SOCIAL SUPPORT, MENTAL HEALTH, AND QUALITY OF LIFE AMONG OLDER PEOPLE LIVING WITH HIV

Findings from the HIV and Later Life (HALL) project

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Authors:
D Rosenfeld, Keele University; J Anderson, Homerton University Hospital; D Ridge, University of Westminster; D Asboe, Chelsea & Westminster Hospital; J Catalan, Chelsea & Westminster Hospital; S Collins, HIV iBase; V Delpech, Public Health England; V. Tuffrey, University of Westminster; T Porter, University of East Anglia.

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The Executive Summary and the Summary entitled Getting older with HIV: A study of HIV positive people are available at www.keele.ac.uk/hall

For further information about the study, please contact Dr Dana Rosenfeld at d.rosenfeld@keele.ac.uk
I. INTRODUCTION

This report presents the findings of a two-year pilot (exploratory) multi-method, multidisciplinary study entitled HIV and Later Life, or HALL. The research, into the social support, mental health, and quality of life (QoL) of 123 older people living with HIV in the UK, was funded by the UK’s Medical Research Council’s Life-Long Health and Wellbeing Phase 3 Pilot Studies Programme and ran from 2011-2013. We recruited participants from the three populations with the highest proportion of people aged 50 years and over living with HIV in the UK: white men who have sex with men, or MSM; black African heterosexual men (BAM) and women (BAF); and white heterosexual men (WHM) and women (WHF). Together, these groups represent more than 90% of all persons aged 50 and over living with diagnosed HIV. The HALL sample is described below.

Data Collected

- 17 Stakeholder interviews
- 3 focus groups with older people living with HIV (23 participants)
- 76 life-history interviews with older people living with HIV
- 100 surveys with older people living with HIV

Background to the study

Since the availability of effective treatments in the mid-1990s, the survival of people living with HIV continues to improve. As a result, the overall HIV population is ageing (Emlet, Gerkin & Orel 2009; Blanco et al. 2010). In 2009, Gebo & Justice (2009: 246) noted that the number of people living with HIV aged 65> ‘has grown tenfold in the past 10 years’, and cited the USA’s Centers for Disease Control’s estimates that by 2015, 50% of people living with HIV would be aged 50>. This estimate is relevant for the UK, which, alongside the HIV population worldwide (UNAIDS GAP Report 2014), has seen increased rates of survival into later years of people living with HIV (Smith et al. 2011). In 2011, when we began our research, one in five (22%; 16,550) adults living with diagnosed HIV infection in the UK were aged 50>, compared with one in nine (12%; 3,640) in 2002. By 2013, when the project ended, this proportion had risen to over a quarter [27% (21,910/81,512)] and the absolute number of people living with diagnosed HIV infection aged 50 and over had increased six fold compared to 2011.
Alongside improved survival, the overall rise has also been due to increasing numbers of people first diagnosed at an older age (Cresswell & Fisher 2013; Greysen et al. 2013; Smith et al. 2011). Over the ten year period 2002 – 2011, there was a year on year steady rise in the number of people first diagnosed with HIV aged 50 years or older, and the number reported in 2013 [868] was double that of reports in 2002 (434). It is also noteworthy that the proportion of persons diagnosed as older adults among all reported cases rose over the 2002-2011 period. In 2011, there were 6250 newly diagnosed persons reported to the national HIV database, of whom 868 (14%) were aged 50 years and over. This represents a substantial increase over 2002, when there were 6281 newly diagnosed persons reported to the database, of whom 434 (7%) were aged 50 years and over.

The ageing of the HIV population has prompted a number of studies into how ageing and HIV intersect to shape daily life, social relationships, and mental health (Lyons et al. 2010; Power et al. 2010; Sankar et al. 2011; King & Orel 2012; Rosenfeld et al. 2012; Owen & Catalan 2012; Greysen et al. 2013; Rosenfeld et al. 2014; Emlet et al. 2014; Masten 2015; Nevedal & Sankar 2015; Beuthin, Bruce, and Sheilds 2015; Slater et al. 2015). Of direct relevance to our research, some early studies (e.g. Shippy & Karpiak 2005) pointed to the ‘fragile’ social support networks of older people living with HIV and the negative effects of this fragility on their QoL. Chesney et al. (2003) found that while older people living with HIV ‘experience more stress’ than their younger counterparts ‘when managing advanced HIV disease’ and ‘are less likely to have the social support needed to buffer effects of chronic stress, because of decreased health functioning’, their sample of older HIV-diagnosed MSM ‘reported relatively higher levels of distress than did younger men’ at ‘lower levels of social support’. However, ‘as social support increased, its impact on decreased distress appeared to be greater for older men’. The authors noted that, for the HIV population, ‘elevated distress and low social support take on added importance because they can accelerate disease progression’ (ibid).

These findings confirm the need to better understand the social circumstances and support networks, and their connections to mental health and QoL, among older people living with HIV. Yet, research into the social dimensions of ageing with HIV, while growing, continues to lag behind research into the clinical aspects of ageing with HIV. Moreover, few relevant social-scientific studies have included a life history approach, which is essential for placing this older population’s concerns and experiences in the context of decisions and circumstances that unfolded over the course of its members’ lifetimes. To help address this gap in knowledge, the HALL project team gathered survey, focus group, and life-history
interview data with older (age 50+) people with HIV who were living in and/or accessing HIV services in London, a city with a particularly high proportion of older people living with HIV. (In 2013, over 4000 MSM living with HIV in the UK, and aged 50 years and over, were residents in London, comprising about 40% of all MSM living with HIV in the UK in that age group. Furthermore, almost half (1405/2854) of all the black African women living with HIV in the UK, and aged 50 and over, were living in London). Our goal was to uncover the distinctive circumstances, concerns, and challenges that ageing with HIV introduces, and to document how social support, mental health, and QoL interconnect within the lives of people living with HIV in their 50s and beyond.

The Hall Study’s Core Research Questions

- What are the personal histories, concerns, social circumstances, relations, resources, and support systems of older people living with HIV in the UK?
- What is the mental health and quality of life of this older group?
- What are the relationships between social support, mental health, and QoL, and how do these impact on the QoL of people ageing with HIV in the UK?

Core findings

Our findings show that the older persons who took part in our study share many of the same experiences and concerns as do younger people living with HIV, that is: concerns over HIV-related stigma (e.g. Nachega et al. 2012), isolation (e.g. Audet et al. 2013), disclosure of their HIV status (e.g. Squire 2014), and forming romantic partnerships given their HIV status (e.g. Fair & Albright 2012). However, they also have unique experiences and concerns that are specific to later life. These include

- ageism intersecting with HIV stigma to further stigmatize older people living with HIV
- fear or difficulties in relation to disclosure of their HIV status to their children and sometimes grandchildren
- uncertainties over how HIV, HIV medications, and ‘normal ageing’ intersect to influence physical and mental health
• threats posed by the stigmatization of HIV and, for MSM, homophobia, specifically in relation to the quality of long term care

• romantic prospects being undermined by virtue of other older people being particularly ignorant about the realities of HIV

• the consequences of interruptions to professional careers by HIV and, especially for the longer-term diagnosed, of changes to Disability Living Allowance

• the need to reformulate plans for later years (e.g. retirement) given diagnosis, often health, and interruptions to career

• coping with futures that are uncertain, foreshortened, and derailed from their original course.

Our study also shows that the mental health and QoL of this older population varies. Despite the concerns expressed, two-thirds of people taking part in the study had good mental health and QoL. Factors associated with poor mental health and QoL were predominantly social rather than related to physical health: being single, on benefits and/or earning less than £10,000 per year, geographically separated from family, and diagnosed before the age of 40, which for some, disrupted their career progression. Moreover, for most participants, good QoL was a struggle rather than a given quantity: even those whose self-rated QoL was good or moderately good described working to secure good QoL in a number of ways. These included viewing their own lives in positive ways by, for example, comparing their lives to those less fortunate than themselves or with the lives they had feared they would have when they were first diagnosed; seeking the experience-based knowledge of other people living with HIV; and organizing their social worlds so as to minimize the role that HIV played in their personal lives.

Another core finding was that participants felt that only those living with HIV could fully appreciate what it was like to live and age with the virus. As a result, for most participants, the support provided by members of their social networks who were not known to be living with the virus was highly valued, but needed to be supplemented by support from other people with HIV who had what we term in this report ‘experiential knowledge’ of HIV. Typically, MSM had access to this experiential knowledge within their social networks, but heterosexual men and women more often needed to seek out this knowledge, primarily through HIV organizations and support groups. For all participants, including MSM, who attended these groups at the time of interview, and for most who had done so in the past, these groups provided much-needed information, emotional support, solidarity, a sense of belonging, and a ‘safe space’ in which to express their
concerns. For many participants, including heterosexual men and women, these groups also provided the opportunity to support others living with HIV through sharing their own experiences and experiential knowledge, acting as mentor, guide, or ‘wise elder’, and serving as ‘living examples’ of survival, wellbeing, and successful ageing with HIV. Particularly for participants who were on benefits, HIV support group attendance was a key contributor to good mental health and QoL.

II. METHODS

The research team used multiple research methods to address the project’s core questions. We used life-history and focus group interviews designed to capture participants’ perspectives, experiences, and social relations, networks, and support, and to generate insights into social dimensions of ageing, the life course, health, medicine, and chronic illness. We used validated survey instruments to assess mental health (measured by levels of depression and anxiety); QoL (with respect to physical and psychological health, social relations, level of independence, environment, and personal beliefs); and participants’ concerns about their memory in everyday life. In addition to the contributions of social scientists on the team, medical, epidemiological, and mental health researchers and practitioners brought specialised knowledge and insights to the research and analysis.

We engaged people living with HIV from the outset to ensure that the study was relevant to their own concerns. We began the research by meeting with HIV positive advocates with an interest in HIV and ageing. This was a one-off community meeting to introduce the overall aim of the study, elicit feedback on its core questions, shape the proposed methods, and secure advice on how to conduct ethical and effective recruitment and data collection that addressed the concerns of people living with HIV. This HIV Community Advisory Board (CAB) advised the research team on the construction of core research questions. The HALL team sent CAB members regular updates on the progress of the research and analysis, and invited them to respond to these and to raise questions and concerns. Thus we were able to capture the life histories and lived experiences of older people living with HIV while remaining sensitive to medical and service needs.
Ethics

We secured ethical clearance from Keele University and from an NHS-Research Ethics Committee in London. Given the stigmatisation of HIV, we took several steps to assure that all participants’ contributions to the study were anonymous and confidential. We fully anonymised interview and focus group transcripts, changing participants’ names and other identifying information (such as place of birth and past and present profession) in transcripts. We also changed the names of all HIV organisations, clinics and hospitals, and other support organisations. However, we retained the sex, age, sexual orientation, ethnicity (e.g. European, black African) and socio-economic, parental, and partnership status of each participant for analysis purposes. The professions of those providing services related to participants’ HIV or legal status (e.g. social worker, consultant/nurse, GP, lawyer, and therapist/psychiatrist) were not changed.

Recruitment

We recruited focus group participants through HIV community-based organisations and recruited interview participants through the same organisations as well as two inner city NHS specialist HIV outpatient clinics, and one mental health clinic serving a particularly high number of patients living with HIV, in London. In the clinics, HIV clinicians reviewed records to identify patients who met the study inclusion criteria, including having been diagnosed with HIV for at least 12 months, and not having acute psychological symptoms. Staff at HIV-specific service organisations pre-selected potential participants using the same criteria. Staff informed these pre-selected older patients or service users of the study and provided contact information for the study interviewer, who was often on site. Information on the study was provided verbally by the interviewer and by way of the study information packet.

Once written consent was obtained, a researcher interviewed participants in private sections of the organisation or clinic, or in participants’ homes. All participants were given a list of support organisations. Written consent was obtained for the surveys as well (see below), and interviewees completed these independently or with the help of the researcher. Supplemental surveys (see below) were gathered through the same recruitment sites and through word of mouth.
Data collection

Initially, we interviewed 17 stakeholders in the HIV and/or ageing arenas about the challenges they thought older people living with HIV faced, and how policies and services could best meet them. These interviews helped us to frame the questions we posed in focus groups and individual interviews. We then held three focus groups with older people living with HIV, asking participants to reflect on what it was like to live with HIV in later life. These focus groups, in turn, helped us to make our interview questions more attuned to the concerns of older people living with HIV. We then conducted 76 face to face interviews with people living with HIV aged 50 and over, elicitng narratives on daily lives, personal histories, relationships, personal histories with HIV, social relations and social support, QoL, ageing with HIV, hopes and concerns for the future, and HIV group attendance. The interviewer also encouraged participants to raise issues that they felt were relevant to the study’s core questions but were not covered by specific interview questions. Interviews lasted 90-120 minutes, and were recorded and transcribed verbatim by a professional transcription company before being fully anonymised (see above), coded, and analysed.

