is that individuals are members of multiple collectivities, some dominant, others subordinate). Thus, for example, gay men and women's oppression stems from cultural biases, but these biases' consequences are partly economic, as coming out 'poses economic risks' (ibid.) that undermine this group's ability to fight homophobia. This chapter thus brings empirical knowledge about ageing with HIV into Fraser's framework for the first time. Fraser's framework does not specifically identify people living with stigmatising illnesses as bivalent collectivities, nor does she consider age, but, as this chapter shows, age and, in this instance, living with HIV are not only bivalent identities in themselves but intersect with such other collectivities as ethnicity, sex and sexuality in ways that subject OPLWH to socio-economic and cultural injustice.

Here, we draw on qualitative data gathered for our HIV and Later Life (HALL) study into OPLWH's mental health, social support and quality of life (QoL) to explore those challenges that best resonate with Fraser's three domains of inequality: *recognition* (social status, cultural visibility and cultural worth); economic, social care and support *resources*; and *representation* (social and political participation and access to justice). In our data, these intersect in ways that challenge Fraser's divisions. We argue, for example, that while social care 'belongs' in Fraser's 'resources' category, given OPLWH's cultural invisibility outside the HIV sector, and their impoverishment by recent statutory shifts regarding disability payments, social care more naturally falls into the 'representation' category, as does the defunding of HIV service organisations.

## Methods

The HALL team included HIV consultants, social scientists, mental health professionals, epidemiologists and a community advisory board (CAB) of HIV activists and advocates who were living with HIV. We secured ethical approval before conducting 17 stakeholder interviews, and three focus groups, and 76 life-history, semi-structured interviews with recently and longer-term (diagnosed for <10 years or ≥10 years at time of interview, respectively) White MSM, Black African heterosexual men and women, and White heterosexual men and women, all aged 50+. We recruited OPLWH through two HIV clinics, one mental health clinic serving a high number of OPLWH, and HIV organisations, all in London.

At interview, OPLWH were asked about their typical day, personal histories and histories with HIV, social relations and support, QoL, ageing with HIV and hopes and concerns for the future. OPLWH whom we interviewed completed a survey combining questions on QoL, depression and anxiety, and a further 24 OPLWH completed the same survey containing supplemental questions on social relations and support, demographics, physical health and history with HIV. All interview data were transcribed ad verbatim; a researcher took notes on focus groups as they were conducted; and all data were fully anonymised. OPLWH interview data were subjected to open and closed coding before being uploaded into NVivo 10 folders, then analysed using a thematic, constant comparative approach (Glaser and Strauss, 1967; Strauss, 1987). Survey data were subjected to bivariate and multivariate analysis, specifically, step-wise multivariate linear regression, using SPSS.

Our interview and survey sample consisted of 53 MSM (50 gay, three bisexual), 12 Black African heterosexual men, 18 Black African women (17 heterosexual, one of unknown sexual orientation), nine White women (eight heterosexuals, one bisexual), and nine White heterosexual men. Their ages ranged from 50 to 87, with 94% of the sample aged 50 to 70 (median age 56.0, mean age 58.4 years). Age at diagnosis ranged from 24 to 79 years (median age 47 years, mean age 47.2 years); 23 participants were diagnosed <40 years. Years since diagnosis ranged from 1 to 32 (median 10 years, mean 11.4 years); 21 participants were diagnosed pre-1996. Fifty-nine participants lived alone, and one in three was partnered. Ninety-seven per cent of Black African and 82% of White heterosexual, versus 17% of MSM, participants were parents.

Almost half of the sample was in full- or part-time work (28%) or retired (20%); 52% was not in paid work. As a result, and in keeping with the UK's wider OPLWH population (58% of whom live before the poverty line, up from 48% in 2010, double that of the HIV-negative population, and one-third of whom rely on benefits – Terrence Higgins Trust, 2017), incomes were low (median £10,400, mean £20,430), with almost half of the sample earning <£10,000/year, and 80% earning <£31,000/year. Fifty-five per cent were in receipt of one or more welfare benefit (e.g. Disability Living Allowance, or DLA; Employment and Support Allowance, including Incapacity Allowance; Housing Benefit), with women and Black African participants over-represented (78% and 73%, respectively, versus 53% of White heterosexuals and 45% of MSM).

To ensure confidentiality, we identify OPLWH whose accounts figure here by membership in one of our core groups (MSM; Black African males and females as BAM and BAF, respectively; and White heterosexual males and female as WHM and WHF, respectively), recently or longer-term diagnosed (RD or LTD) and age by decade. We further identify focus group participants by reference to their host focus group: RD MSM, LTD and BA.

