‘The Own’ and ‘the Wise’ as Social Support for Older People Living with HIV in the United Kingdom

Dr Dana Rosenfeld and Professor Jane Anderson, on behalf of the HIV and Later Life (HALL) team

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Abstract As the HIV population ages, how the ageing and HIV experiences intersect to shape the lives of older people living with HIV (PLWH) becomes an increasingly pressing question. This multi-method study investigated social support, mental health, and quality of life among 100 older PLWH in the United Kingdom. Drawing on data from three focus groups and 74 lifePage 1 of 33 For Review only 2 history interviews with older (aged 50+) white men who have sex with men (MSM), and black African and white heterosexual men and women, living with HIV, we explore participants' distinctions between, evaluations of, and access to sources of social support. Participants distinguished between support from the HIV-negative (Goffman's 'the own') and experientially-based support from other PLWH (Goffman's 'the wise'), and viewed the former, while valuable, as needing to be supplemented by the latter. Furthermore, access to experientially-based support varied across participant groups, whose communities had different histories with HIV/AIDS and thus different degrees of knowledge about HIV and avenues for connecting to other PLWH. Thus, social support among older PLWH cannot be neatly divided into 'formal' and 'informal' domains, or fully appreciated by applying traditional social support measures, including, in the context of health conditions, 'peer support' created through formal service organisations. Rather, older PLWH's own distinctions and evaluations better illuminate the complexities of social support in the context of ageing with HIV.

Keywords: social support, HIV, Goffman

Introduction

As people living with HIV (PLWH) age following the introduction of effective antiretroviral therapy (ART) 1996 (Sabin 2013), which changed HIV from a typically fatal condition to a potentially long term manageable one, research into the social dimensions of ageing with HIV is growing (Emlet 2006a, 2008; Wallach and Brotman 2013; Nevedal and Sankar 2015; Hutton 2016; Furlotte and Schwartz 2017; Catalan *et al*. 2017; Wallace and Brotman 2017). Much of this research documents the distinctive challenges that ageing introduces to the experience of living with HIV (within the HIV context, the term 'older' refers to those aged 50 and above - see e.g. Centers for Disease Control 2017; Sankar *et al*. 2011). While both younger and older people living with HIV (PLWH) experience HIV-associated stigma (Porter *et al*. 2015) that can compromise relationships (Grov *et al*. 2010) and weaken social support, and must manage the complexities of disclosure, older PLWH (OPWLH) also face unique social stressors and challenges introduced by later life. These include uncertainty about how HIV's physical, psychological and social consequences impact on 'normal' ageing (Rosenfeld *et al.* 2015; Solomon *et al*. 2014), and disproportionate financial disadvantage, with 58 per cent of OPLWH (versus 30 per cent of HIV-negative older people) in the United Kingdom (UK) now living on or below the poverty line, largely due to work careers interrupted by ill health (Beer, James, and Summer 2014).

These challenges, evidence that the psychological costs of social isolation and inadequate support are especially high among older people (Tomaka, Thompson and Palacios 2006), and Shippy and Karpiak's (2005) early work on OPLWH's 'fragile' social support have sparked a growing body of research into ageing with HIV (see e.g. Bekele *et al*. 2013; Mavandadi *et al.* 2009; Brennan-Ing, Seidel and Karpiak 2016), much of which focuses on barriers to this older group's social support. These barriers include, for example, the limitations posed by OPLWH's poor physical and mental health (see e.g. Brañas *et al*. 2017;

Eaton, Craig and Wallace 2017; McGowan *et al*. 2017; Hearps *et al*. 2016; Guaraldi *et al*. 2011; Schouten *et al*. 2014) to their ability to secure or remain in paid work (see e.g. Kordovski et al. 2017), making them 'less likely to get social support through employment' (Rueda, Law and Rourke 2014: 328).

Yet, while advancing knowledge about ageing with HIV, this scholarship generally treats social support as a purely measurable variable (e.g. Emlet 2006b), thereby overlooking how OPLWH themselves distinguish between forms and sources of support – distinctions which, as studies of other stigmatized groups (e.g. Smith 2012), including PLWH (e.g. Veinot 2009), show, structure these groups' social networks, interactions, and relationships. Goffman's seminal (1963) book on the social worlds of the stigmatized identified two types of 'sympathetic others who are ready to adopt [the stigmatized person's] standpoint in the world and to share with him the feeling that he is human and "essentially" normal in spite of appearances and in spite of his own self-doubts' (1963: 19-20). One sympathetic group is the individual's 'own', who share his stigma, understand and can empathize with his experiences of it, and can provide 'instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support' (1963: 20). The second type is 'the wise': 'normals' (those without the stigma in question) whose professional or family/friendship relationship with the stigmatized person make them 'intimately privy to' his 'secret life'; while accepting and supportive, they cannot provide the instruction or empathy offered by 'the own'. These internal distinctions, and the relative value that the stigmatized attribute to various sources and types of support within and, potentially, across these core groups, resist quantification and demand investigation in their own right, including in the HIV and ageing context.