Finally, each of the study’s 76 interview participants completed a survey designed to measure general wellbeing (mental health and QoL). The survey combined the 13-item Royle and Lincoln (2008) Everyday Memory Questionnaire (Cornish 2000), questions on depression and anxiety adapted from the Bournemouth Questionnaire (Bolton & Humphreys 2002), and the World Health Organisation’s WHOQOL-HIV BREF (WHO 2012; WHOQOL HIV Group 2004), which measures self-rated QoL, both overall and in six separate domains (physical, psychological, level of independence, social relations, environment, and personal beliefs).

We also gathered a further 24 of these surveys, primarily through our project website (some of these surveys were completed on a hard copy and mailed to the HALL office). We expanded these web-based surveys to include questions designed to capture the same information we asked participants to provide at interview, including demographics (e.g. income, work status), social relations (e.g. ‘closest to’, support group attendance), physical health, and history with HIV (e.g. year of diagnosis). In this way, we could search for connections between social support, mental health and QoL within the stand-alone survey data, as we were doing with the interview data (as focus group participants did not complete the survey, they were not included in the statistical analysis or description of participant socio-demographics below). Additionally, we entered the same information captured in these expanded online surveys that appeared in narrative form in the life-history interviews into our survey database. The result was a
statistical database covering the same demographic, social, physical, and mental health domains across interview and survey-only participants.

Analysis

Qualitative data analysis was attentive to our initial research questions and to themes that emerged at interview. We generated codes through close readings of each interview and focus group transcript, then, using NVivo software, generated folders containing sections of interviews that related to these codes. We analysed the content of each folder, generating sub-codes that emerged through the analysis to find patterns and deviations. We verified our initial findings across cases and types of data, and tested emergent conclusions. Team members meet at 4-6 month intervals to review the coding, analysis, and findings. Survey data were subjected to bivariate and multivariate analysis, specifically, step-wise multivariate linear regression, using SPSS.

III. THE HALL STUDY PARTICIPANTS

Socio-demographics

All of the interview and focus group data were gathered from participants who, regardless of where they lived, accessed health or community services in London. At the time of data collection, all survey and interview participants lived in the UK: 87% in and 13% outside of London (12 in England and one in Wales). 58% of all participants were born in the UK, 8% were born elsewhere in Europe, 28% were born in Africa, and 6% were born elsewhere (e.g. Canada, the USA, South America, and Australia).

N.B. As with all statistical data presented in this report, all figures depict findings based on survey data, and do not include focus group participants. Throughout the report, we round the statistics up or down to the nearest full percentage point.
Reflecting the disproportionate presence of MSM within the older HIV population in the UK, interview and survey participants were largely male and white, with 73 male and 27 female participants from various white (70%) and black African (30%) ethnic backgrounds (see Figure 2).
Nearly all (94%) participants were aged between 50 and 70 years of age, and 51% were between 50-56 years old (one white male participant was aged 80 and one was aged 87). The median and mean ages for interview and survey participants were 56.0 and 58.4 years. The age distributions across genders, ethnicities, and sexual orientations were similar. With the exception of two survey participants, no participant had been living with diagnosed HIV for less than one year (this was an exclusion criterion for interviews). Years since diagnosis ranged from 1-32 years (median 10 years, mean 11.4 years, SD 7.8 years), and age at diagnosis ranged from 24-79 years (median 47 years, mean 47.2 years, SD 10.5 years). Twenty-one participants (21%) (three WHF, one WHM, one BAF, one BAM, and 15 MSM) had been diagnosed in, or prior to, 1996, when for the first time, combination therapy reported durable rather than short-term benefits from treatment. Twenty-three (23%) participants were diagnosed before the age of 40 (15 MSM, two BAM and two BAF, three WHF and one WHM), of whom 17 were diagnosed before 1996.

28% were in full or part-time paid employment, and 20% were retired. 52 (52%) participants were not in paid work, of whom 10 were working as volunteers. Over half (55%) of participants received some form of welfare benefit, including Disability Living Allowance, or DLA (31), Employment and Support Allowance, including Incapacity Allowance (26), and housing benefit (24). Several participants received more than one of these benefits. Women disproportionately received some form of benefit payment (78% versus 47% among men), as did black African participants (73% versus 53% of white heterosexual and 45% of MSM participants). Among the study’s black African participants, 83% of female, versus 58% of male, participants received benefits (among the white heterosexuals, six of the nine women, and three of the eight men, received some form of benefit).

Income ranged from £0-120,000 per year, with a median income of £10,400 and a mean income of £20,430 (SD £24,240). Almost half (42, or 48%) of the 87 participants who stated their income earned less than £10,000 per year, which places them below the official poverty line for UK households. 80% earned less than £31,000 per year.

Participants are thus clustered at the lower end of the income scale, signalling a significant degree of financial stress, particularly given the fact that 87% lived in London, where living expenses are high. Moreover, a higher proportion of women (15/21, or 71%) were low income earners (below £10,000 per year) compared
to 27/66, or 41%, of men. Black African participants were disproportionately more likely to have annual income <£10,000 (20/24, or 83%) compared to white participants (22/63, or 35%).

**Figure 3: BAR CHART SHOWING PERCENTAGE DISTRIBUTION OF ETHNIC GROUPS BY INCOME CATEGORY**

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>Less than £10K p.a.</th>
<th>£10K to £31K</th>
<th>£32K or more p.a.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black African</td>
<td>20</td>
<td>40</td>
<td>20</td>
</tr>
<tr>
<td>White</td>
<td>63</td>
<td>35</td>
<td>15</td>
</tr>
</tbody>
</table>

**Figure 4: BAR CHART SHOWING PERCENTAGE DISTRIBUTION OF GENDER GROUPS BY INCOME CATEGORY**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Less than £10K p.a.</th>
<th>£10K to £31K</th>
<th>£32K or more p.a.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>60</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>Male</td>
<td>40</td>
<td>30</td>
<td>10</td>
</tr>
</tbody>
</table>

Participants’ social networks were varied and often extensive, and included family, friends, partners, work colleagues, neighbours, and fellow members of churches and other community groups (including HIV organisations and support groups). When asked about the people they felt closest to, participants most
often named or listed friends (78%), children (33%), partners (28%), sisters (28%), parent or parents (26%), brothers (15%), and nieces or nephews (11%).

Over two-thirds (67%) were single (46 white and 21 black African participants). Of the 33 partnered participants (24 white and nine black African participants), five were married, two were engaged, and seven were in a civil partnership. Three-fifths (59%) of participants lived alone (17/30, or 57%, of black African participants, 31/53, or 59%, of MSM participants, and 11/17, or 65%, of white heterosexual participants). One in five participants lived with a partner, and 15% lived with one or more children (see Figure 5).

Overall, slightly more than half (52%) of participants were parents. Parenthood was unevenly distributed across sexual orientation, with almost all (29/30, or 97%) of black African and four out of five (14/17, or 82%) of white heterosexual participants identifying as parents, versus less than a fifth (9, or 17%) of MSM (all of these MSM participants had become fathers while married to women, and had subsequently divorced). One-quarter of participants stated that they were grandparents, but of these 24, only one was an MSM, whereas three-fifths (18/30, or 60%) of black African participants and less than one-third (5/16, or 31%) of white heterosexual or bisexual participants were grandparents.
**Participant groups**

All participants had first learned of or encountered HIV in their young to middle adulthood and at a time when it almost invariably led to AIDS, and this shaped their experiences at diagnosis and into later years. They also viewed ageing with HIV as particularly challenging due to the stigmatization of HIV and of HIV in later life in particular; lack of knowledge about how the natural ageing process intersected with HIV and HIV medications to affect health; actual or potential impacts of their HIV on friendships, romantic attachments and family relationships in later life; and disruptions to expectations they had had about how they would live in their later years. But their identities as black African migrants, MSM, and white heterosexuals introduced distinctive circumstances that both reflected and shaped their experiences with HIV over the course of their lives.

**Participant Identifiers**

To ensure that none of the quotes presented in this report can be traced to individual participants, we refer to interview participants by participant number, age by decade (i.e. in their 50s or 60s), and group membership (black African men as BAM, black African women as BAF; white heterosexual men as WHM, white heterosexual women as WHF; and men who have sex with men as MSM), and as recently-diagnosed, or RD (living with HIV for between one and nine years) or longer-term diagnosed, or LTD (living with HIV for ten or more years). We refer to focus group participants by type of focus group (black African, or BA; longer-term diagnosed, or LTD; and MSM), age by decade, group membership, and recently or longer-term diagnosed, as above.

**Black African Heterosexual Men and Women**

All black African participants were born and raised in an African country with a high prevalence of HIV and a history of high AIDS mortality rates. Many had lost friends, neighbours, and family members to AIDS and/or war, and/or had witnessed high numbers of AIDS-related deaths and high rates of HIV-related illness in their immediate communities. Although several of these participants had immediate family in the UK, others were separated from family members, including children and grandchildren, and, sometimes, spouses, who remained in their home countries. Almost all had been diagnosed with HIV after arriving in the UK, often in the context of a health crisis, and many remained in the
UK because effective medications had not been made available in their home countries. Given their migration status, many risked being barred from re-entry to the UK if they returned home. Many of these participants’ professional careers were disrupted by their HIV, and time spent away from work and career made it difficult to return to meaningful employment. Thus at interview, many were living in significantly reduced financial circumstances. But the effects of being separated from their home country were not just financial; with applications for ‘indefinite leave to remain’ still under consideration, many felt ‘stuck in limbo’. Moreover, the severe stigmatization of HIV within the black African community, which endured, these participants explained, despite its high prevalence within the same community, made it difficult to secure emotional support from their community.

“My main concern is formalising my papers. I’m not too sure of the level of treatment for HIV in my home country. The past five years I have not been able to travel outside the UK. I can’t go anywhere. The major fear I have now, which I think about occasionally, if my mum dies and I leave, that’s my last day in England. But if I have to be there, that’s just it, I have to go there (P57, RD BAM, 50s).

MSM

The vast majority (85%) of MSM participants had been born in, and had established networks of family and friends, in the UK. 83% had self-identified as gay men in late adolescence or early adulthood, with the remaining 17% having identified as gay after heterosexual marriages and after having fathered children. MSM participants were aware of the history and impact of HIV/AIDS within gay communities. Several had been politically active in the 1980s-1990s; had been living with HIV for over ten years; and/or had acquired HIV before the emergence of effective antiretroviral therapies in the mid-1990s. Almost all recalled having witnessed the severe stigmatization of people living with HIV/AIDS, and high mortality rates among MSM, in the 1980s and 1990s. Many had lost friends and/or partners to AIDS in the early years of the epidemic. Within our study, these participants were generally the most knowledgeable about HIV and the most likely to know and to be friends with other people living with HIV.

“At a relatively young age, we lost lots of friends, which usually happens when you are older. It was almost like what happens
during a war, when almost a whole generation is wiped out. And it affects those people who are left behind in a very significant way. It does make you think about death. If something happens and kills them off it can't help but focus your attention on that side of life... a lot of gay people with HIV are lonely because a lot of the people they should have grown old with have gone and been killed off (MSMFG#3, RD MSM, 60s).

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 (P49, RD MSM, 50s).

White heterosexuals

As with MSM participants, most (71%) white heterosexual participants were born, raised, and had family and friendship networks in the UK. Like black African participants, most had been married and most (82%) were parents. But unlike these other groups, almost none had known anyone living with HIV before they were themselves diagnosed with HIV, and their pre-diagnosis knowledge of HIV was minimal. They viewed themselves as particularly isolated from other people living with or knowledgeable about HIV, and as therefore likely to be stigmatised and misunderstood by people within their immediate social circles. These participants also saw their access to romantic partners as being especially limited given their ethnicity and HIV status.

I'm in a minority, because HIV is a minority in itself, I'm heterosexual, and, being white ... I'm not sure what the statistics are. But it feels like a minority within a minority within a minority. You’re one of a kind. There are not many people in this situation (P47, LTD WHF, 60s).