## Recognition

Participants situated their social status within two broad contexts. The first was *PLWH's low cultural worth*, grounded in damaging myths about HIV's

infectiousness and its transmission, by ‘deviant groups’, through ‘immoral’ activities (specifically, sexual excess and/or impropriety, and drug use). They viewed HIV stigma as a more significant barrier to well-being than was physical ill-health (‘the big burden I carry isn’t a health burden, it’s the stigma’ – P48, LTD WHM, 50s), although several participants, especially the LTD, did suffer from poor health. Thus, participants viewed the recent equation of HIV with other chronic, manageable diseases as misguided and naive: as P70 (RD WHF, 50s) explained, HIV ‘doesn’t feel like diabetes. Medically it may be, but emotionally and mentally it’s very, very different’. To P48 (LTD WHM, 60s), whereas ‘cancer’s kind of bad luck, not because you’ve been injecting drug users or screwing around or anything else unpleasant, HIV is “deviant behaviour”’.

This stigma was, in these accounts, grounded in enduring fears and myths about HIV’s transmission (through casual contact, and through sexual promiscuity, prostitution or the abuse of drugs) and of HIV as a ‘Black’, ‘African’ or ‘gay’ disease. Thus P47 (LTD WHF, 60s) described the stereotype of PLWH as ‘people who sleep around, people that are drug addicts’, and P50 (RD MSM, 60s) knew ‘how people think: people deserve it, there are African Blacks, these gays . . . it’s the same as they see minority groups, whatever they are. . . . I’m very aware about prejudice on the left and on the right. That’s why I decide not to tell’.

The myths’ endurance was, participants said, exacerbated by the diminution of HIV health promotion messages since the early days of the AIDS epidemic. As a result, participants explained, the HIV-negative population still (mis)understood HIV through the lens of the UK government’s infamous 1980s ‘tombstone’ public health advertisements: as a highly infectious and fatal condition:

Years ago, way back, when it came up, they had these horrible adverts with gravestones on or whatever, and from that point, nothing . . . they need to do something to push out that it is there, and that it does affect every single age group. It would be wonderful if they did a documentary . . . on HIV.

(P5, RD WHF, 50s)

The second context was these *myths’ intersection with ageist attitudes* (see also Emler, 2006); for example, P23 (RD MSM, 50s) said ‘It’s not only being HIV positive, but it links into other prejudices around age, around sexuality, maybe even around disability, and the older you get, those compound even more’. The most relevant ageist bias was the normative expectation that sexual activity should diminish, and self-restraint, discretion and rational decision making increase, with age. As P47 (LTD WHF, 60s) explained, HIV-negative people think ‘we shouldn’t be having sex anyway, because after like 30, people think you shouldn’t be having sex’. This contributed to making disclosure especially difficult for OPLWH: ‘As an older person, to be seen as HIV positive, alarm bells ring out from the people who you think should know better. And sometimes, because of that, people don’t talk about it’ (BAFG#4, LTD BAM, 50s).

Here, cultural worth is a heightened concern with real and imagined consequences. These included embarrassment: when asked how the HIV-negative

viewed OPLWH, P36 (LTD WHF, 50s) replied, 'Drugs, or maybe I was sleeping around, I don't know. So, it's a bit embarrassing'. LTD BAF, 50s, whose children know her HIV status, described 'times when I sit and wonder what's going on in their minds, that she was promiscuous after she divorced our father', adding 'but I don't ask'. But participants described the spectre of abandonment or rejection by the HIV-negative as more damaging and more likely. If discovered, participants said, their HIV status would subject them to assumptions of age-inappropriate activities and thus to even greater stigma and discrimination. P5 (RD WHF, 50s) felt that OPLWH 'would be more discriminated against. They would absolutely think you were the dregs of the earth'.

These intersecting stigmas placed participants at a disadvantage regarding social relationships. Both RD and LTD participants imagined that their existing relationships could end or become more distant, and new relationships precluded, should their HIV status become known. For P48 (LTD WHM, 50s), 'The social stigma risk is a big deal. My biggest fear in life is my family, my friends, my neighbours, the guys I work with, finding out'. Few participants had experienced rejection, largely due to disclosing their HIV status strategically, to those with whom they were particularly close<sup>2</sup> (or to people they knew were PLWH), but rare instances of rejection were deeply hurtful. For P72 (RD MSM, 50s), HIV remained 'a huge influence on everything I do in my life, especially when you're rejected. If you say to somebody 'Oh, by the way I'm HIV'. Luckily, I think I only get about 10% rejection, but it still is like being knifed'. After P63 (RD BAM, 60s) disclosed to his son, his son 'didn't say anything', but 'changed completely', moving out of their shared flat: 'It's two years I don't see him. I don't know where he lives. I'm asking, I don't know. As soon as he heard'.

Most single participants wanted to form a romantic relationship but considered the prospect of doing so to be complicated, even precluded, by their HIV status. After her diagnosis, P70 (RD WHF, 50s) thought 'relationship-wise, that's it now . . . it was difficult enough finding someone anyway, and I sort of resigned myself to thinking I probably won't have a sexual partner again'. P58 (RD BAF, 50s) considered herself:

still young enough to have a boyfriend or to get married and enjoy life. But because of this HIV now, you're afraid that maybe I'll hurt myself if I find a man and this man knows and they'll leave me again. If you're lucky, they accept you, then you can start living again and have a partner, someone who'll look after you. So, you're in a dilemma. You don't know because of the age again . . . you don't know to start it or not.