Research into ageing with HIV also often treats support from friends, family, and romantic partners as equivalent regardless of their HIV status and of the shape that PLWH's social networks take in response to the pressures of living with HIV (Schrimshaw and Siegel 2003; Slomka *et al*. 2013 – but see Poindexter and Shippy 2008), and typically glosses support into ‘formal’ (provided by professionals and organizations), and ‘informal’ (emanating from personal networks) spheres. This renders invisible efforts to secure support grounded in shared experience of HIV from both domains. As Peterson *et al*. (2012) show, this elision is exacerbated by scholars’ adoption of Dennis’s (2003: 239, emphasis added) definition of peer support ‘within the healthcare context’ as ‘the provision of emotional, appraisal, and informational assistance *by a created social network member* who *possesses experiential knowledge* of a specific behavior or stressor and similar characteristics as the target population’. Drawing on their empirical investigation of PLWH’s peer support, Peterson *et al*. (2012) expand this definition to include other PLWH ‘embedded’ within personal networks (embedded networks ‘occur naturally, including spouse/partner relationships, and other friends and family members’ - ibid: 299).

This conceptual expansion highlights the existence of support based on shared experience within both created support settings and more organic social networks in which other PLWH are ‘embedded’. It thus offers a new route to uncovering OPLWH’s own understandings and experiences of, and strategies for securing, social support. However, it leaves unanswered the question of how, if at all, PLWH are differentially positioned in relation to embedded or created experientially-informed support, a question further complicated by the distinctive communities and circumstances in which people live and age with HIV. In the UK, the three largest groups of OPLWH (in descending order: White men who have sex with men, (MSM); Black African heterosexual men and women; and White heterosexual men and women – see Yin *et al*. 2014) occupy very different social spaces. *MSM* are ageing in a gay community deeply affected by the HIV/AIDS epidemic of the 1980s-1990s (Rosenfeld, Bartlam and Smith 2012; Halkitis 2013) and a wider homophobic society, *Black African heterosexuals'* uncertain migration status limits their income, ability legally to work, and access to public services (Chinouya, Hildreth and Goodall 2014), and *White heterosexuals* report 'considerable isolation, financial concerns and a sense that existing services do not prioritise their needs' (Beer and Summers 2014: 10).

Thus, any investigation into social support among OPLWH must include attention to both local understandings and strategies, as above, and community contexts. This article seeks to uncover these understandings and strategies in community context through analysis of interview and focus group data that we gathered from MSM and from Black African and White heterosexual OPLWH in the UK as part of the HIV and Later Life (HALL) study. We begin with a summary of our methods and sample, including a description of how our preliminary findings led us to engage with Goffman's (1963) work on the social worlds of the stigmatized as an especially useful theoretical framework for capturing the distinctive shape of OPLWH's social support as it emerged in our analysis. Our presentation of findings is followed by a discussion of their theoretical and policy implications.

Methods and sample

We collected the interview and focus group data presented here during a two-year (2011-2013) multi-method study investigating social support, mental health, and quality of life (QoL) among PLWH aged 50+ in the UK. With continuous input from an advisory board composed of PLWH, and after securing clearance from the UK's National Health Service Research and the Principal Investigator's (PI) university ethics committees, we sought a purposive and proportional sample of recently- and longer-term diagnosed (living with an HIV diagnosis for 1-9 or for 10 or more years, respectively) White MSM, Black African heterosexual men and women, and White heterosexual men and women living with HIV in the UK. To protect participants' mental wellbeing, we excluded those diagnosed with HIV for less than 12 months or experiencing severe mental health or trauma issues.

We recruited OPLWH for our focus groups through HIV organizations, and interview and survey participants through these same organizations, two HIV specialist clinics, and one mental health clinic serving a high proportion of PLWH, all in London. HIV clinicians and HIV organization staff reviewed their records to identify potential participants, informing them of the study and providing them with contact information for the study's interviewer, who was often on site. All interviews, focus groups, and surveys (see below) were conducted in English, and all participants received an information sheet and a list of HIV and other support organizations and gave written informed consent.

To capture the specific concerns of our participant groups and the impact of recent and longer-term diagnosis on the experience of ageing with HIV, we conducted three focus groups (one with recently and longer-term diagnosed Black African heterosexual men and women, one with longer-term diagnosed OPLWH across groups, and one with recently-diagnosed MSM) in spaces provided by HIV organizations. The PI ran the focus groups, with the researcher taking notes. Themes raised in these groups (e.g. parenthood, migration) informed our life-history interviews with 76 OPLWH living in and/or accessing HIV services in London; for example, we expanded our original interview topic guide to reflect several focus group members' concerns over parenthood and ageism. Interviewees were asked for demographic information, and about their typical days, personal histories and histories with HIV, social relations and social support, experiences of living and ageing with HIV, and QoL. They were also encouraged to raise any additional issues that they considered relevant to the study's central questions. Finally, we gathered data from 100 OPLWH using surveys containing mental health and QoL questions (76 with interviewees, and 24 stand-alone surveys containing supplemental social support questions).