Knowing the little I do about the African community, I think it would be very rare for them to disclose as much as I have disclosed to my friends. So, in that respect, 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. I think in the gay community, where there’s a stronger understanding, there’s always going to be someone you know indirectly or directly who has it (P70, RD WF, 50s).
IV. MENTAL HEALTH AND QUALITY OF LIFE

Mental Health

Our survey included one question on level of depression and one question on level of anxiety, both taken from the Bournemouth questionnaire. Responses to these questions were highly correlated, with only one participant scoring very differently on each of these measures. The combined responses provided an overall mental health score.

Overall two-thirds of participants had a good to moderately good mental health score – a finding echoed in participants’ overall good self-rated QoL (see below). But one third was experiencing high levels of depression and anxiety in the ‘few days’ before the interview. Nearly two-fifths (38%) of participants declared themselves to have been particularly depressed (including extremely depressed) ‘over the past few days’ (i.e. ≥ 7 on a 10 point scale; see Figure 6). An almost identical picture emerged in relation to a question on self-rated anxiety (see Figure 7). In answering this question, over one third (35%) of participants placed themselves within the 7-10 range of the scale.

Figure 6: BAR CHART SHOWING PARTICIPANTS’ SELF-REPORTED LEVEL OF DEPRESSION

Over the past few days, how depressed (down-in-the-dumps, sad, in low spirits, pessimistic, lethargic) have you been feeling, on a scale where ‘0’ is ‘not at all depressed’ and ‘10’ is ‘extremely depressed’?
Over the past few days, on average, how anxious (uptight, tense, irritable, difficulty in relaxing/concentrating) have you been feeling, on a scale where ‘0’ is ‘not at all anxious’ and ‘10’ is ‘extremely anxious’?

The majority of participants (63%) stated that they experienced ‘negative feelings such as blue mood, despair, anxiety, depression’ quite often, very often, or always, indicating high levels of psychological distress (see Figure 8).

How often do you have negative feelings such as blue mood, despair, anxiety, depression?
The poor mental health of one third of participants is particularly noteworthy given that (a) all participants were in receipt of some HIV-specific support (clinical and/or through HIV organizations), (b) those diagnosed for less than 12 months before interview/survey were excluded from recruitment, and (c) clinics and organizations through which we recruited excluded those with severe mental health challenges as potential participants.

**Quality of Life**

Participants' self-rated QoL (derived from a single survey question) was higher than their mental health scores. When asked to rate their QoL (as Very poor, Poor, Neither poor nor good, Good, or Very good), over half (56%) rated it as good or very good, and 24% as neither good nor poor. Only 9% rated it as poor and 1% as very poor. Our interview data contained many accounts of ‘happy’ lives and ‘good QoL’, which participants variously measured by reference to their financial security; physical independence; good physical and mental health; a positive attitude to life and to living and ageing with HIV; supportive friends, family, and partners; good living environments; an active social life; holding a fulfilling and enjoyable job; and the fulfilment of being a parent and/or grandparent. Several longer-term diagnosed participants described their joy at having survived into later life, which they had not expected given the absence of effective medications in the early years of their lives with an HIV diagnosis and, often, given the poor health they had experienced before these treatments became available. Recently-diagnosed participants often described their ‘good fortune’ in having been diagnosed at a time when they could benefit from these treatments. All participants rated the HIV-related medical care they received as excellent, and many linked it to their own good QoL.

I have a good life. I have a fulfilled life, nice friends. As a gay man, to be a dad, I am pretty lucky. I have family that I’m not overly close to but close enough to, in my mind; I have a son who I’m incredibly close to; have a partner who I love dearly, and I know loves me. I have a nice circle of friends. So in terms of my quality of life it’s really good. I have a job I like. So, what more could I really ask, other than not to be HIV? But if I wasn’t HIV would I be as fit as I am now? I don’t know. Perhaps I wouldn’t care so much about my health (P44, RD MSM, 50s).

I’m fine. I’m happy, I can eat what I want, and do everything for myself, so I think I have the quality of life I need (P21, LTD BAF, 50s).
When I reached 60 and they gave me my freedom pass, I said, I never ever thought in my mind I was going to stay around this long. So can you imagine how I feel? I feel over the moon! (P20, LTD MSM, 60s).

When asked to describe their QoL at interview, however, most participants did so in less absolute terms than appeared in the above quotes. Many stated that their QoL was good but ‘could be better’. A substantial number described their QoL as ‘up and down’, ‘patchy’, and subject to ‘pluses and minuses’, with the positive aspects of their lives listed above (i.e. financial security, good health, fulfilling work, and close family, friendship, and romantic ties) existing alongside significant stresses introduced by their HIV status. Several compared living with HIV with living with other chronic diseases, typically cancer, which they saw as a more significant threat to good QoL than was HIV. For these participants, their good or moderately good QoL was a personal evaluation made after balancing the positive and negative aspects of their own lives and, often, comparing them to the lives of other people and/or to the lives they had had in the past or had imagined they would have in later life. In answers to interview questions about QoL, and across the qualitative data, good QoL typically emerged as a goal whose achievement required significant work: for example, securing appropriate information and social support, adhering to medical treatments, remaining optimistic, and organizing personal and social life to make HIV seem less central to personal and social identity and to sense of self. Again, most participants rated their QoL as good or very good on the questionnaire, and most interviewees described benefitting from robust social support networks and excellent medical care. But, as this report will show, participants’ good QoL was an ongoing project that required careful attention to social aspects of living and ageing with HIV – aspects that were often difficult and distressing.

Most people cope with private and professional, and once they retire the professional world becomes the family world. And then with being HIV there’s a third element. I have most of the parameters of having a good life. Meaning money, intellectual interest, relationship, my own house, travelling, friends. So I’m ticking all the boxes, and then there’s a question mark of future. What effect will it have on my health? What effect will it have on the longevity? And, one way or another, will it influence my work? (P50, RD MSM, 60s).
It’s neither happy nor unhappy. I know that it could be different, better, but I also know that it could be worse. I think it could be better if I had a friend who was still living. It could be better if I were HIV negative. It could be better for a lot of things (P14, LTD MSM, 50s).

As I probably said in the questionnaire, I probably feel quite dissatisfied with my life at just an emotional level, and yet logically I can see that it’s not that bad. But emotionally it feels that way, because I feel as if I’m on my own in life, to a large extent. I think that’s the problem (P45, RD WHM, 50s).

Factors associated with good and poor mental health and QoL

Within this overall picture, certain groups stand out as having better mental health and QoL than others. Less than one-third (29%) of the variability in QoL was related to participants’ rating of their health (as Very Poor, Poor, Neither poor nor good, Good, or Very good) or to how satisfied they were with their health. Thus while health was an important source of stress in itself, the poor QoL reported by a tenth of participants, and the good QoL reported by more than half of participants, were less connected to concerns over physical health than they were to social factors. For example, the overall QoL score depended on receipt of benefits and partnership status, and, for those on benefits, HIV support group attendance. QoL and mental health were also associated with specific domains within the WHOQoL-BREF, either in addition to or independent of the total QoL score.

WHOQoL mean scores were significantly lower among participants identified as not in paid work, in receipt of benefits, and earning less than £10,000 per annum. Participants receiving benefits and participants not in paid work also had significantly lower mean WHOQoL-HIV scores across all QoL domains. Other outcomes were also strongly associated with income: mean depression and anxiety scores were significantly higher in those with low income compared to higher income. Participants identified as earning less than £10,000 per annum had significantly lower scores in physical, independence, social relations, and environment domains. Participants receiving benefits scored lower psychological domain scores than participants not in receipt of benefits, and participants identified as being out of work, volunteering, or retired (considered as a single variable) scored lower psychological domain scores than participants in paid
work. Within multivariate analysis, participants’ benefits status remained a significant predictor of lower psychological domain scores.

One of the strongest links to mental health and QoL was partnership status. Single participants reported significantly more depression (median 5) than partnered participants (median 2), and were more anxious (median 5) than were partnered participants (median 3). Single participants had poorer QoL, were less satisfied with personal relationships, and had negative feelings more often, than partnered ones. Partnered participants also scored higher mean psychological domain scores than did non-partnered participants. Partnership status remained an important predictor of QoL after multivariate analysis, with partnered participants scoring significantly higher than single participants in social relations and in overall WHOQoL-HIV score. However, these associations were mediated by ethnicity: for black African participants, being partnered worsened their mental health as measured by depression, anxiety, and negative feelings. Black African participants who were partnered had similar scores for satisfaction with personal relationships as did black African participants who were single, whereas white participants who were partnered scored higher than single white participants in this regard. This ethnic difference in the positive effects of partnership is likely due to black African participants’ geographical separation from spouses, and to the strains of being responsible for a spouse while living in a state of uncertainty regarding finances, work, and migration status.

As regards sexual orientation, MSM were less depressed, had higher QoL scores, and were more satisfied with support they received from friends, than were heterosexual participants. Length of time since diagnosis did not affect mental health or QoL, but participants who had been diagnosed before age 40 had worse mental health and QoL scores than did those who had been diagnosed after the age of 40 (this association was particularly strong for MSM participants). This association likely reflects the long-term consequences of disruptions to social relationships and professional careers that diagnosis introduced in middle age, including having to leave work due to ill health, and the more recent effects of facing cuts to DLA that had been put in place around the time of interview. Additionally, for the 17 of these participants who were diagnosed before 1996, their worse mental health and QoL compared to that of more recently-diagnosed participants likely reflect the long-term, cumulative consequences of the distinctive challenges they faced in the epidemic’s early years (i.e. witnessing multiple deaths of friends and partners and living through a period of high uncertainty over their own and close others’ health given the absence of effective treatments).
Participants with the Highest QoL and/or Best Mental Health

- MSM
- Men
- Participants diagnosed after age 40
- Participants who were working, not on benefits, and/or earning over £10,000/year
- Partnered participants of white ethnicity

Finally, women’s levels of depression and anxiety were slightly higher than those of male participants, and women were less satisfied than men were with their QoL, health, and support from friends. Bivariate analysis of the WHOQoL-HIV BREF mean scores supported this finding, with male participants having significantly higher overall mean scores, and significantly higher means scores across physical, independence, social relations, and environment domains.

Our qualitative data strongly supported these variations in mental health and QoL. Participants varied in how severely the stresses of living and ageing with HIV impacted their own mental health and QoL. But across interviews and focus group discussions, participants’ accounts reflected significant mental stressors experienced in the context of a society that severely stigmatised people living with HIV; within social networks that many, but not all, participants feared could become depleted or threatened by HIV; and, for some, while living in social isolation linked to migration status, unemployment, or poor mental health itself. The most significant strains that participants directly related to HIV are listed below.
Challenges to Mental Health and QoL

- Stigmatization of people living with HIV and of older people living with HIV in particular
- Uncertainties about the physical, psychological, and social impacts of ageing with HIV
- Difficulties of forming romantic partnerships in later life due to HIV status and to the perceived tendency of all older people to hold stigmatized beliefs about HIV
- Perceived lack of support and understanding as people living and ageing with HIV, even in the context of strong social networks
- Concerns over remaining independent in later years and over the quality of long-term care given the stigmatization of HIV
- The complexities of disclosure and fears of rejection, especially as parents and older people seeking romantic relationships
- Disruptions to the lives and social roles envisaged in later life
- Being financially stressed, alone and fearful about the future

Other sources of stress that participants did not directly relate (or only rarely related) to their HIV status included low income, unemployment, being single, and uncertain migration status, although, as we will show, these were often linked to participants’ HIV diagnoses.

Some of these stressors were specifically linked to mental health by participants themselves, and others emerged as relevant to mental health and QoL through our analysis of the data. A surprisingly high number of participants stated that they had experienced such mental health challenges, even illness, as obsessive-compulsive disorder, clinical depression, agoraphobia, and tendencies to self-harm and to think about suicide. Several had had long histories of mental health care, even hospitalization, before they were diagnosed. Of the various triggers of depression and anxiety that participants identified, some were unrelated to HIV (e.g. relationship breakdowns, or anniversary of bereavements), and some were specific stressors from which others were sheltered (for example, financial strain and uncertain migration status). But for most, depression and anxiety emerged post-diagnosis, and the vast majority described a range
of stressors related to their HIV that endured well past the initial shock of diagnosis (although participants’ initial responses to diagnosis varied according to group membership, as shown below). For some, these mental health issues overshadowed the impacts of HIV, while for others, HIV diagnosis exacerbated pre-existing mental health challenges. For some, HIV diagnosis provided new resources by bringing them into mental health services, social support groups, and counselling services attached to or suggested by HIV services. For participants experiencing severe mental health difficulties, formal mental health services were essential, but so were HIV-specific organisations and support groups, whose benefits we explore below.

