


# 'It feels like my visibility matters': Women ageing with HIV overcoming the 'violence of invisibility' through community, advocacy and the radical act of care for others

Women's Health  
Volume 18: 1–9  
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DOI: 10.1177/17455057221095911  
journals.sagepub.com/home/whe  


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## Abstract

**Objectives:** A participatory qualitative study exploring women's experiences of ageing with HIV in London, United Kingdom. The research considered how the concept of 'community' was relevant to women's experiences and what constructions of 'community' could be discerned in the experiences, accounts given and discourses employed by older women living with HIV.

**Methods:** The research presented in this article was conducted as a PhD study between 2015 and 2019. The study was structured in multiple and overlapping phases, and adopted a feminist and participatory approach. The methods used in the research were as follows: participatory literature review, participatory creative workshops, policy review and stakeholder interviews, life story interviews, and a participatory analysis workshop.

**Results:** Eighteen women living with HIV aged over 50 participated in creative workshops and fourteen women in life story interviews. Women's experiences of ageing with HIV are shaped by intersecting identities, community responses, and personal connections. Ageing with HIV brings challenges, added to and augmented by other difficulties women face in their lives, but women draw on individual and community assets in order to adapt, cope and thrive. Belonging to a community of women living with HIV and a broader community of people living with HIV created a vital space of safety, in which women found support, advice, and meaning.

**Conclusions:** Women ageing with HIV countered the 'violence of invisibility' through forming community with other women living with HIV, rejecting stigma, and enacting a personal form of advocacy through care for others.

## Keywords

advocacy, ageing, community, HIV, participation, women

Date received: 30 September 2021; revised: 4 March 2022; accepted: 29 March 2022

## Introduction

Women living with and ageing with HIV face intersecting stigma and discrimination, on the basis of HIV, age, gender and, for many women, race, ethnicity and immigration status.<sup>1</sup> The experience of growing older with a stigmatized condition, in an ageist, sexist, and racist society, impacts women's experiences in significant, overlapping, and reinforcing ways. To claim, publicly and proudly, ownership of a stigmatized identity and belonging to a stigmatized group, is a radical act of refusal and self-care, that was replicated in different ways in the stories shared by women

living with HIV in a study conducted in London between 2015 and 2019. In this participatory, feminist-oriented study, women aged over 50 living with HIV described the intention, and value behind their visibility as women living with HIV, whether as activists in national media, in peer

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support groups or in personal relationships. Regardless of the stage upon which their visibility was set, there was a clear shared sense that visibility had value, for themselves and for others. In this article, I discuss the meaning and intent behind visibility for older women living with HIV, and how it connects to community belonging and care for others. The implications of this for advocacy, and research as a form of advocacy, are also discussed.

### *HIV and ageing in the United Kingdom*

Advances in HIV treatment and associated care mean that people diagnosed promptly with HIV can expect a near normal life expectancy and to remain in good health.<sup>2</sup> Consequently, more people are growing older with HIV. The research presented in this paper was conducted between 2015 and 2019 in London, United Kingdom. At the time the research was carried out, 39% of people accessing HIV care in the United Kingdom were aged over 50 and this proportion was increasing.<sup>3</sup> The rate of new diagnoses of HIV was increasing for older people, with 20% of new diagnoses in people aged over 50 in 2017, compared to 11% in 2008.<sup>3</sup>

Women accounted for 29% of the total population of people living with HIV in the United Kingdom.<sup>3</sup> The specific needs, priorities, and experiences of women living with HIV in the United Kingdom are under-researched and under-prioritized.<sup>1</sup> While the evidence base on ageing and HIV is growing exponentially, the study presented here aimed to explore women's experiences in particular.

As women living with HIV age, they may be affected by increasing co-morbidities and health conditions associated with ageing. This includes healthcare needs linked to ageing in the same way as women not living with HIV might experience, such as cancers, diabetes, and frailty.<sup>4,5</sup> In addition, HIV and/or long-term HIV treatment may cause or exacerbate conditions such as kidney and bone density problems.<sup>6</sup> The psychological impact of ageing, mental health conditions, and polypharmacy may also affect older women living with HIV.<sup>7-9</sup> Women may also develop social care needs linked to mobility or physical health issues, or the impact of dementia or related conditions.