Four participants did not fall neatly within our three core participant groups: one White bisexual woman and one Black African women of unknown sexual orientation, whose interviews and survey data we analyzed, and one heterosexual man and one heterosexual woman of Black Caribbean heritage, whom we excluded from qualitative analysis while retaining their survey data, which are not shown here (see Rosenfeld *et al.* 2015 and Catalan, Tuffrey, Ridge and Rosenfeld, 2017 for survey data analysis and findings). We stopped recruiting after preliminary analysis achieved theoretical saturation (Charmaz 2014).

Sample: Our survey (n = 100) data consisted of 76 surveys completed by interviewees and 24 stand-alone surveys completed by participants whom we did not interview. We expanded stand-alone surveys to include similar questions to those posed at interview, including social relations (e.g. 'closest to', HIV support group attendance), physical health, demographics (e.g. income, work status), and history with HIV (e.g. year of diagnosis). We also entered the same information captured in stand-alone surveys that participants provided at interview into our survey database (as focus group participants did not complete the survey, they were not included in the statistical analysis or description of participant socio-demographics below). We thus produced a statistical database covering the same domains across interview and survey-only participants. We subjected our survey data to bivariate and multivariate analysis, specifically, step-wise multivariate linear regression, using SPSS, from which we derived our overall sample characteristics, as below. Our analysis showed that participants completing interviews and stand-alone surveys had similar demographic, health, financial, and social characteristics.

Our interview and stand-alone survey sample included 53 MSM (50 gay men and three bisexual men), 16 White heterosexuals (eight men and eight women), one White bisexual woman, 12 Black African heterosexual men, 17 Black African heterosexual women, and one Black African woman of unknown sexual orientation. Participants' ages ranged from 50-87, with a median age of 56 and a mean age of 58.4 (age distributions across genders, ethnicities, and sexual orientations were similar). Age at diagnosis ranged from 24-79 (median 47, mean 47.2). All survey and interview participants lived in the UK: 87 per cent in and 13 per cent outside of London. Most (58 per cent) participants were born in the UK, with the rest born in Africa (28 per cent), other European countries (8 per cent), or e.g. Canada, the USA, South America, and Australia (6 per cent).

One in three (25 White and nine Black African) participants were single, with 67 percent (46 White and 21 Black African participants) in romantic partnerships (of these, five were married, two were engaged, and seven were in a civil partnership). One in five participants lived with a partner, 15 per cent with one or more children, and 60 per cent lived alone. While slightly more than half were parents, parenthood was unevenly distributed, with 97 per cent of Black African, 82 per cent of White heterosexual, and 17 per cent of MSM having children (MSM who were parents had fathered children in previous heterosexual marriages before identifying as gay).

Reflecting the lower income and employment rate, and the higher reliance on benefits, among OPLWH in the UK (Terrence Higgins Trust 2017), our study's participants had high rates of financial disadvantage. While annual income ranged from no income to £120,000, median and mean incomes were £10,400 and £20,430, respectively, with four in five participants earning less than £31,000 per year and 48 per cent (76 per cent of women, 41 per cent of men, 83 per cent of Black African, and 35 per cent of White participants) living on less than £10,000 per year, placing them below the £10,000 threshold for the official poverty line for UK households. Over half (55 per cent) of the sample received a range of benefits, including Disability Living Allowance, Employment and Support Allowance (including Incapacity Allowance), and housing benefit, with women (78 per cent) and Black Africans (73 per cent) more reliant on these than were White heterosexuals (53 per cent) and MSM (45 per cent). This high reliance on benefits, and low income, was connected to low employment:

only 28 per cent of the sample was in paid work, with 20 per cent retired and 52 per cent not in paid work.

Coding and Analysis: Interviews were transcribed *ad verbatim* and all qualitative data fully anonymized before being thematically analyzed (Attride-Stirling 2001; Boyatzis 1998) through a process of open and closed coding that, while attentive to our core research concerns (social support, QoL, and mental health), was primarily devoted to capturing such emergent themes as disclosure, relationships and romance, and religion and spirituality. The process began with the PI and one co-investigator (the two members of the team with the strongest backgrounds in qualitative analysis) and the interviewer subjecting a sample of the transcripts to close, line-by-line readings, generating open codes (e.g. stigma, parenting, physical health, and diagnosis). After group discussion, we expanded and refined these open codes into a set of closed codes that accommodated subtle differences in, and the full range of topics embedded in, the data. For example, we subdivided the open code 'disclosure' into two more precise codes: 'disclosure' of one's own HIV status *to* others, and 'discovery' of one's own HIV *by* others.