V. HIV KNOWLEDGE, STIGMA, AND COMMUNITY HISTORY

HIV stigma emerged as the most significant issue for focus group and interview participants. Without exception, those who discussed HIV stigma identified it as a barrier to good QoL whose impact rivalled that of physical ill health itself. Most characterised the non-HIV population’s knowledge about HIV and sexual health as weak, incorrect, or even non-existent. Although participants viewed HIV-negative people of all ages as insufficiently educated about HIV, they described MSM and black Africans as the groups most likely to have personally encountered and even experienced HIV, and younger and older persons as being more or less likely, respectively, to have up-to-date knowledge about HIV. Many called for public health efforts to increase awareness and understanding of HIV, including its prevalence within older groups. These participants emphasized the importance of good access to accurate information about HIV, including relevant scientific and medical developments, HIV’s transmissibility, interaction with ‘normal ageing’, prognosis and management, and how to live with HIV. Participants also explained that decisions to disclose their HIV status were primarily shaped by others’ knowledge of the nature and consequences of HIV.

“Years ago, when HIV came up, they had these horrible adverts with gravestones, although at that point it was a terminal illness, there was only AZT and drugs like that. Since then, there’s been nothing at all, absolutely nothing... It would be wonderful if they did a documentary for a few weeks on HIV” (P5, RD WHF, 50s)
There is still, in the general community, a really big misunderstanding about living with HIV and life expectancy. Some people, when you say I’m HIV positive, they don’t expect you to live longer than five years (P44, RD MSM, 50s).

HIV-related stigma was, by all accounts, rooted in mythology, for example, that HIV was easily transmissible through casual contact, and in the racist and/or homophobic myth that HIV is a ‘black’, ‘African’, or ‘gay’ disease. Participants also discussed the myth of HIV infection as having been caused by sexual promiscuity, prostitution, or the abuse of drugs. To participants, the ongoing stigma disproved recent claims that advances in HIV treatments had made HIV ‘just like’ other chronic, manageable conditions.

It’s still something that people are scared of and that you can’t go up and talk to somebody confidently about. Because maybe, with a bad response, you’re made to feel dirty, you’re made to feel cheap, you’ve brought this on yourself (P22, RD MSM, 50s).

As detailed above, black African and MSM participants were members of communities that had been, and continue to be, heavily affected by HIV and AIDS. As a result, their social worlds had been built up within a community familiar with and largely organised around HIV, and they had good knowledge of HIV and AIDS before diagnosis. But while all UK-born participants had encountered the HIV/AIDS health promotion messages of the 1980s, and knew about the role that HIV and AIDS played within the MSM and black African populations, white heterosexual participants had very rarely knowingly encountered people living with HIV or AIDS before they entered the world of HIV care. They often had little or no knowledge of HIV pre-diagnosis, and what knowledge they had at the time was misleading in retrospect.

These differences in HIV knowledge were most evident when participants described what they had known about HIV before they were diagnosed. But they also served as a significant background to issues surrounding disclosure and social relations. Participants imagined what others knew about HIV based, in great part, on their social characteristics, with people living with HIV, adults and middle-aged persons, and MSM and black Africans assumed to be the most informed. These assumptions affected how, and where, they sought support for their issues and concerns related to living and ageing with HIV.
‘What had you known about HIV before you were diagnosed?’

Oh, everything. I lived with it for 20 years. My ex-partner and I had many friends die. My ex-partner, all his friends died. We’ve lived with the demons and the shadows of HIV. Many friends are HIV positive (P2, RD MSM, 50s).

HIV was in my country, in Africa, and one of my best friends had it. I saw her very ill, going through all the stages of it, in the 1980s, until she died. And one of the top musicians in Africa stood out positively. At that time there was no medication. He lived with it until the very end, but he sang a positive song to educate the whole world. So that is what I knew about it in my country (P9, LTD BAF, 50s).

I remember when they had all the advertising – the tombstones and everything. So at that time, I knew you died. Also, it was virtually all gay. It was just an illness transmitted between gay men, or drug users. I knew that heterosexually you could catch it, through prostitution etc. But it wasn’t something I thought about (P71, LTD WHM, 60s).

Knowledge and HIV diagnosis

Participants’ different knowledge of HIV shaped their pathways to diagnosis. Given their extensive familiarity and experience with HIV, MSM participants described seeking testing in the absence of physical symptoms or in the aftermath of physical symptoms that they suspected signalled seroconversion. Despite their personal familiarity with HIV in their countries of origin, and related to severe HIV stigma, black African participants were more likely to have been diagnosed after a protracted illness, during a health crisis, or as a feature of a non-specialist health visit. White heterosexual participants were most likely to have been diagnosed after a lengthy period of unexplained health problems, or via a routine examination (e.g. for health insurance, or while in prison).

Differences in knowledge about HIV also affected participants’ initial responses to diagnosis. For MSM diagnosed before 1996, being told they were HIV positive meant a frighteningly shortened life span. For MSM diagnosed after the development of life-saving therapies, diagnosis was still a very frightening time, and, for more recently-diagnosed MSM, knowledge of medical improvements
tended to lessen, but not erase, their fears regarding the health consequences of HIV. For heterosexual participants, however, regardless of when they were diagnosed, diagnosis tended to conjure up fears of early mortality. For black Africans, diagnosis triggered memories of AIDS-related deaths and lack of access to HIV medications in their home countries, leading them to view their diagnosis as an effective ‘death sentence’. White heterosexual participants were stunned, and, with little correct information on which to draw to make sense of their diagnosis, recalled the high mortality rates in the epidemic’s early years. At the time of diagnosis, few white heterosexual participants envisioned being able to live with HIV as a manageable condition.

"Going back to the 80s and early 90s, around that time I lost a number of friends in London to HIV, before any drugs were available. I knew drugs were available, but I understood, in the early days at least, they had very nasty side effects, and people didn’t really know how long they’d work for. But fortunately, by 2002, when I was diagnosed, people knew the condition could be stabilised, to a great degree, with those drugs, and they were being improved and refined... it just gets better and better (P24, LTD MSM, 50s).

All I knew was that it’s not something that can be cured, and once you get diagnosed, that’s the end of you. And if somebody told me that I’m going to be here now, I wouldn’t have believed it. I thought by the next week, I would be dead. And when my doctor was sitting down there telling me [about effective treatment], I said, really, is that true? I don’t believe you (P12, LTD BAM, 50s).

I just thought you got HIV, then you got AIDS and you died, and that was basically how it is. At that point, I didn’t know there was drugs. Absolutely no education whatsoever on HIV (P5, RD WHF, 50s).

"In the period immediately following diagnosis, participants imagined the physical implications of living with the virus, including an apparently shortened life. But most also experienced anxiety over the implications of their HIV status for their social relationships. The vast majority focused on the stigmatisation of HIV, which made them imagine that others would view them as being highly infectious through casual contact, morally culpable for having acquired HIV, and thus deserving of rejection, abandonment, and other forms of social isolation."
I remember thinking, oh, God. We can’t tell anybody. Because the stigma around AIDS back in those days, even within the gay community, was horrendous. Good friends would stop talking to you (P60, LTD MSM, 50s).

HIV stigma and ageism

According to participants, these stigmas were further exacerbated by a pervasive ageism. The explained that while all people living with HIV were viewed by those outside of the HIV sector as lacking in judgment, restraint, etc., the pervasive stereotype of HIV as the result of sexual promiscuity, prostitution, or the abuse of drugs took on added significance with age, as these activities jarred with expectations that people become increasingly wise, responsible, discrete, mindful, and sexually inactive as they age. Here, the combination of the negative association made between HIV and ‘risky’ or ‘irresponsible’ sex, and the taboo against sexual activity among older persons, made HIV among older people a doubly stigmatising condition. If discovered, participants explained, their HIV would subject them to the negative treatment that all people living with HIV face, and to further condemnation as older persons living with a stigmatised condition. Some participants stated that older people living with HIV faced greater stigma and discrimination than did younger people living with HIV as a consequence of their age, and a small number of participants felt that younger people living with HIV were themselves biased against older people living with the virus. Some participants also evaluated themselves with reference to these age-norms, with some female participants stating that they felt ‘dirty’ and some male participants stating that they felt ashamed for having ‘taken risks’ that were appropriate for, or at least expected of, younger men, but were inappropriate for men of their age.

Being an older man with HIV can be difficult, and if you’re alone and you’re not out then it could be hugely difficult. 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, I think (P23, RD MSM, 50s).

It’s difficult, because they don’t think older white women should get it. I think they think we should know about it, we shouldn’t be having sex anyway, because after like 30 people think you shouldn’t be having sex (P47, LTD WHF, 60s).
[Young people] all sleep together, and that you expect, but at my age you don’t expect it, because you’re not doing that. So I didn’t expect it to happen to me. It makes you feel dirty, it’s degrading. Because at my age I shouldn’t have HIV (P5, RD WHF, 50s).

I felt ashamed. I just felt awful. I said to this lady doctor, fancy an old man like me getting that at this age. I said, how stupid can I be? But she didn’t make any comment (P54, RD MSM, 60s).

VI. SOCIAL RELATIONS AND DISCLOSURE

For all participants, HIV introduced the possibility of withdrawal, rejection and abandonment by those who learned of participants’ HIV status through disclosure or discovery (for example, through gossip). These dangers raised dilemmas related to disclosing their HIV status to others, including those to whom participants stated they were very close: partners, children and parents, and friends. Participants experienced and managed these dangers from the vantage point and social circumstances of older age, as, for example, parents and older people embarking on dating and romantic attachments.

When deciding whether to disclose, to whom, and when, participants considered their own relationship to these others, whether these persons ‘needed to know’ about their HIV status, and their knowledge about HIV, drawing upon actual experiences with that person and/or on their own evaluation of what this other person could be assumed to know. Because those who held stigmatised, and thus incorrect, understandings about HIV were the most likely to react negatively to disclosure, participants felt that it would be easiest, and most fruitful, to disclose to those with correct knowledge of HIV and its transmissibility and health consequences. Not surprisingly, participants viewed those who were also living with HIV, or were members of a community with a history and understanding of HIV, as the most knowledgeable and trustworthy audience for disclosure. Others’ ability to keep confidences was an equally important factor in deciding to whom to disclose. Participants evaluated the risk of specific people informing others of the disclosure, thereby increasing the range of persons who might view and, possibly, treat, them in negative ways.
I only told gay friends, because they had friends who died. And some of them were HIV positive, so they were not judgemental (P14, LTD MSM, 50s).

I had to be very careful, that whoever I did tell was very discreet. Not because I was ashamed of it, but because it might get back to people who wouldn’t understand (P23, RD MSM, 50s).

Compared to fears that disclosure would prompt negative reactions, first-hand experiences of rejection after disclosure were rare, and generally occurred in the context of dating. Several participants described having been rejected by casual and romantic partners, or people with whom they would like to have become romantically involved, once participants disclosed their HIV status to them. These instances of rejection underscored the importance of carefully choosing to whom to disclose, and of accurately predicting how specific people would respond to disclosure.

There’s this guy I met in church, he said I love you, I want to marry you. He gave me a lift. So when we got home I asked him, you said you love me, he said yes. I said I’m HIV positive. The way he disappeared; he got to the door and went away, just disappeared (P7, RD BAF, 50s).

The funny thing during that time was, the people I should have nurtured and told, that would have been there, I didn’t. The ones that I did tell didn’t want to know… that brought me right down and then I was planning to take my own life (P33, LTD MSM, 50s).

For some, concerns about rejection or abandonment were lessened by close others responding positively to disclosure. Many of these positive reactions included declarations of continued commitment to the relationship. These positive responses were more likely when participants disclosed to those with HIV knowledge and/or personal experience of HIV. MSM in particular were embedded in social networks whose members possessed this knowledge and experience. But regardless of these positive outcomes and of the number of years since diagnosis, participants continued to experience or imagine negative reactions.
My partner was very supportive. It was frightening. He was very scared. He got tested and he was clear. But the support I got from him was incredible. He was just there for me all the time, no matter what (P16, LTD MSM, 50s).