When P60 (LTD MSM, 50s) disclosed to potential partners, 'they either run away or they ask questions. . . . It's hurtful because you think, "it's just an illness. I'm still the same person you thought you liked. Now you don't want to have anything to do with me and I'm not even allowed to touch you". That hurts sometimes'. For many participants, the prospect of being romantically



unattached in later life had worrying implications for support, general well-being and mental health: when asked how HIV had affected him, P45 (RD WHM, 50s) answered, 'Just the endless solitude of it, how you get a deep, meaningful relationship. The close relationship thing's clearly been directly associated with the HIV, I'd say'.

## Resources

### *Economic resources*

While some participants were financially secure, most were struggling financially due to their HIV: for example, P59 (RD WHF, 60s) 'went from being somebody that was self-supporting, earning well and so on, to someone that was left not being able to'. Three core factors placed many participants under significant financial strain: *interrupted work histories due to ill health and/or migration, changes and threats to DLA and migration status*. For participants with interrupted work histories, time spent away from working or from working in jobs for which they had originally been trained made it very difficult to re-enter the employment sector at their original level, if at all.

For Black African participants, financial hardship due to interrupted work careers was exacerbated by uncertain migration status, which limited their right to work. All had been diagnosed while visiting the UK and remained in the UK for HIV treatment that was unavailable or unaffordable in their countries of origin. LTFG#5 (LTD BAF, 60s), who was 'still waiting for my papers', 'came to the UK to attend [a family function]' but could not return 'because I became very sick'. P63 (RD BAF, 60s) was also awaiting the Home Office's decision about his migration status:

The first application was before I was diagnosed. It was for diabetes and blood pressure. They said you can go back to Africa where you can treat diabetes. But now it's diabetes, blood pressure and this one. You see? It became difficult. In Africa the treatment's very difficult.

Many Black African participants had earned good salaries in their countries of origin as e.g. specialists in banking and finance, the media, and law, but were now unemployed, significantly underemployed and/or on benefits. P9 (LTD BAF, 50s) 'couldn't continue with the same career and the same lifestyle I had in my country. I had to go low. I started off with cleaning jobs here. I'd never done a cleaning job in my life'. P7 (RD BAF, 50s) needed financial help 'because if I was granted my status I could be working and financially I'd be all right, but now I have to wait for the vouchers. Sometimes it's hard for me to buy maize to cook my traditional meal'.

Migration's effects were psychological as well as financial: participants whose applications for indefinite leave to remain were still under consideration described being stuck in limbo. P55 (LTD BAF, 50s) did not know 'where



I'm going to be next year . . . I just want to know if I'm going to get deported, so I can deal with it'. Uncertain migration and work status also affected these participants' family lives, as most of their family members (including, in many cases, children, spouses and parents) lived in their countries of origin. P66 (RD BAM, 50s) was depressed and

missing my wife, my children . . . to bring my wife over, I need to be earning, like, £18,000 a year . . . right now I'm feeling sick, I can't look for a job to start working, so how am I expected to bring her out?

Many LTD participants, primarily MSM, had left the workforce due to ill health pre-1996, when most PLWH were thus advised by health providers and/or social workers given PLWH's short life expectancy at the time. These participants had been placed on DLA, were ageing with limited financial capital due to lack of earnings (and therefore pensions) over time and faced draconian changes to the benefits system, whereby DLA recipients were to be reassessed and, if deemed eligible to work (based on what participants considered unfair criteria, as below), expected to apply for jobs. As MSMFG#3 (RD MSM, 60s) explained, 'There's a big move to get people back to work, including those with HIV. . . . That's coming next year. Everyone has to be re-interviewed. I've seen a draft of the questions and they're much harder. You have to be a blob of jelly in a bucket'.

These impending changes introduced financial concerns ('My main worry's losing DLA. That would leave me financially devastated' – MSMFG#1, LTD MSM, 50s) and uncertainty: MSMFG#4 (RD MSM, 50s) said, 'You can't plot a course for your life. You have this thing going on. It's constantly changing'. Being 'constantly threatened' with having his DLA revoked had caused P60 (LTD MSM, 50s) 'a lot of trauma over the years':

If the government changes their policy they can still take them away, and it actually says that in the letter: 'The fact that you've been awarded them indefinitely does not mean you will receive them indefinitely'.

Imminent changes to DLA also introduced the spectre of having to disclose HIV status to prospective employers. Moreover, the relapsing/remitting, or 'good days/bad days' (Charmaz, 1991), nature of HIV-related symptoms made assessment of capacity to work dependent upon the randomly generated assessment date rather than on actual ability. This, alongside stigma and OPLWH's age, would, MSM participants said, limit their work opportunities:

I'd like to go back to work but I know the situation: when you get there and have to fill out the form, you'll have to disclose, so there's no chance in hell they'll take you on over a young person.