We assigned each code an NVivo folder and populated each folder with relevant segments of interview text. We achieved analytic rigor *via* constant comparison (Glaser and Strauss 1967), with the PI and a dedicated qualitative analyst with a background in ageing and health comparing similar datum to arrive at analytic themes reflecting similarities between and variations within the data as a whole, then uncovering their connections to other themes. For example, comparing accounts of HIV stigma uncovered participants' understanding of this stigma as grounded in incorrect information about HIV (as e.g. a 'gay' or 'Black' 'disease' and/or one acquired through irresponsible sexual activity or drug misuse). This generated the code 'HIV knowledge', which, upon analysis, we recognized referred to either 'experiential knowledge', based on the biographical experience *of* living with HIV, or ‘informational knowledge’ *about* HIV, garnered through secondary sources. This distinction also appeared in accounts of social relations and social support, with participants depicting support provided by those with experientially-informed knowledge as distinctive and essential for living and ageing with HIV. Our knowledge of Goffman’s and others’ work on the lived experience of stigma (see Rosenfeld 2003), which we revisited in light of these analytic findings, made clear the link between these distinctions and Goffman’s (1963) categories ‘the own’ and ‘the wise’.

Results

Challenges of ageing with HIV

In keeping with previous findings on the social dimensions of ageing with HIV (see above), our study’s participants described their experiences of living with HIV as bisected by several overlapping age-inflected challenges and circumstances. These are reported in more detail elsewhere (Rosenfeld *et al*. 2012; Rosenfeld, Ridge and Von Lob 2014; Rosenfeld, Ridge, Catalan and Delpech 2016), but, briefly, included ageism exacerbating HIV-related stigma (see also Emlet 2006b), with, for example, BAFG#3 (LTD BAF, 50s)[i] saying ‘with age, the stigma gets worse because as an older person you’re expected to set good morals. And to say you’re HIV positive, people start thinking, “This lady, what was she up to?” … If you say you’re HIV positive and of a certain age, they start judging you’. Ageing also introduced chronic uncertainty about the physical, psychological, and social impacts of ageing with HIV. As P75, RD MSM, 50s, said, ‘It’s a negative thing, this frustration of having these different negative forces inside - your HIV, ageing, secondary health problems which may or may not be related, and it’s this not knowing sometimes what’s really causing the problem’. This uncertainty made it difficult for participants to predict their future care needs. For example, when asked about his care and support needs, P50 (RD MSM, 60s) said ‘I suppose, as I get older, I will need medical support in case of side effects. I don’t know because the [health service] doesn’t know. When you ask them, they say we don’t know, it’s a new area of learning. So I have no idea if I will need support’. Another age-inflected theme was the sense of loss over disruptions to the lives and social roles participants had envisaged having in later years: as P12 (LTD BAM, 50s) explained, ‘In Africa, people believe that if you’re 50, that’s the benchmark for achievement, because at 50 you’re supposed to be a governor or a minister or something. But if you’re battling with HIV then they begin to feel somehow - you’re not sure about your life’. In contrast to OPLWH, he said, ‘those who are negative are progressing in their life’.

Participants also described difficulties in forming romantic partnerships, partly due to the greater likelihood that older people would hold stigmatized beliefs about HIV; when describing her desire to form a romantic partnership, P59 (RD WHF, 60s) said ‘My daughter’s generation, they’re not shocked’ by HIV, which they see as just another ‘hazard of life … Whereas for my generation, HIV is like “Oh, my God!”’ Grounding these concerns was a fear that disclosure to HIV-negative persons, including long-standing members of their social networks, would result in personal rejection. Thus P16 (RD MSM, 50s) explained that ‘A lot of older people have a strong foundation of friends. And one day you turn around to these people you’ve known for years and tell them “I’m HIV positive”, having to worry about what the effects of telling these people you’ve known for so long are going to be. Because what’s the first thing that comes into people’s minds? “What, are you a drug user?”’ A central technique that participants described using to manage these challenges, and to offset the stresses they caused, was to supplement support from ‘the wise’ with experientially-informed support from ‘the own’.