The social stigma risk is a big deal. My biggest fear is my family, my friends, my neighbours, the guys I work with, finding out (P48, LTD WHM, 50s).

Just people talking to you, you think to yourself, you wouldn’t talk to me if you knew I was HIV positive. It does affect your mind a lot, the mental side, it really does (P5, RD WHF, 50s).

These concerns were, to many participants, a source of continuous strain. Participants described decisions surrounding disclosure, and other people’s actual or imagined negative responses to disclosure, to be one of the most distressing aspects of living with HIV in later life. While HIV was no longer life threatening, they explained, it continued to threaten social standing and relations, and in turn, mental health and QoL. Yet participants also discussed the mental toll of concealing their HIV status and not being honest with others. As a result of this complex relationship between stigma, the desire to maintain and to build new close relationships, and the strains of concealment, participants described the decision to disclose as a complex one requiring careful consideration and planning, and investing a significant amount of time, energy, and thought into maintaining control over who knew about their HIV status.

I still hide, but I feel guilty, like I’m lying to my daughter. My daughter is grown up now. She looks at me and obviously I feel guilty and I feel pain. I can’t tell her. Sometimes I can’t sleep and I get worried. It’s psychological (BAFG#2, LTD BAF, 50s).

It’s not pleasant to mentally live like this. Maybe you just have to be very open about it and tell everybody that matters to you and get rid of the guilt. Maybe you just have to do what you have to do and take the pain and if the pain’s a short pain that’s better. I don’t like the lies. I don’t like lying to people that matter (P51, RD MSM, 50s).
Dating, romance, and disclosure

Many of the study’s 33 partnered participants described the impact of HIV upon their partners, and several participants identified romantic partners as the people (other than themselves) most significantly affected by their diagnosis. Regardless of when in the romantic relationship participants were diagnosed, participants said, the diagnosis needed to be disclosed to their desired or actual partner.

With few exceptions, these instances of disclosure were met with support, and few of these relationships ended as a result of the disclosure. But most single participants described hoping to establish romantic relationships. These participants considered the prospect of romantic relationships to be complicated, even precluded, by their HIV status. Several participants described a narrowing field of potential partners as emotionally distressing, and feared loneliness in later life. Overall, participants were less satisfied with their personal relationships than they were with the support they received from friends, reflecting both the low proportion of partnered participants in the sample and the difficulties of forming romantic attachments while living with HIV in later years.

When you got someone and you see someone more than once, I think it’s time to be honest and start discussing things. And you’re thinking that person is going to reject me because I’m HIV (P20, LTD MSM, 60s).

After I was diagnosed, I felt, 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 (P70, RD WHF, 50s).

If I didn’t have HIV, I’d feel I’d still have optimism. I’d feel like I’d still got a reasonable amount to offer, I’d feel there’s a good chance there’d be somebody out there I could meet (P45, RD WHM, 50s).

Participants balanced their desire to avoid transmitting HIV to sexual partners against the risk of rejection or abandonment after disclosure and the gulf in understanding that participants stated was a typical, but not universal, feature of sero-discordant relationships. Very few participants described having actively kept their HIV status hidden from potential or actual romantic partners. Participants recognised that transmitting HIV was significantly reduced through condom use, but condom use itself introduced the possibility of unintentional
disclosure. This was particularly the case for heterosexual participants, who felt that older heterosexuals were unused to condom use except for purposes of birth control, which was no longer a concern for women over the age of 50. Thus, while participants felt that keeping their HIV status from sexual and/or potentially long-term partners was practically difficult and morally irresponsible, disclosure introduced the risk of rejection.

“... At my age I’m not likely to get pregnant, and also I’m not likely to be mixing with people that are screwing around. And at my age I can hardly claim I’m going to be pregnant and I’m worried about contraception because of pregnancy. So with relationships, it just brings you to a total complete halt (P59, RD WHF, 60s).

If the woman likes me, and I like her, then it can get to a stage whereby I must tell her my status, and then if that lady is not positive, she’ll run away. And if she runs away, she will tell people, that man, so and so (P79, RD BAM, 50s).

Dating was further complicated by participants’ sense that members of their own generation were most likely to hold stigmatized beliefs about HIV and those living with it. Participants viewed older people, particularly older heterosexuals, as being less knowledgeable, and younger people as more knowledgeable, about HIV. Participants imagined that disclosing to older people would most likely inspire a judgemental response informed by stigma and ignorance of HIV— a fact that, given their age, single participants felt limited their romantic prospects.

“... My daughter’s generation, they’re not shocked ... They see a sexually-transmitted disease as being a hazard of life... and HIV is just one of them. Whereas for my generation, HIV is like oh, my God! And the thing about telling someone is you can’t tell them unless you’ve got them for an hour, because you have to educate them as to what it actually means (P59, RD WHF, 60s).

The young ones don’t care, the middle ones are informed, the older ones are just not informed. I’m lucky that most of the guys I date are much younger than me. Very few are over 40. Most are 25 to 35. In that age range they’re educated, they know what they’re doing, and nine times out of ten they don’t really care about HIV (P72, RD MSM, 50s).
Disclosure to children

Participants who were parents typically saw their own HIV status as a potential threat to their children’s emotional wellbeing. These participants described having to balance the (eventual) need to disclose to their young children with these children’s capacity ‘to understand’ the nature and implications of HIV infection, which they assumed would develop in their late teen to early adult years. Timing disclosure to match the child’s maturation was thus key. But timing was further complicated by two possible situations that would ‘force the issue’. The first was their children learning of the participant’s HIV status from others. This brought with it the dangers of children receiving incorrect information about HIV, and of learning of their parent’s HIV status when they were too young to understand or had not yet been properly educated about HIV. The second was changes in participants’ health and ability to remain independent – changes that were expected, but whose timing was difficult to predict – in the context of their children becoming more aware of their surroundings with age and thus more likely to notice (and question) participants’ medication use, declining health, and/or need for help at home. In these instances, children would learn of their parent’s HIV status, ill health, and need for care while coming to terms with their having been ‘kept in the dark’.

“ If I became ill constantly, there would come a point where we’d have to be more forthright with him [son]. But I don’t think he needs to know at the moment (P51, RD MSM, 50s).

There is a kind of plus in disclosing to the family because as you grow older you get weaker and you need someone to give you medicine. If they find out that you have to take that medicine, and you didn’t tell them about it, they will be cross with you, why didn’t you tell them, I didn’t know I had to give you that medicine, and there will be a clash between you and them (BAFG#9, LTD BAF, unknown age).

If before, you disclosed it and you told your children why you have it, you’re okay. But if you have never told them, and then they come to know that you’re HIV, a lot of people think, HIV people were like sleeping with men. It puts you in a corner (P10, LTD BAF, 50s).”
VII. ON AND OFF TIME: AGE AND LIFECOURSE DISRUPTIONS

For participants, the impacts of ageing with HIV were not limited to relationships with other people. Participants also expressed grief over their HIV ‘robbing’ them of the later lives they had envisioned before they were diagnosed. For many participants, older age softened the social impacts of HIV. This was evident through such statements as ‘at least I’ve married and had children’, ‘age is on your side’, and ‘by the time I got diagnosed, I was old enough to be able to accept it’. But many participants, including those who felt that being diagnosed at a younger age was more damaging than being diagnosed in later life, felt ‘off time’. That is, they imagined that their futures would be uncertain; foreshortened; and derailed from their original ‘course’, with social relationships altered, compromised, or precluded, thereby changing the social worlds they expected to have at this point in their lives and in the future. Several spoke of having ‘no future’, and of ‘living day to day’. These changes to expected futures unfolded in the context of social and family roles, such as parenthood or being the adult child of ageing parents, and had particular resonance given that later life typically offers fewer opportunities to build new relationships and careers than does younger age.

Uncertain health

Participants generally felt secure in the knowledge that medications had shifted their HIV from an acute crisis to a long-term, chronic condition. But a common theme raised by participants at interview and in focus groups was the possibility (and, to some, likelihood) that HIV would shorten life expectancy. Participants who raised this topic expressed concern that early death would affect their children and/or partners, and some described having to re-evaluate their plans to work to retirement age.

“I’m thinking, well, how long am I going to live? And then looking at the children we are bringing up, how will the children cope, how are we going to leave the children? What support is there for them? (P9, LTD BAF, 50s).
I want to have a quiet retirement, even if I have that in my late 50s when most people have to have it later, but equally I know I have to make that happen sooner. I can’t wait for my legal retirement because it might not ever arrive in time (P75, RD MSM, 50s).

Moreover, participants were unclear about these medications’ effects on their health and longevity, and about the long-term consequences of the interplay between these medications, the ‘normal’ ageing process, and HIV itself. This lack of clarity was, for many, a source of anxiety, especially given the critical importance of taking these medications on a daily basis, which all interviewees mentioned. This concern was particularly heightened in the accounts of those who had lived with HIV for many years, and who had spent a long time taking a variety of medications, some of which had caused severe side-effects. Several participants described having asked their specialist consultants about the long-term effects of HIV medications, only to be told that they did not understand them either. Others stated that while their doctors told them that they could live a normal life span due to the medications, this information in itself did not shed light on the medications’ long-term consequences, if any, on their health.

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 (P75, RD MSM, 50s)

My concerns are long-term medication; is it okay or not. Maybe you have taken it over 20 years. Will it work or will it not work? When you grow older, like me now, we might experience bone problems, some people experience heart problems, liver... (P6, RD BAF, 50s).

It’s the risk that there are long term effects that they haven’t found out yet, and considering I’m one of the people that’s been on the medication longest I’ll be a good guinea pig for what happens when I’ve been on it 20, 25, 30 years (P48, LTD WHM, 50s).

These accounts of uncertainty linked to some participants’ concerns about their future independence and care needs. Several participants described situations in which their health had already deteriorated and they lacked sufficient support to keep their homes clean and organised and to complete daily chores. For some
participants, this help was only needed when their health was particularly poor. For others, this support was needed on a more constant basis. For example, P31, a RD MSM in his 70s who lived alone and did not have any children, said that he needed domestic support due to his hypertension and HIV. He relied on a friend for this support, but explained that she would no longer be able to help him due to her own family obligations, a prospect he found ‘frightening’, as he no longer knew ‘who is going to take care of me’. Some participants, while well connected to others, nonetheless lacked the kinds of relationships that translated into the effective practical support they needed.

I suppose, as I get older, I will need medical support in case of side effects, I don’t know because they don’t know. The NHS 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 (P50, RD MSM, 60s).

My daughter just treats it as if there’s nothing wrong with me. It annoys me sometimes because when I’m struggling, when I don’t feel so good, and I’m still doing all the shopping and the housework and she’s sitting, watching the TV or something. That annoys me because I think she could do more to help me. I don’t think it crosses her mind, because to her, I’m not ill (P70, RD WHF, 50s).

I think living in isolation’s quite difficult for me. I don’t know how long I’m going to be mobile. I presume I will be okay, but I look at my parents and my father can’t walk. And I keep thinking, gosh, if that happens to me, I don’t know what I’m going to do. And then I’ve been thinking, maybe I’ll go into a home as I get older and that worries me (P76, RD MSM, 50s).

Few participants said that they were concerned about, or had even considered, formal long-term care, despite many accounts of concern regarding their own long-term health emerging in the data. Most stated that they had not thought that far into the future, were ‘living day to day’, or that all older people faced similar issues. However, some did expect ‘to start dropping down’ due to their HIV. Concerns over receiving formal personal care or entering a long-term care facility were, when raised, strongly shaped by expectations of poor treatment of people living with HIV by care staff and other residents who held stigmatized views about HIV. For example, one man had witnessed a gay male friend living
with HIV being subjected to ‘snide comments’ by another resident at a nursing home. These concerns were generally raised by MSM, who attributed the current lack of HIV (and gay-specific) long-term care or sheltered housing to the failure of HIV/AIDS organisations and the NHS to recognise that once HIV shifted from a fatal to a chronic condition, people living with HIV would survive into later life. MSM worried about homophobia within the long-term care sector, particularly as they generally did not have children to look after them in old age.

“If I ended up in an old folks home when I’m 80 and I’m 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 round? Because the nurses are going to have to dish out medication (P48, LTD WHM, 50s).