(MSMFG#4, RD MSM, 50s)

How do you explain to your new employer that you have to go to hospital?  
(MSMFG#3, RD MSM, 60s)

One day you feel OK, another day you feel like shit. One day you can get out of bed and feel horrible.  
(MSMFG#4, RD MSM, 50s)

No one's going to employ you anyway if you tell the truth. . . . At our age, and our condition, we're not going to get jobs.  
(MSMFG#2, RD MSM, 60s)

Why would they take someone 50 or 60 when they can [hire a younger person] and pay them less?  
(MSMFG#1, LTD MSM, 50s)

As long as you're seen to go through the interview process, and they reject you, you can't say you've been discriminated against, because you've been interviewed.  
(MSMFG#1, LTD MSM, 50s)

### ***Social support***

Several participants had what Shippy and Karpiak (2005) termed 'fragile' social networks. For example, while a friend had been helping P31 (RD MSM, 70s), who lived alone and had hypertension, he was 'frightened now that she's going to have a baby. Who's going to look after me now?' Because a friend who was helping P69 (LTD BAF, 70s) had returned to Africa, 'no one's helping me'. P61 (RD WHF, 60s), who lived alone, said 'when I was ill I couldn't manage with my housework, I had to pay someone'. Others, especially MSM, were lonely because

At a relatively young age, we lost lots of friends, which usually happens when you're older. It was almost like what happens during a war, when almost a whole generation is wiped out . . . a lot of gay people with HIV are lonely because a lot of the people they should have grown old with have gone.

(MSMFG#3, RD MSM, 60s)

But most participants had close connections with friends and family, and, again, one in three were in supportive and fulfilling romantic partnerships. Participants valued support from HIV-negative friends and family, including children – for example, P80 (RD WHM, 60s) appreciated his daughters and friends 'preparing a meal in time for me to take my medication' – but they also contrasted this support with that provided by other PLWH who held what we term 'experiential

knowledge’ of HIV’s clinical, social and psychological impacts. Participants viewed support from other PLWH who were, in several participants’ words, ‘in the same boat’, as irreplaceable (Rosenfeld and Anderson, 2018). As P47 (LTD WHF, 60s) explained, ‘that’s the only answer: having friends in the same situation’.

This made access to other PLWH critical for mental health, well-being and social support. In this context, *HIV organisations and support groups* provided essential practical support (e.g. guidance on managing HIV and such related challenges as medication management, housing and other benefits) and combatted isolation: LTDFG#5 (LTD BAF, 60s) said, ‘we need centres to socialise, those for HIV positive people and older people. . . . Maybe do some dancing. Loneliness – I’m old, I can’t do a lot of walking. But if there’s a certain place I have to go to, I can do that’. HIV support groups, participants explained, provided access to other PLWH for mutual understanding, social support and solidarity – ‘If I hadn’t joined those groups’, P63 (RD BAM, 60s) said, ‘maybe I’d have died now, because it’s those groups that actually told me “Look, you’re not alone in this fight”’. Meeting other OPLWH was also crucial: while ‘some people, when you say, “I’m HIV positive”, don’t expect you to live longer than five years’ (P44, RD MSM, 50s), HIV groups showed participants that they could live long, healthy lives:

When you’re newly diagnosed, they say, ‘Oh, that’s the end of me, I’m going to die’ and so on. But they’re always given the support. They say, ‘You see this one, you see here also, some have already spent more than even ten years being ill’ and so on, so they pick up that courage.

(P18, RD BAF, 60s)

Finally, HIV organisations and support groups provided a ‘safe space’ that stood in stark contrast to the awkwardness, hostility or misunderstanding participants expected to experience in non-HIV-dedicated spaces should their HIV be known. P78 (LTD BAM, 50s) said that the ‘moral support’ and opportunity to ‘meet your friends, chatting, speaking the same language’ offered by HIV organisations ‘helps a lot. Because some places you go, you keep mum, you don’t say anything, you listen. You can speak, but you feel it’s not okay. There’s a barrier’. P43 (LTD MSM, 60s) described entering ‘a room full of HIV people’ when he first attended an HIV organisation:

You didn’t worry about judgement, because when you’re applying for things, you start using euphemisms for what you’ve had, and you don’t want to tell people because it’s early days. You think they judge, and you start worrying about that. Here, you were just left to breathe.

## Representation

In Fraser’s inequality model, representation refers to social and political participation and access to justice. In the developed West, and especially in the UK,

‘access to justice’ issues that had dominated the HIV sector’s early years – access to medication, legal protection from discrimination in employment (although, as we have shown, still a concern) and housing, and representation in scientific research and medical policy – are now less on the radar and did not emerge in our data as core concerns. Rather, our analysis uncovered three obstacles to representation as defined by Fraser: changes to DLA, HIV-related stigma and homophobia in long-term care settings, and defunding of HIV service organisations.