Supplementing social support

Overall, participants' social networks were varied and often robust, including relationships with family, friends, partners, work colleagues, neighbors, and fellow members of churches and other community groups (including HIV organizations – see below). These networks were embedded in wider community contexts that shaped participants' knowledge of HIV and access to 'their own'. In general, *MSM* had come of age in a community with high of AIDS-related mortality (many had lost friends and/or partners to AIDS) and an intensive and organized political response to the epidemic in its earlier years (in which several participants had been involved). MSM participants were the most knowledgeable about, and the most likely to have friends and/or partners living with, HIV. *Black African* participants had migrated (typically pre-diagnosis) to the UK from countries with high HIV prevalence and AIDS mortality rates. Many had lost friends and family to AIDS. Most were married with children but geographically separated from family, including spouses and children, who lived in their countries of origin. Almost all were awaiting indefinite leave to remain in the UK (a source of significant uncertainty and stress). High levels of HIV-associated stigma amongst Black African communities made it particularly difficult for these participants to secure HIV-specific support within their own networks. Finally, most *White heterosexual* participants had been married and were parents, with family and friendship networks in the UK. But they also had the least knowledge of HIV pre-diagnosis, were the least likely to know other PLWH in their pre-diagnosis networks (almost none had known other PLWH pre-diagnosis), and, as a result, viewed themselves as particularly isolated from 'their own' relative to other PLWH.

'The own' and 'the wise'

'The wise'*:* To cope with the challenges of living and ageing with HIV, participants typically sought support from social connections with 'the wise' that predated their diagnosis, such as friends, family, work colleagues, neighbors, partners, and, for a small minority, formal mental health services. Most had disclosed their HIV status to at least some family members, who then provided practical and emotional support. As LTDFG#5 (LTD BAF, 60s) explained,

> HIV comes with a lot of sickness. So what do you tell your family? Someone has to lift you up … The surrounding people will say a lot about your sickness. But my family sympathizes with me, supports me. They want me to be happy and don't want me to die.

For participants in romantic relationships, partners also provided emotional and practical support (28 of our study's 33 partnered participants identified their partners, regardless of their HIV status, as the people to whom they felt the closest). To P51 (RD MSM, 50s), his HIV-negative partner was his 'core relationship', which he characterized as 'very honest, very open, very supportive'.

But participants also stated that 'the wise' could not provide the experientially-informed social support they needed as PLWH. Across the qualitative data, others' ability to 'know what it's like to live with HIV' was a dominant theme, with participants describing living with HIV as so complex, nuanced, and, to a great extent, inexpressible and even unknown, that only other PLWH could comprehend its experience and impacts. P70 (RD WHF, 50s) said that while her HIV-negative friends 'offered a lot of support', and that 'it was helpful being able to speak to them up to a point, obviously, they don't quite understand what I'm going through'. P75 (RD MSM, 50s) characterized friendships with 'the wise' and 'the own' as 'all valid', explaining that 'the obvious differences' between them 'doesn't mean relationships with non-HIV friends are any less strong, because they're not … They're all supportive, but the support from people who are HIV is usually a little more on the nose, a bit more aligned … If someone's going through or has already gone through the same thing as you, then you're going to attune and have a better empathy for those people, and *vice versa*'.

‘The own’*:* This gap in understanding led participants to secure support from ‘their own’. Both single participants and those already partnered with other PLWH cited the benefits of forming *romantic partnerships* with ‘their own’, describing these partnerships as, in P76’s (RD MSM, 50s) words, ‘easier and simpler’. For example, P52 (RD BAF, 50s) attributed her preference for a partner who was ‘already HIV positive’ to ‘the thought that someone might reject you simply because you’re infected. I wouldn’t like that. I want someone who’s already in the same situation, someone I don’t have to explain myself to’.

To these participants, romantic partnerships with ‘the own’ were emotionally closer than were those with ‘the wise’, with shared experience grounding deeper mutual understanding. P22 (RD MSM, 50s) was open to a relationship with an HIV-negative partner, ‘but I think, for easiness, HIV positive. Because you can empathize a lot more and both will be clued up in some areas of medications or side effects and know what to do if something happens’. Here and in other accounts, the intimacy that comes from living together is significantly affected by the partner’s HIV status, with ‘wise’ partners supporting HIV-related health practices and concerns, but not participating in them in the same way as would ‘the own’. As P70 (RD WHF, 50s) explained in relation to her HIV-positive partner, ‘We support each other. We always say “Oh, remember your tablets”. I couldn’t imagine having a relationship with someone who wasn’t in the same position as me. More than anything, that’s been really nice in terms of our relationship, to share that’.

Participants also sought *non-romantic connections* with and support from ‘their own’. As P47 (LTD WHF, 60s) said, ‘that’s the only answer: having friends in the same situation’. P44 (RD MSM, 50s) described supporting an HIV-positive friend ‘if he wants to talk about it. I’m in the same boat. I understand how somebody feels. I think to actually be able to empathize properly, you need to be in the same boat. It’s very easy to say “Well, you know, it must be difficult to live with it” or “It must be easy to live with it”; if you aren’t in that situation, then it’s not so easy’. As we show below, MSM had readier access to other PLWH than did the heterosexuals in the sample, but for many MSM, and all heterosexual, participants, the most usual means of finding non-romantic support from ‘the own’ were HIV-dedicated websites (some of which were dating sites) and HIV organizations and groups, which 55 per cent of participants attended at the time of interview, with most of these attending no other kind of group (those who did not attend these groups cited being sufficiently informed and/or seeking to avoid having their HIV ‘define’ or ‘dominate’ their lives – see Rosenfeld, Catalan and Ridge 2018). Of these 55 participants, most were Black African (80 per cent versus 44 per cent of White participants), female (74 per cent versus 48 per cent of male participants), and heterosexual (74 per cent versus 32 per cent of MSM). These proportions speak to the larger role that formal HIV organizations played in connecting heterosexuals with ‘the own’: the explanation given by P23 (RD MSM, 50s) for not attending HIV support groups post-diagnosis (he had ‘already got the support’ and had ‘always known where to get the support … because I’ve been around it’) was repeated, in various ways, across MSM participants’ accounts, but no heterosexual participant made a similar statement.