The social and psychological impact of HIV may introduce further complications, for example, through social isolation and lack of support,<sup>10</sup> stigma creating barriers to care and support,<sup>11</sup> and the challenges of negotiating a potentially unplanned-for older age.<sup>8</sup> Women diagnosed in later life may struggle to adapt to and accept an unexpected diagnosis.<sup>10</sup>

In addition to challenges related to ageing, women living with HIV face broader barriers linked to socio-economic and other factors. Stigmatization of HIV creates barriers to access testing, treatment, care, and support.<sup>12</sup> Socio-economic factors including poverty and unstable housing impact on adherence and treatment outcomes,<sup>13</sup>

partially accounting for higher rates of poor treatment outcomes among women compared to gay men.<sup>14</sup>

### *Visibility, stigma, and discrimination*

The visibility of women living with HIV has increased in recent years, largely thanks to the visible advocacy of women living with HIV. For example, in 2019 Public Health England produced their first ever data report focused on women and HIV,<sup>15</sup> in response to advocacy building from a national study, 'Invisible No Longer', led by two third sector organizations.<sup>1</sup> This study responded to the invisibility of women living with HIV across HIV prevention, care, and support and aimed to highlight the priorities and needs of women in this group.<sup>1</sup> It did so in similar ways to the study presented in this article, through recognizing the intersectional experiences of women ageing with HIV and through the participation and advocacy of women living with HIV in shaping and producing research.

As this study aimed to explore the experiences of a diverse, under-represented, and often invisible group, I adopted participatory methods to centre women living with HIV in the research, through participatory literature review, workshops, interviews, analysis, and dissemination. I suggest this approach to research is in itself a form of advocacy, seeking to challenge and change inequities in epistemic production and visibility. This responds to the advocacy demands of women living with HIV, articulated elsewhere in this collection, for research that prioritizes the concerns of women living with HIV and explores their experiences holistically.<sup>16</sup>

In workshops and interviews with women living with HIV and stakeholders involved in working with women living with HIV, the invisibility of women living with HIV, especially older women, was frequently highlighted. Ageism, sexism and HIV-related discrimination can interact to decrease the visibility of older women living with HIV and to limit their involvement in research and advocacy by creating risks to participation. The UK HIV response has historically been shaped by an epidemiological approach that does not consider women as a group, and leads to research, services and data that do not focus on women as a class or on gender as a social structure impacting the experience of HIV.<sup>17</sup> The form and impact of HIV stigma for many women is gendered, interacting with gendered ideas of appropriate behaviour for women and judgements formed based on these sexist ideas.<sup>18</sup> Ageing too is a gendered process, including biological processes such as the menopause, as well as social expectations, norms, judgements and experiences of ageing.<sup>19,20</sup>

### *Research questions*

In this article, I present findings from a study exploring women's experiences of ageing with HIV, with a focus

**Table 1.** Summary of participants in participatory creative workshops and life story interviews.

| Participants         | Workshops         | Interviews       | Total         |               |
|----------------------|-------------------|------------------|---------------|---------------|
| Age                  | 18                | 14               | 32            |               |
|                      | 50–60             | 60–70            | 70–80         |               |
|                      | 25                | 6                | 1             |               |
| Ethnicity            | Black African     | White British    | White other   | Black British |
|                      | 22                | 8                | 1             | 1             |
| Time since diagnosis | Less than 5 years | Five to 10 years | Over 10 years |               |
|                      | 2                 | 6                | 24            |               |

on visibility and advocacy as an overarching theme that was identified in the experiences and narratives women shared in this research. The main research question explored in this study was: ‘What are the experiences of women ageing with HIV in London? How are these experiences understood and expressed?’ A number of sub-questions were also explored, including: ‘how are these experiences mediated by gender, sexuality, ethnicity, migration status and experiences, or other factors?’ The study was constructed broadly, recognizing that the evidence base on women’s experiences of ageing with HIV was limited, and that intersectional experiences shape and inform the experience of ageing with HIV. First, I describe the methods, then I present results, organized by three themes: persistence; participation and personal connections; and, resilience. Within and across these themes, visibility was a unifying thread, as women described building community and supportive connections with peers as an embodied form of advocacy, predicated on care for others, and a rejection of stigma and the violence of invisibility.