### *Changes to DLA*

Since the completion of our study, DLA has been reconfigured into Personal Independence Payments (PIP), designed to cover a long-term condition’s added costs. A National AIDS Trust’s (NAT) report showed that PIP’s ‘fundamental assessment design and criteria’ (NAT 2017a, 27) significantly disadvantage PLWH: ‘compared to the overall population of people claiming DLA’, PLWH are ‘less likely to be awarded PIP following reassessment; less likely to receive an increase in their rate of benefit when moving from DLA to PIP; [and] more likely to receive a decrease in their rate of benefit when moving from DLA to PIP’ (ibid., 2). PIP’s criteria and descriptors do not adequately capture PLWH’s distinctive mental health (e.g. ‘risk of isolation due to HIV-related anxiety’), mobility, medication management and nutritional needs, and disregard ‘the support needs around managing toilet needs and incontinence which are more likely to apply to’ PLWH due to immunological compromise and/or medications’ side-effects. Moreover, HIV’s stigmatisation is directly linked to ‘the stress which the face-to-face consultation causes’ PLWH (ibid., 3). Given OPLWH’s (especially the LTD) disproportionate reliance on benefits, the shift to PIP clearly constitutes injustice and introduces barriers to social participation (via a diminution of support for, e.g. travel outside of the home) and political disenfranchisement.

### *Long-term care*

Given our sample’s relatively young age, few participants had considered long-term care, but those who had done so expressed concerns that care staff and other residents would hold stigmatised beliefs about HIV that would compromise the care they received. For example, P48 (LTD WHM, 50s) wondered what would happen ‘if I ended up in an old folks’ home when I’m 80 and on the medication and the staff in the old folks’ home, there’s 100 people in it and there’s 99 who are negative and I’m the one positive one, what happens when word gets around? Because the nurses are going to have to dish out medication’. Similarly, P22 (RD MSM, 50s) was concerned that, eventually,

I’m not going to be able to look after myself, which will mean that I’ll need someone to look after me and tend to me. Who can I trust? Where

am I going to be? Am I going to be having people, carers, that aren't going to want to come in to tend to me because I'm HIV positive?

Most participants who had considered long-term care were MSM who feared that homophobic attitudes, combined with HIV-related stigma, would undermine the quality of long-term care. To P81 (RD MSM, 70s), who, while visiting a gay male friend living with HIV in a nursing home, witnessed 'this patient opposite continually ma[king] snide comments – "oh, the queers are here"', concerns that all older people had regarding long-term care were 'exacerbated because of sexuality, and because of HIV'. As P43 (LTD MSM, 60s) explained, 'Care is based for heterosexuals':

What if I can't stay in my flat, and I'd be one of these little old biddies hanging onto the stair rail saying, 'I don't want to leave'? . . . If you're a gay person in a heterosexual nursing home, where would you fit? And then they find out you're HIV, and a lot of heterosexual people don't understand HIV, so they'd be throwing their china away. So, what do you do? Have HIV ghettos?

These concerns echo those raised across the HIV sector. Relevant research, while both limited and new, shows that, while protected under the 2010 Equality Act, OPLWH in the UK fear encountering HIV-related stigma and discrimination in care settings, and are concerned about home-based and residential home care providers' lack of training in HIV-related health needs and treatments (Beer, James and Summer, 2014). Indeed, HIV-related stigma and discrimination in health care (Nöstlinger et al., 2014; NAT, 2014) are widely documented, and emerging research documents stigma, inadequate understandings of HIV, and reservations about admitting OPLWH among care-home staff (see e.g. Naudet et al., 2017). HIV-related stigma often translates to discriminatory practices (i.e. refusal to admit or care for PLWH, forced isolation within care homes – Terrence Higgins Trust, 2017). Such recognition of intersectional factors such as stigma and privilege are critical for deepening understanding of access to resources in later life – including good health and access to quality of long-term care – where hostile providers are a real threat, particularly to those with fewer resources (Westwood, 2016). Finally, apprehensions about confidentiality in LTC settings increase as OPLWH's care teams widen from health care professionals who regularly uphold confidentiality to include carers who may be less well-trained (Beer, James and Summer, 2014). As the experience of ageing with HIV within residential care settings, and in the context of home-based long-term care, remains significantly under-researched, OPLWH, and HIV organisations are still working with limited knowledge of long-term residential care for OPLWH, but concerns over justice as described earlier continue to characterise relevant discussions.

### ***Defunding of HIV organisations***

Given HIV service organisations' central role in providing OPLWH with much-needed social support, connections and solidarity, the recent defunding of HIV organisations (by an average of 28% across England between 2015–16 and 2016–17 – NAT 2017b) is a pressing concern for the HIV sector, as it was for many of our study's participants. BAFG#4 (LTD BAM, 50s), for example, said 'Unfortunately, a lot of these organisations are going out of existence, because of lack of funding, which is putting more pressure on the older generation'. Some participants' access to HIV organisations had already been curtailed by funding cuts at the time of our study, well in advance of more recent cuts. For example, P41 (LTD MSM, 70s) used to attend an HIV support group, which was 'quite nice, quite useful', before it closed due to funding cuts. Moreover, since 'HIV organisations have consistently highlighted the intensive advocacy and support needs which their clients have needed to initiate, undergo, and complete the assessment journey' related to the new PIP system (NAT 2017a, 22), these organisations' defunding intensifies injustices caused by the shift from DLA to PIP.