When asked why they attended HIV groups, participants most often listed ‘emotional support’, ‘practical information’ (e.g. about disability benefits or immigration applications), and ‘meeting people’, followed by ‘social activities’ and ‘spending time in a safe space’. Perhaps most significantly, these groups allowed participants to support and be supported by ‘the own’, with benefits including sharing experiences of living and ageing with HIV, exchanging HIV knowledge and information about relevant services, HIV medication, the physiological impact of HIV, and disclosure, and a vital sense of social solidarity, unity, belonging and familiarity.

Several participants contrasted their ability openly to discuss HIV-related concerns in these ‘safe spaces’ with the constraints on such discussion in non-HIV dedicated settings, including those for older people. As MSMFG#2 (RD MSM, 60s) said, ‘If you have HIV, there’s a tendency to stay with the HIV community because you know you’re safe there. Like here [in this HIV organization], you can talk freely. If I went to my local over 60s afternoon tea party, I couldn’t talk about this’. Similarly, P43 (LTD MSM, 60s) explained that, in HIV organizations, ‘at least you know the common denominator’, whereas at ‘the council old people’s home, you don’t know’. This ‘common denominator’ provided participants with a sense of solidarity with ‘the own’. P78 (LTD BAM, 50s) considered other HIV support group attendees ‘family’:

> Here, you get a lot of moral support … White, Black, anything, I try to interact with everybody, because we’re the same status, we’re one family here. We’re the same. You make friends, which is very important. You sit down, chat - even chatting for one minute, it’s enough. They’re there for you. I love to come, I don’t want to miss, and when I do miss, I feel I’m missing something.

Associating with ‘their own’ in these groups also showed participants that they could live healthy and productive lives despite their age and HIV status. P52 (RD BAF, 50s) explained, ‘Here, there’s quite a lot of support. And you can live a normal life. It’s almost normal. There’s a group of people in the same situation with you’. P18 (RD BAF, 60s) who lived alone and was separated from her adult children, described ‘feeling loneliness, homesick, so many things in life – stressed’ following her HIV diagnosis; as a result, she said, ‘I wasn’t myself. At times I begin talking to myself. “Why should I have to suffer all this? Why me?”’ When a friend introduced her to another PLWH, who took her to support groups,

> I started seeing people; I said, ‘Oh, we’re in the same boat’. I started feeling relieved; I said, ‘I thought I was alone, but we are many’. When I saw those

> people, I couldn't believe that they have HIV. I said, 'Is that person sick?' I said, 'Well, if they're sick, then I'll be okay'.

This benefit derived from seeing healthy PLWH was one that several participants actively sought to replicate by serving as living examples of healthy survival into later years with HIV – examples that were rare, given the only recent ageing of the HIV population. P60 (LTD MSM, 50s) 'became the oracle' when he 'was part of the support groups'- if other PLWH 'wanted an answer, they'd come to me because I'd lived the longest, so I knew more about it than anybody else'. P64 (LTD BAM, 60s) provided 'counseling and peer support' to newly diagnosed PLWH who, he said, benefitted from seeing him live as an OPLWH and thus realizing that PLWH can attain a normal life span. 'Most of them that are diagnosed', he explained, 'are still youthful. I say "Look, this disease, you can live a normal life, you can live longer, you can plan your future. I stopped planning. I didn't see where I am now. I was planning on a day-to-day basis, but now I'm living here, so you should be thinking of dying at your own pace. So, it's not the end of the world"'.

Access to 'the own': Gaining support from 'the own' required knowledge of and access to them and/or to venues through which to meet them. Some participants used the internet to locate HIV organizations or groups and/or to connect with other PLWH. P79 (RD BAM, 50s) first learned about HIV groups through a friend he made online. When they met in person, 'she told me, "I heard of this group". It was news to me'. But locating appropriate websites also often required guidance from 'the own' and/or 'the wise' - access to whom varied, again, across the MSM, Black African, and White heterosexual communities.