Care is based for heterosexuals. You haven’t had old HIV people. We are technically the guinea pigs and first generation of old HIV people, and from what I gather, I know it’s being discussed now. But up till now, no one discussed it because no one thought it would happen. That we’d be old HIV people (P43, LTD MSM, 60s).

That is one of the issues we have to confront. As you get older you have to face up to that idea that you may need care. And a lot of gay people don’t have families. Your care may well come from the community and that really doesn’t seem to have been addressed in any big way (MSMFG#3, RD MSM, 60s).

Derailed and uncertain futures

Some participants’ social relations had already been interrupted before their diagnosis due to, for example, migration and/or unemployment, and HIV introduced further disruptions to an already-disrupted life. For others, HIV diagnosis disrupted, and tested, social relations that had been relatively stable pre-diagnosis. Most participants stated that the social relationships and roles that they had expected to have made or sustained in their later years had been precluded or severely compromised by their HIV. This was generally raised in the context of romantic relationships (see above), which most single participants felt they were less likely to form given their HIV status and their age.
I’m still young enough to have a boyfriend or to get married. You can get a man and get married and enjoy life. But because of this HIV now, you are afraid that maybe I will hurt myself if I find a man and this man knows and they will leave me again. But if you are lucky, they accept you, then you can start living again and have a partner, someone who will look after you. So you are in a dilemma. You don’t know because of the age again. If they accept me then I’ll be lucky, so you don’t know to start it or not (P58, RD BAF, 50s).

Some participants also expressed a sense of disappointment, loss, and sometimes failure when they described their HIV preventing them from accomplishing such expectations attached to mid- and later life as financial stability, long-term partnership, parenting and grand parenting, and a successful and fulfilling career. This theme also emerged very strongly in black African participants’ accounts of homesickness and the emotional distress of missing their family members. These participants were living in the UK and away from their families, partly because the HIV-related health care provided by the NHS was largely unavailable in their countries of origin. Black African participants who were parents often worried about their ability to provide for their children due to financial constraints and to provide daily guidance and help. This inability conflicted with the role of supportive parent which they had expected they would be able to sustain in their later years. These participants’ migration status was also a key source of mental stress and uncertainty, making it difficult to engage in meaningful activities.

I’m thinking to myself if I was going to live up to 80, then maybe with HIV I won’t. It’s like a cycle. The anger is always lingering because of the fear of death as you grow older. With HIV I could have gone up to 90 or 95. I might not get to see my grandchildren get married, things like that. As I grow older I get angrier with myself. The anger is always there. I could have avoided this. I could have done better (BAFG#3, LTD BAF, unknown age).

I have no money or anything. I mean, it did totally change my life like that. I went from being somebody that was self-supporting, earning well and so on, to someone that was left not being able to (P59, RD WHF, 60s).
In Africa, people believe that if you are 50, that’s the benchmark for achievement, because at 50 you are supposed to be a governor or a minister or something. But if you are battling with HIV then they begin to feel somehow - you’re not sure about your life. So those who are negative, they are progressing in their life, they’re not thinking about medication (P12, LTD BAM, 50s).

Emotionally, I still see it very much as a death sentence. It limits your horizons. We talk about when we retire and all that but I don’t see that on the horizon for me. I see in terms of ten years or less. I don’t see myself as an old wrinkly on the beach enjoying my retirement. I kind of see myself at some point in the not too distant future, or the intermediate future, it’s unlikely to go much longer than that (P51, RD MSM, 50s).

Isolation and lack of financial support

Most participants described their social, romantic and family relationships as supportive. But some described themselves as lacking in practical, emotional and financial support and/or as socially isolated. Participants also commonly cited economic needs as pressing, with participants from all subgroups (though predominantly black African participants) describing precarious financial situations as contributing to poor mental health and QoL. Again, almost half (42, or 48%) of the 87 participants who provided data on income earned less than £10,000 per year. Although a small number received financial help from family members, several were distressed and worried about their ability to pay their bills, buy food, and remain in their homes. For example, after P63, a RD BAM in his 60s, told his son about his diagnosis two years before the interview, his son moved out of their shared flat and has failed to contact him. At the time of interview, P63 did not know where his son was or whether he was paying the rent on the flat. Being without work or income, he was highly anxious about his own future.

My son and my brothers support me so I don’t really have undue stress in that area. But if not for that support it would be very, very difficult for me because for about four years now I’ve not been working, I’ve not had any income. So that would have been very, very difficult for me. Now, I can’t work and I can’t apply for benefits (P57, RD BAM, 50s).
As noted elsewhere, our quantitative analysis showed that, alongside partnership status, the strongest correlation with poor mental health was being in receipt of benefits. Benefits, while providing income, also reflected circumstances that were stressful in themselves – for example, being out of work or having limitations on abilities (in the case of DLA). For MSM, who had depended on DLA, often for many years, being on benefits represented years spent out of the workforce. Changes to the policy threatened to force re-entry into the workforce at a time when these participants felt unable to do so due to their own physical and/or mental health challenges, a cumulative loss of work-relevant skills, gaps in their employment histories, and ageism.

At the moment there’s a big move to get people back to work including those with HIV. A year ago my disability living allowance was taken away. I appealed against it, and I failed. Technically they could try and make me go to work. They won’t, because in 10 months I’ll be a pensioner. It seems like the good news with HIV is we have drugs to keep you reasonably alive. Now we’re going to destroy you mentally by driving you up the wall with all this rubbish, a lot of which doesn’t make sense. I am in serious financially difficulty. I don’t fit into any available pigeonhole for help (MSMFG#3, RD MSM, 60s).

I get my benefits from the government, and I’m constantly threatened to have them taken away. That’s horrible, and that’s caused me a lot of trauma. I’ve just been awarded my DLA, they said for life. But 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 (P60, LTD MSM, 50s).

Low or, more rarely, no income translated into stressful and unhealthy living environments, for example, lacking a proper bed and having to sleep on the floor or having to choose between paying utility bills and eating nutritious meals. For some, the stress of financial insecurity made good QoL a remote prospect. P78, a LTD BAM in his 50s, was homeless and now lives in temporary accommodation. He was worried about his Freedom Travel Pass, which was being withheld by the local authority council, and struggled to attend his hospital appointments and HIV support group as a result. P9, a LTD BAF in her 50s, identified financial strains introduced by having to use her limited benefit payments to support both
her partner, who is not permitted to work in the UK, and her two children while trying to ‘live a healthy lifestyle’.

“You have electricity to pay, gas to pay, water to pay, that is where your transport comes from and that’s where your food comes from, and you have children (P6, RD BAF, 50s).

It’s all because of immigration, because if I was granted my status I could be working and financially I would be all right, but now I have to wait for the vouchers and sometimes it’s hard for me to buy maize meal to cook my traditional meal (P7, RD BAF, 50s).

If you sleep on the floor, it won’t be warm. It’s cold. That’s why I’m cold. I’m cold at night (P3, RD BAM, 50s).

Lack of meaningful social connections and feeling isolated and alone were also significant sources of distress. Some participants believed that their mental health problems were caused or aggravated by their social isolation, while others stated that their social isolation was the result of their mental health problems. Several participants stated that they needed people to be involved in their daily lives and provide encouragement and ‘reminders’ to engage in activities that were essential to their physical and mental health – in short, to ‘check in’ on them on a steady basis.

“I was depressed before, but I find I get more depressed now, and I think it’s because I won’t allow myself to get close to people, especially my own folks, but it’s because I don’t want to have to tell people (P5, RD WHF, 50s).

I don’t know what to do in my life. I feel very insecure. Apart from this depression I feel all right, but when that does kick in... I’m on antidepressants. I feel better when there’s someone around me. I feel very lonely sometimes (P54, RD MSM, 60s).
VIII. MENTAL HEALTH RESOURCES AND STRATEGIES

To cope with these stresses and strains, participants made use of social resources that they had established or used before their diagnosis, such as friendship networks, family, and, for a small minority, formal mental health services. But participants also employed learnt techniques for mental health management (including those taught by mental health professionals, such as cognitive behavioural therapy) and devised new mental health strategies to cope with stresses that were specific to their HIV. These included strategies such as volunteering, ‘keeping busy’, ‘keeping one’s mind active’, exercise, remaining socially active, and redefining their HIV to make it less central to their lives and identities. Participants also sought out people (e.g. health professionals) with whom they could discuss their HIV-related fears, concerns, questions, and problems. But many participants also searched for support, knowledge, and empathetic understanding that could, they explained, only be provided by people living with HIV, forming romantic partnerships and other social connections with them and attending and, often, volunteering at, HIV support groups and organizations.

Informational versus experiential knowledge

Although these are our terms, participants distinguished between informational knowledge (available to anyone, regardless of HIV status) and experiential knowledge (held by people living with HIV, and unavailable to even the most open and supportive HIV-negative friends and family members). Throughout the focus group and interview data, and across all topics and themes, others’ ability to ‘know what it is like to live with HIV’ was a central topic. While participants had friends, family members, and sometimes romantic partners who were HIV-negative, almost all sought out people living with HIV whose experiential knowledge offered mutual understanding and support and minimised the burden of relative misunderstanding or, in the most extreme instances, the threat of personal rejection based on a lack of correct informational knowledge about HIV. Participants described these sources of support as critically important for good mental health and QoL. Participants explained that while the help and support (primarily instrumental, although sometimes financial and occasionally emotional) provided by HIV-negative family and friends was invaluable, these persons could not truly appreciate or understand the physiological,
psychological, or social challenges and uncertainties of HIV. This, they explained, made it necessary for them to find and connect with other people living with HIV.

It’s interesting because my close friends, three are positive and four are not, and while I’ll talk as openly to both categories, there’s no difference, it’s obviously easier to talk about technical things to do with drug therapies and conditions with people who are either experiencing or have experienced them…. the support from people who are HIV is usually a little more on the nose, it’s a bit more aligned (P75, RD MSM, 50s).

I have a close friend, he’s also HIV and I think I’m more close to him because we understand most of the same things. When I feel depressed I just call him and he gives me a bit of support and I give him as well. We help each other. This is my really close friend. Other friends, I don’t particularly feel too close, just casually (P20, LTD MSM, 60s).

While social support was by no means solely provided by formal HIV support groups, those participants who used, or had used, HIV organisations and support groups spoke of the therapeutic or positive value of meeting other people living with HIV, learning from them, and gaining a sense of belonging, membership and social solidarity. Some participants described these benefits in therapeutic terms, but most described them using such terms as ‘lifting me up’, ‘making me feel better’, and ‘improving my morale’. Several stated that the therapeutic support they received from formal mental health services, while helpful, needed to be supplemented by peer-based support from HIV organizations and groups for them to be mentally healthy.

**Social support**

Most participants enjoyed close and, often, long standing relationships. Informal support was commonly provided by family, friends, work colleagues and neighbours they had known prior to their diagnosis of HIV, as well as romantic partnerships. Several of these participants described their families having provided valued and necessary practical and emotional support immediately after and in the years following their diagnosis. For example, P56, a RD WHM in his 50s, remembered how his son and mother were his ‘prime carers’ when he was ill. Practical support included help with activities of daily living (e.g. cooking,
cleaning, shopping), and emotional support included encouragement, ‘checking in’ (see above), expressions of concern, and the comfort of knowing that these family members were invested in their happiness. As with other participants, for black African participants who were geographically separated from their families, emotional support was often provided long-distance through telephone and Skype calls.

My family, my sisters are very good. I think if they weren’t there, I’d find it very hard. They help with the nitty gritty of life. The everyday sort of things. Loneliness as well. It is good to have family. We are pretty close and that does help. I’m not too lonely. At the same time, in some ways, I don’t mind having my own space. I don’t need someone there all the time (MSMFG#4, RD MSM, 50s).

HIV comes with a lot of sickness, so what do you tell your family? Someone has to lift you up. I have had support from my daughter. My daughter did everything. The surrounding people will say a lot about your sickness, but my family sympathise with me, support me. They want me to be happy and don’t want me to die. I have no shame about it. They ask me what is wrong. I tell them what is bothering me (LTFG#5, LTD BAF, 60s).

For participants who were in long-term romantic relationships, these partnerships were important sources of emotional as well as practical support. 28 out of the study’s 33 partnered participants identified these partners, including those who were not themselves living with HIV, as the people to whom they felt the closest. For example, P51, a RD MSM in his 50s, described his HIV-negative partner as his ‘core relationship’, which he characterised as ‘very honest, very open’, and ‘very supportive’. These sero-discordant partnerships were not without their difficulties, however, as some participants described their partners failing to appreciate the difficulties introduced by their HIV status.