### **Conclusion**

OPLWH face stressors that distinguish them from their HIV-negative peers and from younger PLWH. While some adverse effects of ageing with HIV are HIV-related (e.g. stigma, ill health, discrimination), others relate to ageing in a society that denies older people their full humanity (e.g. the denial of sexuality), or statutory policies that make it more difficult for older people, who are more likely to live with chronic and/or disabling conditions, to secure support. These same policies disadvantage PLWH and especially OPLWH, as they are even more likely than their HIV-negative peers to be disabled and/or in poor health. If we are to take Fraser's seriously notion of bivalence, whereby bivalent collectivities are composed of individuals whose social positions and experiences are independently shaped by economic structure *and* social status orders, then all PLWH are clearly (and at the very least) bivalent, with their HIV status continuing to receive economic and cultural responses that are, at base, unjust.

By the same token, each PLWH embodies other bivalent identities, as their gender, class, migration/work/parental status, ethnicity and sexuality are shaped by both economic factors and the social status order, which operate independently. These will intersect in unique ways, as when sexuality and HIV status combine to heighten fears over ageing with HIV in long-term care settings. But ageing with HIV introduces yet more characteristics that produce bivalence: age itself, and long-term survivorship. Some factors producing bivalence in this population (class, sexuality) are recognised by Fraser, while others – most notably age and health – are not. The data we explored here, we suggest, signal the need to include age and health in the index of bivalence.

Fraser's domains of inequality are useful entrees to the challenges and sources of injustice that OPLWH face because of their age/ing and HIV status. Under *recognition*, OPLWH face HIV-related stigma, intersected and exacerbated by racism, homophobia, ageism and the state's abandonment of health-promotion messages. Fraser's *resources* domain captures challenges to OPLWH's economic security (interrupted work histories, benefit changes, migration status) and to their social support (fragile social networks, defunding of essential HIV support organisations and groups), but this is where Fraser's clear divisions between her three domains begin to erode. The social supports (*resources*) put in place by the HIV sector and PLWH themselves to compensate for the difficulties and injustices emanating from the *recognition* domain and the economic resources element of the *resources* domain are threatened by agents operating within Fraser's third domain: *representation*. Thus while, in Fraser's framework, both social care and service organisations 'belong' in the *resources* category, the politicisation of these resources in the context of neoliberal policies make the domain *representation* equally relevant to them. Accessing essential resources is, thus, an issue of *representation* – a fact of increasing relevance given increases in the number and proportion of older people (and younger people living with chronic and/or disabling conditions) needing care and support on the one hand and the purposive erosion of the welfare state in the UK and the US on the other.

The issue of representation takes on added valence in the context of a significant imbalance in third-sector and governmental organisations' attention to OPLWH, and of OPLWH's own participation of activism and advocacy on their own behalf. While an effective AIDS activist movement developed in the early days of the pandemic (including the AIDS Coalition To Unleash Power, or ACTUP), demanding political action, including faster development of – and better access to – effective treatments (Morris, 2012), the introduction of effective treatments in 1996 lessened the need for activism focused on developing life-saving treatments, although access to these treatments remains uneven (see e.g. Souteyrand et al., 2008). Some notable community activism persists, e.g. to support good and equitable access to PrEP (Pre-exposure Prophylaxis) and PeP (Post-exposure Prophylaxis) via public health systems (Brisson and Nguyen, 2017). Yet, there is also a sense that OPLWH's ability to maintain earlier levels of political activism has waned, as OPLWH, particularly long-term survivors, are exhausted by the traumatic fallout of the epidemic's early years and by the challenges of assimilating the multiple losses of those years. These days, OPLWH are not leading on activism to improve their lives as OPLWH, but rather are participating in research and/or are recipients of help. Here, the voices of OPLWH typically are being represented by researchers, the NHS and charities, rather than by OPLWH-led activism, although many OPLWH do collaborate on relevant research (see e.g. Terrence Higgins Trust, 2017), and long-term survivors provide peer support and engage in advocacy work (see e.g. the 'Let's Kick Ass' group – Anderson, 2015).

Moreover, little overlap exists between the concerns of HIV and ageing activist/advocacy organisations; there is, for example, little reference to HIV



on the Age UK website, compared with the Alzheimer's Society website which provides information on HIV-related cognitive impairment (Alzheimer's Society, 2015), and the recent (2017) Age UK resource guide for professionals designed to 'help health and care professionals meet the needs of older lesbian, gay, bisexual and trans (LGBT) people' makes no reference to HIV despite the disproportionate HIV prevalence among men who have sex with men of all ages. The HIV sector is thus far more attentive to recognising and serving the needs of OPLWH than is the ageing sector – a gap which must be bridged if OPLWH are to achieve adequate representation and, indeed, social justice.

## Notes

- 1 Jane Anderson, Homerton University Hospital NHS Foundation Trust, London, UK; David Asboe, Chelsea and Westminster Hospital NHS Foundation Trust, London, UK; Valerie Delpuch, Public Health England, London, UK.
- 2 Most had disclosed to family members, partners, and adult children – for issues regarding disclosure to young children and older parents – see Rosenfeld et al., 2016.