For MSM participants, finding 'the own' was relatively straightforward: almost all had known PLWH pre-diagnosis, and all knew of (and many had volunteered at) HIV organizations and groups. When he was diagnosed, P72's (RD MSM, 50s) 'circle of friends was ‘very supportive’, as ‘most people I know already knew people with HIV anyway or we’d all experienced problems with people with HIV, either illness or death or whatever’. When asked if he had known other PLWH when he was diagnosed, P49 (RD MSM, 50s) said ‘I’m a gay man, after all. You can’t be a gay man on the gay scene and not know people that have got HIV’. Asked how recently-diagnosed PLWH could locate HIV-specific support, P74 (RD MSM, 50s) replied ‘if you’re a gay person of course it’s so much easier because there was a huge support network put in by gay people many years ago’.

In contrast, White heterosexual participants had limited or no knowledge of HIV pre-diagnosis, and Black African heterosexuals knew more about HIV but lived in a community whose stigmatization of HIV constrained its discussion. As a result, heterosexual participants found forging connections with other PLWH more difficult than did MSM participants – a point many participants, MSM and heterosexual alike, made at interview. For P70 (RD WHF, 50s), MSM living with HIV, whom she met through ‘friends of friends’, were important sources of support, since her ‘wise’ heterosexual friends, whilst emotionally supportive, lacked experiential knowledge of HIV: ‘I think I’m lucky, my friends don’t have issues with it at all but they don’t have a strong understanding of it … gay friends have been really helpful because they know so much about the whole thing. Whereas my other friends who I’ve known since I was 11, it was all new for them. None of us have had direct experience’. Many heterosexual participants described HIV groups as the first and, often, only places where they could form supportive connections with ‘their own’ (assuming they attended these groups - P21 (LTD BAF, 50s), for example, did not attend HIV groups because ‘I don’t know where they are’), several heterosexuals in the sample only knowingly encountered other PLWH in HIV clinics. These meetings provided important opportunities for seeking experientially-informed support, directly from other PLWH and/or through direction to HIV organizations, as for them, HIV clinics were the only settings in which it was safe and prudent to approach somebody as a PLWH. As P79 (RD BAM, 50s) explained:

> You don’t know who’s positive, who’s negative - there’s the problem. Like in a group here now, you know that everybody coming here, we’re all in the same boat, and you can talk about it, but on the street, you can’t ask. You can’t just say to somebody, unless you met them in the clinic. You can’t know. It’s very difficult to know, very difficult.

Thus, despite some overlaps, pathways to connecting with ‘the own’ varied across the sample. Heterosexual participants were the most likely to connect with ‘their own’ through websites or HIV organizations to which they were directed by such ‘wise’ professionals as HIV specialist doctors or nurses, or, less typically, social workers or mental health professionals (some participants had asked their health care providers for information about HIV groups but were told that they did not know of any). P82 (RD BAF, 50s) was given ‘a list of all the groups that were around at that time, so I used to know which group to go to’ by her HIV consultant, who emphasized the importance of ‘looking after yourself, eating well, socializing, and getting more education from other people’. This does not mean that health and social care professionals did not guide MSM to support organizations: for example, ‘one of the [clinic’s] social workers’ directed P17 (LTD MSM, 50s) towards HIV support. But heterosexual participants were much more likely to learn of HIV support organizations or groups through these professionals than were MSM.

Discussion

Ageing introduces new challenges to living with HIV. These unfold in the context of social circumstances, relationships, and statuses unique to later years (e.g. parenthood and grandparenthood, pensions and retirement, and the need to plan for and secure long-term care). Thus, age further complicates ‘Coping with HIV [which] has often meant simultaneously managing its physical demands and experiencing a social status that can diminish social connections, existing resources, and social standing' (Watkins-Hayes 2014: 444). Given this added complexity, how OPWLH seek and secure support, and on what terms, is a central feature of older people's HIV experience.

This article sheds light on this feature of ageing with HIV, uncovering internal distinctions and divisions that previous research has failed adequately to capture. Even in the context of strong embedded social networks including 'wise' friends, family, and partners, participants overwhelmingly stated that they needed support from those who were 'in the same boat', or 'the own', who could provide mutual understanding and important guidance, and from HIV organizations, who provided a 'safe space' in which to discuss and be open about their HIV and opportunities to both witness and personally exemplify ageing well with HIV. Thus, participants' support systems were not, strictly, 'fragile', as Shippy and Karpiak (2005) found in their own research; rather, they were limited in the type of support they could provide. Here, HIV-related experientially-informed support from 'the own' is both distinctive and necessary to supplement the support supplied by 'wise' members of embedded networks. In relevant HIV literatures, this experientially-informed, or 'peer', support has, as Peterson *et al*. (2012) note, traditionally been attributed only to 'created social network members' rather than recognized as provided by members of 'embedded', or 'naturally occurring', networks. Our analysis points to the need to correct this unilateral attribution, as many participants did, in fact, secure experientially-informed support from these embedded networks.

