

Women's experiences of ageing with HIV in London

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Introduction

Out of a total of 101,200 people living with HIV (PLWH) in the UK 31,600 (31%) are women [1]. The UK has an ageing population of PLWH, with over 34% of people accessing HIV care in 2015 aged ≥50 years [1]. In 2016, 8523 women aged ≥50 years were seen for HIV care in the UK, 24.5% of the total from that age cohort [2]. There has also been an increase in the number of people diagnosed with HIV in later life, with 17% of new diagnoses among people in this age group in 2015 [1].

Women negotiating an older age with HIV potentially may face social and medical challenges, associated with ageing generally, added to or amplified by HIV. These include social and economic issues, as well as those directly linked to health such as managing treatment, side effects and comorbidities. Older women living with HIV may experience social isolation and a lack of social, emotional or practical support [3]. The experience or expectation of stigma and discrimination may present barriers to seeking or benefiting from care and support [4]. Long-term diagnosed women may struggle to plan for and negotiate an older age they never expected to reach [5]. Recently diagnosed older women may also face challenges, as they negotiate older age with an unexpected HIV diagnosis.

Whether HIV is a long-term or a recent diagnosis, women necessarily are able to adapt to dealing with it and this influences and alters their experiences of ageing. Moreover, women who are ageing with HIV have developed coping strategies and found ways to live and age well with HIV. The lived experiences of these individuals are a vital resource in understanding how people adapt to needs related to HIV and ageing, and how they and their community (however they define it) have innovated to meet these needs.

The specific experiences of women are the focus of this article, and of the research study from which it is drawn. The experience of ageing, and ageing with HIV, may be meaningfully different for women compared to men. Differing social norms and expectations of ageing, differences in the biological experience of ageing, the menopause transition, and the form and impact of HIV stigma and discrimination, are all impacted by gender and gender norms, and all influence women's experiences. In addition,

women are often under-represented in mixed studies, and some studies on ageing do not disaggregate findings by gender, so the experiences of women are under explored in the literature.

This article presents findings from two phases of a doctoral research study being undertaken by the first author at the University of Greenwich. The study aims to explore the experiences and needs of women growing older with HIV in London and to add to the body of evidence around ageing and HIV using feminist, participatory and assets-based methods. With a specific focus on women and the gendered experiences of ageing, this research explores how women are responding and adapting to ageing with HIV, with a specific focus on community, participation, social support, social and healthcare needs, and experiences.

The research comprises six overlapping and complementary phases: literature review; participatory literature review; creative workshops; policy review and stakeholder interviews; life story interviews; and participatory analysis workshops. Findings from the creative workshops and stakeholder interviews are presented in this article.

Findings from participatory, creative workshops

Three workshops were held, in spring 2016, with the support of HIV voluntary sector organisations the African Health Policy Network, Food Chain and NAZ. These three organisations were selected to provide support in recruiting and hosting workshops, as they reach diverse women living with HIV, in various parts of London and with quite different services and support, ensuring that many women were given the opportunity to participate. Each workshop lasted for about two hours and was recorded, transcribed and anonymised. In addition to the recordings, creative outputs were collected using an adapted body mapping methodology. The workshop was structured flexibly, with core activities and additional discussion points that were used depending on group dynamic and flow of discussion, hence, each workshop varied slightly.

The workshops involved 18 participants in total, divided into three workshops: two of 5 women and one of 8. Participants were all aged ≥50 years, with 13 aged 50–60 years, four aged 60–70 years, and one aged 70–80 years. Fifteen were of black African origin

and had migrated to the UK, and three were white British and born in the UK. The time since diagnosis with HIV varied from 7 months to 27 years, with most participants having been diagnosed for 10–15 years.

Full thematic analysis of the workshops is ongoing, but initial analysis indicates that women experience a range of challenges as they age and have significant concern over how they will manage as they grow older. Isolation and loneliness were major themes, and many other themes that emerged link directly to these issues. Women reported loneliness and isolation both as current experiences and a central concern for the future, exacerbated, or potentially exacerbated, by challenges including access to services and support, stigma, discrimination, and disclosure. Many participants linked this to increasing barriers to access social support and services, citing cuts to funding as a concern:

There used to be one [support group] but now these days because of the cuts you cannot get funds, funding, and it is putting us down because we don't meet anymore, we are just locked indoors. We don't socialise, there is no way we can meet men, unless if we go in those groups so you just, you know, like we are just waiting to die. No life. Just eating, going to the toilet and that's it. Very, very depressed. (Black African woman, aged 50–60 years)

Participants frequently described the value in peer-support groups as sources of social support, as a place to go and a reason to go out, to meet similar people and to share challenges. This value was increased by challenges in disclosing HIV status, and the barrier this presented for some participants to finding support from other sources. For some women, this was linked to fears of, or actual, experiences of stigma and discrimination. In particular, such experiences were a cause for concern in accessing non-HIV specialist health and social care:

Me, I hate my GP, I hate them... they are not knowledgeable about HIV... If I go to the GP the GP says don't tell me about HIV because I don't know anything. (Black African woman, aged 50–60 years)

Me, I think about being discriminated upon, in case you go to care, what is it... sheltered accommodation, then if the carers know that you are HIV, the stigma is just unbearable. (Black African woman, aged 60–70 years)

This was also linked to worries about losing the ability to self-manage medical care and treatment, and the loss of control over disclosure, which may occur with ageing or the onset of conditions such as dementia:

I always think of the time when I'll start losing my senses, not being able to do things for myself, that alone kills me. I personally, I would say, if I had to go, I don't want to get to that age where someone will have to give me my

medication... I mean because of the stigma.
(Black African woman, aged 50–60 years)

The vast majority of participants described themselves as single, and the subject of intimate relationships was not raised much, though some participants stressed their desire for mixed support groups to provide an opportunity to meet men. Where the subject of intimate relationships did arise, participants indicated a sense that their HIV status was a barrier to romantic or sexual relationships, or that the challenges of managing HIV and growing older extinguished interest in pursuing relationships.