I sometimes feel my partner doesn’t understand me, but in saying that, I understand that she doesn’t understand me only in that respect. Like when I’m sitting, I’m tired, doing nothing, on the settee dosing away, it’ll be, oh come on, get up, do something, you lazy sod, and there’s this to do and that to do. I think, well, you don’t understand, and no matter what I say to her she’s not going to understand (P56, RD WHM, 50s).
For many heterosexual participants, however, the prospect of rejection by potential romantic partners, particularly those who were their own age or older, and of what they saw as a lack of understanding of what it was like to live, and age, with HIV, led them to avoid romantic relationships altogether. This strategy was, for some, less difficult due to the waning of their sexual desire ‘with age’ and illness. Others sought out romantic partners who were themselves living with HIV. These participants cited the benefits of partnering with someone who understood ‘what it’s like’ to live with the virus’s clinical, health, social, and mental health - dimensions that required continuous communication and support. Participants generally depicted sero-concordant sexual and romantic relationships as not only easier given the relative ease of disclosure and diminished worries over transmitting HIV, but as more stable and emotionally close than were sero-discordant partnerships. In the interests of forming a sero-concordant partnership, several participants used HIV dating websites, and several described HIV organizations as fruitful meeting places for friends and potential romantic connections.

“Would it be an HIV positive partner or negative? I would say either but I think, for easiness, HIV positive. Because you can empathise a lot more and both will be clued up in some areas of either medications or side effects, and know what to do if something happens (P22, RD MSM, 50s).

I met a lady who is also positive and I have been able to have a very good understanding, so I never really suffered or lacked anything in that aspect. She is positive, I’m positive, because we met at a HIV forum, no issue about disclosure (P57, RD BAM, 50s).

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 has been really nice in terms of our relationship, to share that (P70, RD WHF, 50s).

HIV organizations and support groups

The absence of people with experiential knowledge of HIV in their immediate networks compelled many participants to seek support from formal HIV organisations and groups. More than half (55%) of participants attended HIV groups, and most of those who did so attended no other kind of group . Of these
55 participants, most were black African (80% of black African versus 44% of white participants attended), female (74% of female participants attended versus 48% of male participants), and heterosexual (74% of heterosexual participants attended versus 32% of MSM).

‘Emotional support’, ‘practical information’, and ‘meeting people’ were the most frequently cited reasons for attending HIV support groups, followed by ‘social activities’ and ‘spending time in a safe space’. The importance of emotional support for male heterosexual participants attending these groups differed by ethnicity: 40% of the white heterosexual men who attended did so to secure emotional support (a similar proportion to MSM), while 100% of black African male participants who attended did so for this reason.

While existing friends and acquaintances sometimes provided pathways into these groups, new friendships often emerged from connections made in these organisations and groups. Participants also described these groups as providing the opportunity to support other people, drawing on experiential knowledge that they had developed over the years that they had lived with HIV. For participants attending these groups, the social support, information, empathy, skills, solidarity, and ‘safe space’ in which to discuss their concerns with others who were ‘in the same boat’ that these groups provided were essential to good mental health and QoL.

As detailed above, prior to their HIV diagnosis, many participants had limited or no knowledge of HIV, and limited or no contact with other people living with HIV. This made learning about HIV groups challenging. Several participants stated that, outside of HIV organizations or groups (assuming they attended these), they only knowingly encountered other people living with HIV at their HIV clinics. Making initial connections with HIV support groups or organizations was thus more difficult for some participants than it was for others. Participants with existing connections to other people living with HIV learned about HIV organisations and support groups through them, and many MSM had already known of – even volunteered at – HIV organizations in previous years. Often, participants were directed towards HIV organisations and support groups by their HIV clinic or by other health and social care professionals, although some participants had asked their health care providers for information about HIV support groups or resources only to be told that they did not know of any. Some participants used the internet to locate HIV organizations or groups, and/or connected with other people living with HIV through internet-based forums, including dating sites.
You don’t know who is positive, who is negative, so there’s the problem. Like in a group here now, you know that everybody coming here, we are all in the same boat, and you can talk about it, but on the street, you can’t ask. It’s difficult. 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 (P79, RD MSM, 50s).

The clinic told me about support. I was taken somewhere to meet with other people with HIV. We eat together, chat together, and talk. Just mix together. That helped me a lot (P12, LTD BAM, 50s).

Regardless of how they came into contact with HIV organisations and support groups, participants overwhelmingly described their experience of these groups as positive and beneficial. Participants detailed various ways in which HIV organisations supported them, specifically: advice and information about HIV (e.g. HIV services, the physiological impact of HIV, and HIV self-management); information and assistance in welfare and benefits applications or immigration applications; massage and wellbeing therapies; and training courses in such areas as parenting, coping, and employment skills. Perhaps most significantly, however, participants described the benefits of social contact with other people living with HIV. These benefits included the common understanding of the lived experience of HIV; the exchange of experiential HIV knowledge and information about health and social care services, HIV medication, the physiological impact of HIV, and disclosure within social and romantic relationships; and finally, an intangible but vitally important sense of social solidarity, unity, belonging and familiarity which resulted from being in the company of others, bound by common experience, circumstances, and concerns, in a distinctively ‘safe space’.

When I came here, it had everything I needed to explain to me how to survive and what to do (P43, LTD MSM, 60s).

That is where I get most of the support whenever I need it. They will tell you where to get assistance, whatever kind of assistance I need, so more or less my support has been relying on that (P63, LTD BAM, 60s).

Especially but not only when participants had been recently diagnosed, practical information and guidance provided by HIV organizations was a core reason for attending their groups. This included information and guidance on
matters not directly related to HIV, for example, housing and income benefits and immigration (although, as we have seen, these were typically intimately connected to participants’ HIV status and careers) and matters directly related to the physical, mental, and social aspects of living with the virus – for example, disclosure to friends, family, and actual or potential partners, HIV medication and treatment, sexual health and reproduction as people living with HIV, healthy living, and nutrition. HIV-relevant information and guidance was, these participants emphasised, not simply provided, but shared among people with similar lives, needs, and concerns. Often, experiential knowledge was shared with people who were newly diagnosed, with those who had been diagnosed for longer using themselves as evidence of the ability to live satisfying and fruitful lives.

“I wasn’t myself, actually. At times I found myself talking to myself. Why should I have to suffer all this? Why? Why me? But then somebody took me to the support groups and then that is when I started seeing people; said, oh, we’re in the same boat. I started feeling relieved; I said, well, I thought I was alone, but we are many. But when I saw those people, I could not believe that they have what, HIV. I said is that person sick? You couldn’t believe it, and then I said, well, if they are sick then I’ll be okay. I think when you are newly diagnosed you say, oh, that’s the end of me. I’m going to die and so on. But they see here that some have already spent more than even ten years being ill and so on, so they pick up courage (P18, RD BAF, 60s).

That the practical information and support outlined above was provided by people living with HIV gave it credibility. But it was also rooted in, and contributed to, social solidarity derived from membership in a group of people with shared histories and concerns. Thus, when describing HIV support groups, participants used such terms as ‘moral support’, ‘sharing experiences’, ‘speaking the same language’, and ‘being in the same boat’ to capture the central role that these shared lives played within these HIV groups.

“It’s not a counselling group, it’s about sharing your experiences and giving moral support (P22, RD MSM, 50s).
If I had not joined those groups, maybe I would have died now, because it’s those groups that actually told me look, you are not alone in this fight (P63, RD BAM, 60s).

Having been given these organisations, I made friends there, who are in the same situation with me, so I would encourage doctors to keep on giving all newly diagnosed people the list of organisations that can help, because it really takes off (P82, RD BAF, 50s).

We are family... we are the same. You are going to make friends, which is very important. You sit down, chat, even chatting for one minute, it’s enough. They are there for you. I love to come, I don’t want to miss, and when I do miss, I feel I’m missing something (P78, LTD BAM, 50s).

Furthermore, that HIV support groups and organisations provided a ‘safe space’ where the pressures of disclosure and stigma were less pronounced was a critical component of their value. Participants described these organisations and groups as allowing and encouraging an ‘openness’ about their HIV status and its consequences for their daily lives that would be respected and kept confidential. Several stated that these were the only spaces in which they could discuss their HIV status or HIV-related concerns. Given the social costs of having their HIV status discovered and discussed by people from whom participants wanted their HIV kept private, this safe space was highly valued by participants who attended these groups.

If you have HIV there is a tendency to stay with the HIV community because you know you are safe there. Like here, you can talk freely. If I went to my local over 60s afternoon tea party, I couldn’t talk about this (MSMFG#2, RD MSM, 60s).

Here, you get a lot of moral support, when you meet your friends, chatting, speaking the same language, which 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 (P78, LTD BAM, 50s).

It’s easier where you can meet people with the same status, where you can talk hopefully, because when you are hiding this, it eats at
you bit by bit. When you are not talking about it, it eats at you (P78, LTD BAM, 50s).

Participants also emphasized the importance of HIV organisations and groups combatting isolation, which several explained had emerged post-diagnosis as they withdrew from others in fear of rejection or out of a sense of social disconnection and distress. Participants on benefits in particular gained supportive connections with others which they lacked due to their non-working status. For several participants, regardless of whether their partners and family members knew of their HIV status, this safe space radiated outwards through new friends they made through these groups. These friends, with whom they socialised outside of these support groups and their host organizations, became a continuing source of support. These friendships sometimes spanned the gulf between these ‘safe spaces’ and the ‘outside’ world as participants visited those they met through these groups in each other’s homes, went out together, and telephoned each other to ‘check in’, provide encouragement and support, and discuss matters unrelated to HIV.

It was important to keep oneself occupied and not be on my own. I am an example of this. Because once you have been diagnosed it’s a shocking experience. You withdraw from the people around you (BAFG#4, LTD BAM, unknown age).

You make friends here, these are friends you can call any time, any day you like to discuss HIV issues with. Very valuable friends (P57, RD BAM, 50s).

I’ve about half a dozen people here that I’m quite close to. We occasionally meet outside and do other things, generally with my family... I feel with the people up here I can talk about anything, which is not always the case with my partner, especially regarding the virus and that (P55, RD WHM, 50s).

HIV support groups also offered participants opportunities to support other people living with HIV by providing both practical information and emotional support, on the one hand, and a living example of survival and wellbeing, on the other. Many participants volunteered in HIV organizations, supporting others in either formal (e.g. running support groups and engaging in organisational and health promotion) or informal (providing advice and encouragement)
capacities. Participants explained that this was not purely selfless activity. Rather, this ‘giving back’ was a way to improve and sustain their own mental health as well as that of other people who were ‘in the same boat’. Volunteering at these groups thus provided a sense of purpose and value that balanced the stresses of living with HIV in later life, combatted isolation, and helped to ‘take the focus away’ from their own problems. Acting as mentor, guide, or ‘wise’ older person embodying physical and psychological survival to people living with HIV helped them to contribute to others’ welfare in ways that participants had lost through disruptions to social relationships. For some, this disruption had preceded their diagnosis, but for others, it was closely connected to it (e.g. separation from family in Africa due to the availability of HIV care in the UK and the lack of it in their countries of origin).

For many of these participants, their own experiential knowledge, often amassed over many years, afforded a balanced and informed perspective that they could share with others, especially more newly-diagnosed people, who were in significant need of it. That this experiential knowledge, gained through having undergone painful and distressing circumstance and events, had a beneficial function in the context of peer support helped participants to view their HIV status as something other than a purely personal affair that isolated and alienated them from others. Rather, it was a way to connect with others and to fashion a valued and constructive social position within a community built on similarity and a shared commitment to wellbeing.

“I do like helping people with the practicalities of it, and even people who I’ve met at support groups where ‘I’ve been recently diagnosed, I’ve had it for a month or two months or whatever, and I’m all in a panic’. And I told them my story and said, look, I nearly died of this when actually there was no medication. My CD4 count was zero, it’s now over 1,000, so if you keep to the medication, you’ll be okay (P48, LTD WHM, 50s).

When I was part of the support groups – because there was more than one – I became the oracle. If somebody wanted to know an answer they’d come to me because I knew so much about it and I’d lived the longest, so I knew more about it than anybody else (P60, LTD MSM, 50s).

I was in the lowest low and if it wasn’t for my friend who got me involved in HIV groups, I might not be here. I threw myself into
volunteering. Volunteering is a way to connect, support and feel joy about helping others (BAFG#8, RD BAM, 50s).