## Methods

The research presented in this article was conducted as a PhD study, in London, United Kingdom, between 2015 and 2019. The study was structured in multiple and overlapping phases, and adopted a feminist and participatory approach. The feminist approach adopted was informed by an epistemology that centres subjectivity and privileges story as a valid form of data<sup>21</sup> and a feminist methodology that understands gender as a function of how we perceive our own experiences and form relationships and communities.<sup>22</sup> Participatory approaches aim to transfer greater power to the research participants, and situate the researcher and participant on a more equal footing, including through acknowledging the subjectivity of the researcher.<sup>23</sup> The methods used in the research were: participatory literature review, participatory creative workshops, policy review and stakeholder interviews, life story interviews, and a participatory analysis workshop.

The participatory literature review involved two women living with HIV, recruited through targeted outreach to

women engaged in research on ageing and HIV. Participants reviewed the findings from an empirical literature review on women, ageing and HIV to identify gaps and areas for further exploration in the study. The participatory literature review was conducted by Skype, and followed a semi-structured guide.

Three participatory creative workshops were conducted, with 18 women participating. Participation was open to women living with HIV aged over 50. Participants were recruited through third sector organizations who also hosted workshops, as well as through open calls shared on social media and in relevant newsletters and discussion forums. The workshops included icebreaking and group activities, facilitated discussion using focus group methodologies (with a semi-structured focus group discussion guide), and the creative exercise of body mapping, adapted from a manual developed in South Africa with an HIV support group.<sup>24</sup> Key elements of this process were adapted into a short, individual activity. The mapping process involved six stages: drawing the body; using symbols and pictures to illustrate where you have come from; using symbols and pictures to describe where you are going; describing your support base; drawing on physical pains and marks; and finally drawing on emotional pains and marks. After moving through the six stages and completing their body maps each participant narrated their map, without interruption. This narration was included as verbatim data in the analysis.

Ten stakeholder interviews were conducted with participants including clinicians, researchers, service providers, policy analysts, and older women living with HIV with an additional professional involvement in services, research or policy. Participants were recruited based on a stakeholder mapping exercise. Interviews were semi-structured and informed by a review of relevant policy. The policy review considered the policy context of HIV and ageing, building on a comprehensive review published in 2014 by the organization 2020 Health<sup>25</sup> and including official and grey literature. The review explored the policy context related to ageing with HIV, following the 2013 Health and Social Care Act, which made significant changes to the commissioning and delivery of HIV care and services.

Fourteen life story interviews were held with women aged over 50 living with HIV. Recruitment for the life

story interviews was diversified through different channels and networks. I created a flyer, summarizing the research and what participation would involve, with a contact number and email. I also sent a letter to HIV support organizations, requesting their help in recruitment. In addition, I shared recruitment information on Twitter, and the UK-CAB forum. Multiple organizations supported recruitment, in particular Body and Soul, an HIV support organization in North London, which runs a popular weekly support group. Women who were aged over 50, living with HIV, and living or accessing HIV services in London were eligible to participate. After expressing interest in the study, women were screened to assess the following criteria: age, ethnicity, length of diagnosis, migration experience, sexuality, relationship status, employment status, and whether they had children. This information was used to select a diverse sample of participants and ensure a range of experiences were reflected in the data, although as a small qualitative study, it was not possible to be representative.

Life story interviews create space for a more balanced, wide-ranging and participant-led interview than semi-structured or structured approaches.<sup>26</sup> Interviews opened with the prompt 'where would you like to begin?' and additional prompts were used only as necessary, as participants shared their stories. Prompts included 'how would you describe yourself?'; 'how has HIV shaped or influenced your life?'; 'is a sense of community important to you?'; 'do you feel you are in control of your life?'

The final phase of this research was participatory data analysis, conducted through a workshop with four older women living with HIV, based on a participatory analysis process described by a social sector impact organization and adapted to this project.<sup>27</sup> Participants analysed transcript excerpts, developed and grouped codes and explored meanings and themes from the data.

All data was transcribed, anonymised and stored in accordance with ethical guidance. This study was reviewed and granted ethical approval by the University of Greenwich Research Ethics Committee (UREC), reference 14.4.5.6. UREC reviewed and approved participant information sheets and informed consent forms, as well as data storage and other considerations. All participants provided informed consent to participate in the study, after reviewing a participant information sheet and time to ask questions. Consent was provided in writing at the outset of the data collection (workshop or interview) or in advance through soft copy (stakeholder interviews).