This underscores the need to revisit conceptual frameworks currently used to investigate social support among OPLWH and, we suggest, other groups living and ageing within complex social and community contexts. For OPLWH and other stigmatized groups, Goffman's (1963) work demonstrates the pivotal role of the stigmatized/non-stigmatized divide in delineating relationships on which the stigmatized feel that they can rely for particular forms of support, with ‘the own’ offering empathy and instruction grounded in shared experience which ‘the wise’ cannot provide. Close attention to how those living and ageing within distinctive communities define and distinguish between types of support is thus essential if we are to uncover and document the complexities of social support.

Our analysis also showed that access to experientially-informed support was unequally distributed across participant groups, refracted through their communities’ history with and organization (or lack thereof) around HIV and AIDS. White heterosexuals were the least likely to know other PLWH pre-diagnosis and to imagine that their current embedded networks included other PLWH. As a result, heterosexuals were much more likely than were MSM to seek out experientially-informed support from ‘the wise’ and through formal HIV organizations and groups. But an equally important finding was that the mere existence of ‘the own’ within one’s embedded network did not guarantee access to them – a point highlighted by differences between MSM and Black African participants, both of whose communities had high HIV prevalence. For MSM, experientially-informed support was relatively easily obtained from relationships with PLWH that pre-dated their own diagnosis, and/or through other MSM who they knew were living with HIV and could approach on that basis. Black African participants, however, found their paths to experientially-informed support in their embedded networks blocked by an especially pronounced stigma within the Black African community.

However, these community contexts are not unilaterally shaped by sexual and/or ethnic culture – for example, despite significant levels of HIV-related stigma, the UK, and especially London, offer greater freedom to associate with and seek support from other PLWH than do societies with higher levels of stigma, and fewer organizational, internet-based, or informational venues for connecting with ‘the own’. Securing support from ‘the own’ is also increasingly shaped by changes to HIV funding and service provision since the introduction of both ARTs and of the UK's recent austerity measures that have cut funding to, *inter alia*, non-profit HIV organizations. It is important to note that prior to the ART era, HIV support organizations played as important a role for MSM as our data show they currently play for heterosexuals. That MSM in our sample found it relatively easy to identify and secure support from 'the own' within their embedded networks should not be taken to mean that MSM who are also OPLWH are free from the stresses that HIV introduces, but should, rather, be read as reflecting the range of circumstance and experience among people ageing with HIV. While both the MSM and the Black African communities have a long history of support organizations irrespective of HIV, reduced funding has placed pressure on both communities' support organizations (see below) - HIV organizations increasingly focus on supporting Black African PLWH whose economic circumstances, linked to migration status, make them more vulnerable and more in need of a range of supports. Thus, our findings about HIV organizations providing access to 'the own' are as much about the needs of PLWH ageing in the context of drastically cut services as they are about socio-cultural differences between our three participant groups.

Policy implications

That social support among OPLWH is complicated by membership in communities with relatively open or closed discussion of HIV and relatively easy or difficult access to 'the own' must be appreciated on scientific, policy and practice levels. Given the unknown social, physical and psychological consequences of ageing with HIV, 'bundling' this distinctive population's needs into generic services for older people, which participants explicitly contrasted with HIV-specific settings providing access to 'their own', is inappropriate. HIV-specific and general health and social services should recognize the importance of experientially-informed support for OPLWH, which can assuage the stresses of ageing into an uncertain future and be prepared to direct their clients to appropriate resources.

Yet, in the UK, such resources are under significant threat from both changing funding mechanisms and from austerity measures. While OPLWH have traditionally relied on HIV-specific non-clinical supports (National AIDS Trust 2017) for ‘safe’ social connections and solidarity, our data show the crucial role that these HIV-dedicated settings play for many OPLWH by providing opportunities to connect with ‘the own’ and serve as living examples of ageing with HIV in the wider absence of visible and recognizable emblems. These services’ defunding (by an average of 28 per cent across England between 2015/16 and 2016/17 – National AIDS Trust 2017) adds further difficulties for OPLWH who are coping with the psychosocial strains of ageing with HIV as well as navigating benefits and care pathways. In this broader context, the current strategic emphasis on patient empowerment and self-management (e.g. South 2015; Health Foundation 2016) to achieve best outcomes means that policy makers and funders must prioritize enabling OPLWH equitable access to experientially-informed support and thus help to improve this population’s wellbeing.

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[i] To ensure participants' anonymity, we refer to specific interviewees by participant number, age by decade, and ethnicity and sexuality (Black African heterosexual men and women as BAM and BAF, respectively; White heterosexual men and women as WHM and WHF, respectively; and men who have sex with men as MSM), and as recently (RD) or longer-term diagnosed (LTD). We refer to focus group participants by focus group (Black African, or BA; longer-term diagnosed, or LTD; and MSM), participant number, and other characteristics, as above.