## References

- Age UK. 2017. *Safe to be me: Meeting the needs of older lesbian, gay, bisexual and transgender people using health and social care services*. London: Age UK. [www.ageuk.org.uk/globalassets/age-uk/documents/booklets/safe\\_to\\_be\\_me.pdf](http://www.ageuk.org.uk/globalassets/age-uk/documents/booklets/safe_to_be_me.pdf) (Accessed 28/04/18).
- Altman, Lawrence K. 2011. "30 years in, we are still learning from AIDS." *The New York Times*. May 30. [www.nytimes.com/2011/05/31/health/31aids.html](http://www.nytimes.com/2011/05/31/health/31aids.html)
- Alzheimer's Society. 2015. *HIV-related cognitive impairment*. London: Alzheimer's Society. [www.alzheimers.org.uk/info/20007/types\\_of\\_dementia/36/hiv-related\\_cognitive\\_impairment](http://www.alzheimers.org.uk/info/20007/types_of_dementia/36/hiv-related_cognitive_impairment)
- Anderson, Tez. 2015. "HIV long-term survivors declaration: A vision for our future 2018." *Let's Kick Ass* blog. August 18. <https://letskickass.hiv/with-courage-and-compassion-long-term-survivors-of-hiv-strive-not-only-to-survive-but-also-to-ee056d372994>
- Beer, Gail, Matt James, and Sean Summer. 2014. *Growing older positively: The challenge of ageing with HIV*. London: 2020health.org.
- Brisson, Julien, and Vinh-Kim Nguyen. 2017. "Science, technology, power and sex: Prep and HIV-positive gay men in Paris." *Culture, Health & Sexuality* 19 (10): 1066–1077. doi: 10.1080/13691058.2017.1291994
- Charmaz, Kathy. 1991. *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Deeks, Steven G., Sharon R. Lewin, and Diane V. Havlir. 2013. "The end of AIDS: HIV infection as a chronic disease." *The Lancet* 382 (9903): 1525–1533. doi: 10.1016/S0140-6736(13)61809-7
- Emlet, Charles A. 2006. "You're awfully old to have this disease: Experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS." *The Gerontologist* 46 (6): 781–790. doi: 10.1093/geront/46.6.781
- Fraser, Nancy. 2003. "Social justice in the age of identity politics: Redistribution, recognition, and participation." In *Redistribution or recognition? A political-philosophical exchange*, edited by Nancy Fraser and Axel Honneth, 3–67. London and New York: Verso Books.

- Glaser, Barney G., and Anselm L. Strauss. 1967. *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine De Gruyter.
- Halkitis, Perry N. 2013. *The AIDS generation: Stories of survival and resilience*. New York: Oxford University Press.
- Harris, L.M., C.A. Emler, C. Pierpaoli Parker, and C. Furlotte. 2018. "Timing of diagnosis: Understanding resilience narratives of HIV positive older adults diagnosed pre-and post-HAART." *Journal of Gerontological Social Work* 61 (1): 78–103.
- Kall, Meaghan, Zheng Yin, Andrew Skingsley, Maryam Shahmanesh, Anthony Nardone, Richard Gilson, and Valerie Delpech on behalf of the Positive Voices Study Group. 2015. "Chronic disease in the HIV population in care in the UK: Projections until 2028." 17th International Workshop on Co-morbidities and Adverse Drug Reactions in HIV. Barcelona.
- Karpiak, Stephen E., and Brennan-Ing Mark. 2016. "Aging with HIV: The challenges of providing care and social supports." *Generations* 40 (2): 23–25.
- Kirwan, P. D., C. Chau, A. E. Brown, O. N. Gill, and V. C. Delpech. 2016. "HIV in the UK—2016 report." London: Public Health England.
- Kooij, Katherine W., Ferdinand W. N. M. Wit, Judith Schouten, Marc van der Valk, Mieke H. Godfried, Ineke G. Stolte, Maria Prins, Julian Falutz, and Peter Reiss, and AGEHIV Cohort Study Group. 2016. "HIV infection is independently associated with frailty in middle-aged HIV type 1-infected individuals compared with similar but uninfected controls." *AIDS* 30 (2): 241–250. doi: 10.1097/QAD.0000000000000910
- May, M., M. Gompels, and C. Sabin. 2012. "Life expectancy of HIV-1-positive individuals approaches normal conditional on response to antiretroviral therapy: UK collaborative HIV cohort study." *Journal of the International AIDS Society* 15 (Suppl 4): 18078. doi: 10.7448/IAS.15.6.18078
- Morris III, Charles E. 2012. "ACT UP 25: HIV/AIDS, archival queers, and mnemonic world making." *Quarterly Journal of Speech* 98 (1): 49–53. doi: 10.1080/00335630.2011.638658
- Nakagawa, Fumiyo, Margaret May, and Andrew Phillips. 2013. "Life expectancy living with HIV: Recent estimates and future implications." *Current Opinion in Infectious Diseases* 26 (1): 17–25. doi: 10.1097/QCO.0b013e32835ba6b1
- National AIDS Trust. 2014. *HIV patient information and NHS confidentiality in England*. London: National AIDS Trust.
- National AIDS Trust. 2017a. *PIP and HIV: How personal independence payment is working for people living with HIV*. London: National AIDS Trust.
- National AIDS Trust. 2017b. *Why we need HIV support services: A review of the evidence*. London: National AIDS Trust.
- Naudet, D., L. De Decker, L. Chiche, C. Doncarli, V. Ho-Amiot, M. Bessaud, Q. Alitta, and F. Retornaz. 2017. "Nursing home admission of aging HIV patients: Challenges and obstacles for medical and nursing staffs." *European Geriatric Medicine* 8 (1): 66–70. doi: 10.1016/j.eurger.2016.12.003
- Nöstlinger, Christiana, Daniela Rojas Castro, and Tom Platteau, Sonia Dias, and Jean Le Gall. 2014. "HIV-related discrimination in European health care settings." *AIDS Patient Care and STDs* 28 (3): 155–161. doi: 10.1089/apc.2013.0247
- Rosenfeld, Dana, and Jane Anderson. 2018. "'The own' and 'the wise' as social support for older people living with HIV in the United Kingdom." *Ageing & Society*: 1–17. Published online: 2 August 2018. <https://doi.org/10.1017/S0144686X18000909>
- Rosenfeld, Dana, J. Anderson, D. Ridge, D. Asboe, J. Catalan, S. Collins, V. Delpech, and V. Tuffrey. 2015. "Social support, mental health, and quality of life among older people living with HIV: Findings from the HIV and later life (HALL) project." [www.keele.ac.uk/media/keeleuniversity/ri/risocsci/hall/docs/HALL\\_Report\\_FINAL2%20\(1\).pdf](http://www.keele.ac.uk/media/keeleuniversity/ri/risocsci/hall/docs/HALL_Report_FINAL2%20(1).pdf)