Volunteering at HIV organisations keeps my mind off the immigration because when I’m alone at home I’m thinking when are they going to attend to my case? How long is it going to take? All those things. So I’m busy doing something that will distract me from the immigration (P7, RD BAF, 50s).

Our quantitative analysis shows that attending these groups was of particular significance for those on benefits. For participants on benefits, attending support groups was associated with a better score for the WHOQoL-BREF psychological domain. For participants who did not receive benefits, there was no difference in score between those who attended a group and those who did not. As the HALL study did not measure QoL or mental health over time, we cannot infer the causal relationship between good mental health as measured by the psychological domain and HIV support group attendance – it is possible that those on benefits with better mental health attended HIV support groups, and those with worse mental health did not attend them. However, our qualitative data suggest that attending a support group mitigates the negative impact of being on benefits for psychological QoL.

**Mental health services and strategies**

Many participants used mental health services while also attending HIV organizations, and some saw counsellors and therapists who were affiliated with them. But a substantial number stated that they had chosen to see mental health professionals as an alternative to securing support from HIV organizations and groups, and, as we show below, avoiding these HIV-specific forms of support was in itself a mental health strategy for some. One RD WHM in her 50s who preferred a therapist to HIV groups said, ‘I don’t like the idea of support groups where you’re talking about HIV all the time on a regular basis’ and where attendees ‘endlessly focus on that issue.’ Several participants also stated that they chose therapy or counselling as an alternative to seeking support for their HIV-related concerns and distress from friends, whom they did not want to burden with their troubles, and who might not have the skills to support them effectively.
I’m a bit mixed up and sometimes I just find it useful talking to a third person who is completely removed from my personal life; who isn’t trying to go, no of course you’ll be all right, because they’re my friend or my family (P60, LTD MSM, 50s).

I told all of my friends instantly because they knew I was going to have a test. It was helpful being able to speak to them up to a point but, obviously, they don’t quite understand what I’m going through. That’s why I felt counselling would help, and also I didn’t want to bore them with my issues every time I went out. So that’s why I did decide to have counselling, reluctantly (P70, RD WHF, 50s).

These participants regarded psychological or psychiatric therapies (including counselling from doctors) as highly beneficial for, even essential to, good mental health. Many of these participants praised their personal mental health providers for their skills and their supportive approach, and spoke of establishing good, trusting relationships with them, all of which they linked to improvements in their mental health, overall mood, and ability to cope with the uncertainties and stresses related to their HIV. Very few felt that their mental health care was unhelpful, improperly handled, or damaging. Criticisms of mental health support were usually focussed on issues of funding, with several participants stating that their mental health support had been interrupted due to funding cuts.

My HIV brought me depression. Psychiatric, it helps. Now I’m okay. You become cool, they give you medication, you become all right, they advise you what to do (P10, LTD BAF, 50s).

In addition to using various therapeutic techniques recommended by their counsellors and therapists, participants devised their own strategies to better their mental health and QoL. While mindful of the daily demands of living with HIV, these participants strove to limit its impact. They did this by reframing their HIV status as less consequential than were other, more stressful or significant aspects of their lives, and by declining to associate or identify with formal HIV organizations or groups.

For some participants, this transformation of HIV’s meanings and impacts was enabled, and in some cases, driven, by the existence of such other problems as long-standing mental illness (see above), drug addiction, other physical conditions (e.g. emphysema), and time spent in prison. Some participants
thus found it relatively easy to symbolically position HIV within their lives as a secondary or even tertiary concern – as P43, a LTD MSM in his 60s, said, ‘it’s like a normal life that has pills in it’. But others struggled to make HIV less central to their identities and personal and social lives. This theme emerged several times in discussions about HIV support groups, which several participants stated they wanted to avoid attending lest their HIV begin to ‘define’ them, although as the final quote below shows the struggle not to be at least partly defined by HIV is a difficult one.

“If I were younger, I might almost have done what a lot of people do, which is they make a career out of being HIV positive. I wouldn’t want to do that. Because it’s part of my life, I don’t want it to dominate my life (P59, RD WHF, 60s).

I don’t want to spend a whole evening talking about HIV. To be quite honest, there’s more to life... For some people it is quite a big thing and they will talk about it a lot. For me, it’s definitely not trivial, but it’s not something I want to spend all my time talking about... I made a mistake, I’m paying the price for it, but I can’t afford to let it define my life, although it ultimately does. So there’s a degree of fighting against that, if that makes sense (P44, RD MSM, 50s).

IX. RECOMMENDATIONS FOR POLICY AND PRACTICE

“I think my biggest thing, my own personal thing, and this is towards medical staff, is yes, things have moved on, people have been treated, medication over the years has improved dramatically, but for a lot of people getting HIV is still a big deal. It really is. It’s still a big thing. So, not to turn around and say, oh, well, medication’s working really well, don’t be worried about it, I don’t know why you’re bothered about this, and people are living a lot longer. Yeah, we know all that. I knew all of that, but it is still a big thing. And it is what it is. It’s a life limiting - at the moment - disease that is controlled, can be managed, but that’s what it is (P23, RD MSM, 50s).
Our research found that age-related concerns like parenthood, ageism, retirement, and evaluating one’s own accomplishments from the vantage-point of later life intersected with concerns and challenges faced by all people living with HIV (for example, stigma, disclosure, managing family and romantic relationships, and living with uncertainties connected to a long-term medical condition). For most, these concerns were manageable, and their mental health and QoL were good; but for some, mental health and QoL were poor, with high levels of depression and anxiety across participant groups. For many participants, the support from others with HIV, as well as formal social support – specifically, HIV support groups and specialist mental health services – were essential.

Given that the prevalence and incidence of HIV among people over the age of 50 years continues to rise, and since people living with HIV in later life face distinctive challenges, it is vital that service design, agencies of health and social care, HIV organisations, and professionals and volunteers working with these various providers, meet the challenges faced by this growing population. It is also vital that older people living with HIV should be appropriately involved in all stages of planning, commissioning and delivery of services.

**Education**

Public understanding of HIV requires improvement, particularly in relation to older people. HIV focussed educational and information resources that include appropriate representations of older people with HIV are needed. Non-HIV organisations that serve older people should be made aware they are likely to have service users who are living with HIV, many of whom have specific needs. Considering HIV as ‘similar to other chronic conditions’ (i.e. diabetes) overlooks the full impact of HIV on older persons.

**Diagnosis, health and long-term care**

Health care professionals and policy makers should recognise that for many people diagnosed with HIV in later life, diagnosis often signals ideas of a shortened life and poor health that may be out of date or incorrect given developments in HIV therapy. They should also recognize that although people ageing with HIV are grateful for the development and availability of effective HIV treatments, many older people living with HIV feel some distress over having lost the old age they had imagined and planned for before they were diagnosed.

Prognoses, health plans, and conversations between health care providers and older people living with HIV must be sensitive to the high degree of uncertainty
about their future health that older people living with HIV experience. This uncertainty relates to the unknown consequences for health of long-term use of HIV medications and of the intersection between HIV medication, ‘normal ageing’, and HIV.

People working in the long-term care service sector should receive education about HIV, its impact upon the older population, and the concerns of these older persons regarding stigma, appropriate care, and the need for privacy and confidentiality. These concerns are relevant both to care in the community and to care in residential settings.

**Mental health and quality of life**

Training for healthcare professionals and service providers should instil awareness of the high levels of depression and anxiety, frequency of low mood, and poor self-rated QoL, among some older people living with HIV, and the factors associated with these as outlined in this report.

All agencies and service providers should be especially attentive to the vulnerability to poor mental health and QoL of specific groups within the ageing HIV population. Examples are older people living with HIV who are out of work, on benefits, and/or on low incomes, who are variously under financial stress, experiencing uncertainty regarding changes to benefits, and more likely to be isolated given their non-working status. For black African men and women living and ageing with HIV, unemployment, benefit receipt, and low income likely represent interruptions to career, uncertain migration status and thus continued separation from family members living in their countries of origin, and limited ability to support their families, which could include children and spouses. For MSM, being in receipt of DLA may represent years, even decades, outside of the workforce, which, in combination with limited finances, may contribute to social isolation.

Other older subgroups at risk of poor mental health and QoL include the longer-term diagnosed, specifically, those who were diagnosed before the age of 40, for whom the long-term consequences of interruptions to career (see above) and, often, years spent without access to effective HIV treatments, have especially strong impacts on wellbeing in later life. Similarly, older people living with HIV who are single are more likely to be depressed and anxious, and this is likely due to concerns over forming long-lasting romantic partnerships given their HIV status and their age, as well as to the negative impact of single status on physical and mental health across populations.
Although parental status was not negatively associated with mental health or QoL, healthcare professionals and service providers should recognise that older people living with HIV, including MSM, are often parents. Parenthood adds a further layer of complexity to the experience of living with HIV and may be the cause of additional stress as, for example, the self-management of HIV medications is shaped by a desire to prevent the untimely discovery of HIV status by children, including adult children.

Mental health services are essential to many older people living with HIV. Free and confidential mental health provision must continue to be made available, and mental health professionals should receive training that enables them to deal effectively with the mental health needs of older people living with HIV, both in the time following diagnosis and in the longer term.

**Social support**

It is vital that information about HIV-specific social support is provided at the time of diagnosis. This list of resources should include national organisations that can provide information and guidance, but also local HIV-specific organisations and support groups.

All agencies should recognise that the social support available to older people living with HIV – for example, from friends, partners, and family – may not be sufficient for managing the anxiety and concerns that are introduced by receiving a diagnosis of HIV. Healthcare professionals should be made aware that simply because a newly diagnosed person is a member of a community with a high prevalence of HIV (for example, a member of the MSM community), they do not necessarily have people in their lives to whom they can speak about their status, or that they are willing or comfortable in doing so. Opportunities for older people living with HIV to engage with other people living with HIV, to have access to ‘safe spaces’ (where the pressures of HIV stigma and disclosure are less pronounced), and to contribute to their communities should be an integral part of service provision.

Health providers and policy makers, and HIV-specific support groups and organisations, should appreciate that older people are unlikely to know people in their age group who are living with HIV to whom to turn for practical guidance, or to have any understanding of what ‘successful ageing’ as a person living with HIV might be. This underscores the importance of HIV-specific support groups specifically for older persons, and of making information about ageing with HIV available to and through these groups.
X. REFERENCES


Fair, C., & Albright, J. (2012). “Don’t tell him you have HIV unless he’s ‘the one’: Romantic relationships among adolescents and young adults with perinatal HIV infection. *AIDS Patient Care and STDs* 26(12): 746-754.


XI. ENDNOTES

i. This increase is despite an overall decline in the number of new diagnoses for all ages over the period, which is largely due to fewer diagnoses among persons infected abroad. But, although the overall number of new diagnoses has declined, new diagnoses among persons aged 50+ are on the increase.

ii. Six health professionals, three non-clinical HIV service providers, two academic researchers specialising in HIV, one ageing and three HIV policy makers, and two HIV activist/advocates.

iii. We held one mixed gender black African group, with 12 participants; one mixed gender longer-term diagnosed group, with seven participants, one recently-diagnosed MSM group, with four participants, and one group of recently-diagnosed white heterosexual women, which was only attended by one woman due to others’ illness and travel disruptions. Our attempts to recruit white heterosexual men to meet as a group were unsuccessful. These focus groups were held in community organisations that helped us recruit for and organise these focus groups, offered us space to hold them, and helped with organising refreshments.

iv. As summarised at the start of this report, while slightly more than half (52%) of participants were parents, parenthood was unevenly distributed across sexual orientation, with almost all (29, or 96.7%) of black and four out of five (14, or 82.4%) of white Heterosexual participants identifying as parents, versus less than a fifth (9, or 17%) of MSM. The accounts that appear below are thus heavily weighted towards black African participants, many of whom had some or all of their children and grandchildren living in their countries of origin.

v. That said, these proportions may not be representative of older people living with HIV, as we recruited many interview participants through HIV support groups and organisations. Moreover, as we show below, HIV group attendance varies over the years, with newly diagnosed persons attending to get much needed information, guidance, counselling, and introduction to other people living with HIV in a safe space. Finally, given the severe financial strains with which many of participants are living, the practical support provided may serve as its own draw, particularly for those whose legal status may preclude receiving practical support, including meals, from as many sources as they would like or might need.