In keeping with good ethical practice, anonymization was the first step, implemented during transcribing: no names were ever included in any transcript, and transcripts were checked for additional potentially identifying details to anonymise.<sup>28</sup> I then followed the three main steps of analysis identified by Creswell and Poth (2017)<sup>28</sup>

as organizing the data, coding and condensing codes to generate themes, and representing the data, noting that these steps are not fixed or linear. I used NVivo 11 software to code all workshop and life story interview transcripts. Rigour in the research was supported through participant-checking of transcripts, reflexive engagement throughout the process, reporting of verbatim quotes from participants, and participatory analysis.

## Results

### Participants

Results presented in this article predominantly draw on the workshops (including body maps and accompanying narratives) and life story interviews. Themes are presented that were identified in the narratives shared by women ageing with HIV, and in the analysis of this data by women ageing with HIV. Additional reflections from stakeholders are also considered.

Women aged over 50 and living with HIV were recruited to the participatory creative workshops and life story interviews, through social and other media, and support from third sector organizations who facilitated dissemination of recruitment materials. Participants were selected to ensure diversity across age, ethnicity and length of diagnosis with HIV, as well as other facets of identity.

Eighteen women participated in workshops. Thirteen women were aged 50–60, four aged 60–70, and one aged 70–80. Fifteen participants described their ethnicity as Black African, and three as white British, and correspondingly 15 had migrated to the United Kingdom, while three were UK-born. Of the 15 who had migrated to the United Kingdom, 12 were born in East and Southern Africa, one in West, and Central Africa and two did not answer this question. The time since diagnosis with HIV varied from 7 months to 27 years, with most participants having been diagnosed for 10–15 years. A summary of participant demographics in both the workshops and life story interviews is included as Table 1 below.

Life story interviews were conducted with 14 women. Seven described their ethnicity as Black African, five as white British, one as white other, and one as Black British. Nine were migrants to the United Kingdom. Twelve were aged 50–60, and two aged 60–70. Two identified as bisexual. One woman identified as trans. Length of time diagnosed with HIV varied from less than 5 years for one woman, 5 to 10 years for 3 women, and over 10 years for 10 women.

The data from the workshops (including body map narratives) and interviews were brought together and analysed, including through a participatory analysis workshop in which four older women living with HIV reviewed data samples and generated themes, informing the analysis.

## Themes

Analysis of women's narratives of ageing with HIV generated three themes: persistence; participation and personal connections; and, resilience. Women's experiences of ageing with HIV are shaped by intersecting identities, community responses and personal connections. Ageing with HIV brings challenges, added to and augmented by other difficulties women face in their lives, but women draw on individual and community assets in order to adapt, cope and thrive. The invisibility of women ageing with HIV, in research, policy and practice, was frequently highlighted by study participants, as a barrier and challenge for women to navigate. Claiming visibility and forming community were described as critical to overcoming these barriers and challenges, creating space and opportunity for women to live and age well with HIV.

### Persistence

Six women in the life story interviews used the phrase 'I'm still here', a complicated statement that resonated through many of the interview and workshop narratives. It captures a sense of celebration and also hardship. Negotiating an unexpected older age brings unanticipated challenges, including new health conditions, the loss of parents and friends, and other difficult life events. The uncertainty of ageing with HIV is experienced as a daily burden. HIV is not really survived, it is lived with, every day. In this context, treatment takes on a range of meanings, from something within individual control in lives otherwise subject to ungovernable forces such as the UK immigration system, to a reminder of all those that did not live long enough to access it, to a simple part of a daily routine. The experience of diagnosis and of HIV-related stigma and discrimination were traumatic or difficult life events for many women, as were the loss of loved ones, and experiences of violence, which also shaped women's stories.

Women in the participatory analysis workshop developed the concept of 'survivor conflict', to capture the conflicting emotions of feeling happy or grateful to have survived but also struggling with feelings of loss around opportunities, plans or relationships that changed because of HIV. 'Survivor conflict' is a concept that captures the complexity of persisting despite HIV and other challenges, making meaning and building connections while reconciling the losses that HIV engenders and the psychological struggle of unexpected survival and unanticipated older age. 'I'm still here' echoed through many women's stories, as an expression of surprise, achievement and also loss. Preparing for dying after an HIV diagnosis prior to access to effective treatment had exacted an emotional and psychological toll that continued to influence women's lives and choices, from feeling unable to plan more than a couple of years ahead, to continuing to live with

accommodations made at that time such as, in one example, giving a different family member's surname to a child to facilitate an anticipated adoption after the mother's expected early death. The concept of 'survivor conflict' is evident in the narratives told by women who have lived long-term with HIV. The process of receiving a terminal diagnosis and going on to survive, and adapting to a life with HIV and to an unexpected old age, brought a range of complex emotions and challenges into women's lives.