You see one of the things that I mentioned at [HIV clinic] to do with ageing, because they said to me about relationships, I said 'oh I don't think I could possibly have a relationship'... I couldn't possibly tell anybody... well this is what, she didn't actually say it like that, she said no, 'you'd be surprised,' she had a smile on her face when she said it. I said I just couldn't, I just, I just don't feel like I could. I'd feel, it's that stigma thing, I'd feel like they would automatically assume that I was a promiscuous woman, and I would just wanna die so I thought, I'd rather do without really. (White British woman, aged 70–80 years)

Participants also described a sense of feeling fortunate in having access to good treatment and care, and being able to live into older age, but were keen in many cases to stress the need for social support to complement the medical care they had access to.

Findings from stakeholder interviews

Ten semi-structured interviews were conducted with key stakeholders, including HIV consultants, researchers, advocates, service providers and policy specialists. Interviews took around 30–45 minutes, were recorded and a synopsis developed for analysis. The semi-structured interview guide was developed based on the emerging findings from the creative workshops, as well as the literature review and participatory literature review, in order to explore stakeholder's reflections on the issues identified by older women living with HIV as well as in the evidence base. Stakeholder interviewees are identified by their professional role, and numbered to differentiate between them.

In keeping with the views shared by older women living with HIV, participants in stakeholder interviews reflected that ageing is a key issue within HIV but must be understood broadly, as encompassing social and social-support issues, beyond the clinical experience. As one participant noted:

That's because we've won a lot of the major battles clinically, we have drugs that work, they are relatively free of side effects. We know how to achieve virological suppression. We've

done all of that stuff and we've done it successfully, and patients are now living, they're going to live a normal life expectancy. So we're entering an era where the scope of our clinical work has had to broaden, and it's not really about managing HIV, it's managing everything that comes alongside living with HIV for a long time. (HIV consultant 1)

Specific challenges for women ageing with HIV identified by participants included: loneliness and worries for the future, adequate provision of social care and access to the health system, successfully managing comorbidities, providing appropriate health care through HIV clinics, and uncertainty.

The definition of 'ageing' in the context of HIV was highlighted as challenging, both in the provision of joined-up care and services across a health system that predominately defines 'older' differently, and in research, where participants are often in their 50s, and so findings may not reflect the needs and experiences of older people living with HIV.

Participants who are involved in providing support services for people living with HIV described both the necessity and the popularity of services specifically for women. There was some disagreement over whether a specific focus on women was necessary in ageing research or services. One HIV consultant suggested that as experiences were broadly similar between men and women, services should not be differentiated:

In a funny kind of way I think sometimes it's a disservice to women to make their care exceptional. I think it swings far too far the wrong way. (HIV consultant 2)

Others, though, felt that it was important not just to create services for women, but to ensure their inclusion in research and visibility in advocacy, where there had often been gaps:

There hasn't been a cohort of women coming alongside them if you like, so I think the numbers of women in those positions of power at that age are fewer and their voices are harder to hear and to recognise. And that is an inevitability of the epidemiology of the epidemic in this country, that when you start to talk about older people and their advocacy and their needs, it's nearly always an older gay man who comes to the fore or has the conversations, rather than a woman. (HIV consultant 3)

The need for enhanced visibility was also linked to a sense of being invisible that was felt by women living with HIV. For example, one researcher said:

Conceptually I think it is partly to do with the fact that there is just so little out there in terms of our understanding, so I think women quite often aren't as represented in research, they

aren't as represented in a lot of, just, considerations around HIV policy. There was definitely a sense in the women I spoke to [in a national study of ageing and HIV], they felt that they were invisible, that nobody consulted them, that people didn't understand living with HIV from their point of view. So there was definitely a sense of them being like the forgotten people or the invisible people. (Researcher 1)

Discussion

In both the workshops with older women living with HIV, and stakeholder interviews with participants who work to support them, there emerged a clear sense that women's needs are not sufficiently understood; there are gaps in evidence, support, and services for them. For women growing older with HIV, the uncertainty surrounding ageing, long-term HIV treatment, and wider health implications can be challenging to face, and there is a need for more resources and priority to be given to providing targeted support. Loneliness and isolation are already a significant challenge, and many women expressed concern that this would increase as they grew older. Women's voices are not sufficiently heard and included in research, policy, advocacy or service design on HIV, broadly, and ageing specifically, and this should be addressed with urgency to ensure that women are supported to age well with HIV.

Conclusions

Ageing with HIV is increasingly a major topic in HIV research, policy and advocacy. Yet the different experiences of ageing women compared to men are sometimes missing from that picture. Women have significant concerns about ageing, often linked to uncertainty and lack of knowledge or support, and this should be prioritised to address in future research and policy agendas. Moreover, as women are often unheard and unseen in HIV and ageing research or discussion, there are missed opportunities to learn from about how women have navigated ageing successfully and adapted to changing needs. As services adapt to changing needs and an ageing cohort, in an increasingly challenged funding environment, preserving support and spaces for women will be vital, as will ensuring women's voices are heard to shape the future of HIV services and support in the UK.

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