- Rosenfeld, Dana, Bernadette Bartlam, and Ruth D. Smith. 2012. "Out of the closet and into the trenches: Gay male baby boomers, aging, and HIV/AIDS." *The Gerontologist* 52 (2): 255–264. doi: 10.1093/geront/gnr138
- Rosenfeld, Dana, Damien Ridge, Jose Catalan, and Valerie Delpech. 2016. "Age and life course location as interpretive resources for decisions regarding disclosure of HIV to parents and children: Findings from the HIV and later life study." *Journal of Aging Studies* 38: 81–91. doi: 10.1016/j.jaging.2016.06.001
- Rosenfeld, Dana, Damien Ridge, and Genevieve Von Lob. 2014. "Vital scientific puzzle or lived uncertainty? Professional and lived approaches to the uncertainties of ageing with HIV." *Health Sociology Review* 23 (1): 20–32. doi: 10.5172/hesr.2014.23.1.20
- Shippy, R. Andrew, and Stephen E. Karpiak. 2005. "The aging HIV/AIDS population: Fragile social networks." *Aging and Mental Health* 9 (3): 246–254. doi: 10.1080/13607860412331336850
- Siegler, Eugenia L., and Mark Brennan-Ing. 2017. "Adapting systems of care for people aging with HIV." *Journal of the Association of Nurses in AIDS Care* 28: 698–707. doi: 10.1016/j.jana.2017.05.006
- Smit, Mikaela, Kees Brinkman, Suzanne Geerlings, Colette Smit, Kalyani Thyagarajan, Ard van Sighem, Frank de Wolf, and Timothy B. Hallett. 2015. "Future challenges for clinical care of an ageing population infected with HIV: A modelling study." *The Lancet Infectious Diseases* 15 (7): 810–818. doi: 10.1016/S1473-3099(15)00056-0
- Souteyrand, Yves P., Veronique Collard, Jean Paul Moatti, Ian Grubb, and Teguest Guerma. 2008. "Free care at the point of service delivery: A key component for reaching universal access to HIV/AIDS treatment in developing countries." *AIDS* 22: S161–S168. doi: 10.1097/01.aids.0000327637.59672.02
- Strauss, Anselm L. 1987. *Qualitative analysis for social scientists*. Cambridge: Cambridge University Press.
- Terrence Higgins Trust (THT). 2017. *Uncharted territory: A report into the first generation growing older with HIV*. London: THT.
- Tester, Griff. 2017. "'And then AIDS came along': A life course turning point and sub-cohorts of older gay men." *Journal of Gay & Lesbian Social Services* 30 (1): 1–16. doi: 10.1080/10538720.2017.1408516
- UNAIDS. 2013. *HIV and aging: A special supplement to the UNAIDS report on the global AIDS epidemic*. Geneva: UNAIDS.
- Westwood, Sue. 2016. *Ageing, gender and sexuality: Equality in later life*. Abingdon: Routledge.
- Willson, Andrea E., Kim M. Shuey, and Glen H. Elder, Jr. 2007. "Cumulative advantage processes as mechanisms of inequality in life course health." *American Journal of Sociology* 112 (6): 1886–1924. doi: 10.1086/512712
- Yin, Zheng, Andrew Skingsley, and Valerie Delpech (2015). "Over half of people in HIV care in the United Kingdom by 2028 will be aged 50 years or above." 15th European AIDS Conference, Barcelona, Spain.