### Participation and personal connections

Belonging to a community of women living with HIV and a broader community of people living with HIV created a vital space of safety, in which women found support, advice and meaning. Supporting other women, in particular women diagnosed more recently or who were experiencing other challenges, provided a sense of purpose for many women, both broadly in their lives, and in the specific process of finding meaning in HIV itself. Women's personal communities, defined as a community formed of an individual and their connections involving social interactions of various kinds,<sup>29</sup> importantly included children, partners, family and friends, as well as women living with HIV. Each personal community was necessarily unique, and the role HIV played in blocking or expanding connections within each women's personal community varied.

Connections with other women living with HIV evoked both a personal and a political community for many women, who described belonging to a community of women living with HIV in terms of a political act, caring for others as a way of reclaiming a stigmatized identity and overcoming marginalization.<sup>30</sup> Participation was rooted in community belonging, providing emotional, social and practical support in a mutual, symbiotic process in which the experience of living with HIV is a collective one. This went beyond community formation as a response to stigma, and beyond the practical exchange of information to a full, positive account of a community based on shared identity but also on meaningful connections.

Many women talked about wanting to make a difference for others. Often this was within the supportive framework they themselves had benefitted from: women they met at support groups had shown them it was possible to live well with HIV and they wanted to do that for others. It was somewhat less frequently framed in typical advocacy terms of campaigning, public speaking and related activities, though that did feature for some women. A unifying thread between all the forms of advocacy, from individual to societal level, described by women in their interviews was the centrality of story. Stories, told, shared and heard, are the core of shifting perceptions of HIV, both for those living with HIV and in wider society.

Research itself, as an opportunity to tell your story and to contribute to evidence that supports change, was framed

by participants as a form of advocacy. Understanding the research process as advocacy included, for some participants, placing responsibility on the researcher to act on what they had shared, from sharing findings to advocating to those in power.

Interpersonal advocacy, using your story and experiences to directly inform or influence another individual, featured heavily in women's narratives. Some women, such as this participant at a participatory creative workshop, talked about telling her story to inform professionals and others living with HIV:

. . . one thing that I have found positive is that we are living examples that HIV cannot define you, to a younger generation who are living with HIV if they saw us, if we went and gave them our testimony that always give their hearts, encourages them, it motivates them, that is one thing that I've found.

Political participation or advocacy were also important to many women, who often expressed different motivations as well as challenges. Yvette, a 58-year-old black African woman diagnosed with HIV for 16 years, struggled with the technical language used and the expectations placed on community members to understand it. Alice, a 68-year-old white British woman diagnosed with HIV for about 8 years, alternatively, was drawn in by recognizing that her background and skills enabled her to be 'useful', by sharing information with her peers and communicating in ways that they could understand.

Rebecca, a 64-year-old white British woman, was diagnosed with HIV while in prison, 30 years prior to the interview. She was involved in both Positively Women and the International Community of Women living with HIV, advocating for the rights of women living with HIV in the United Kingdom and internationally. She described her motivation to advocate for women and to be part of a global movement for women's rights as having been somewhat surprising, as she had not previously identified with feminism or as an activist. Instead, she was motivated by realizing there were barriers to women accessing support in mixed-gender spaces where they felt uncomfortable speaking openly, and that women faced different issues such as caring for children. Her story reflects a different form of feminist advocacy rooted in care for others.<sup>30</sup>

Participating in clinical trials, engaging with medical students and informing care and practice were also important to some women in this study, who saw these activities as a way to make a difference. The desire to make a difference also motivated participation in other forms of research. Each woman who joined a workshop or an interview came with her own motivations for doing so, and all demonstrated an awareness of the recording, the role of the researcher and the aims of the study, as well as their own aims in taking part. Some talked about wanting to make it easier for other women like them, in the hope that the

research would have positive outcomes in terms of knowledge or services. In some cases this was made explicit, through direct requests to the researcher. As described by Corinne Squire in her work with people living with HIV in South Africa, this also reflected an understanding of the researcher as a conduit or channel to an audience, to authority figures, and to change.<sup>31</sup>

Beyond the formal participation of research, women described the value in being visible and sharing their stories. Asked to reflect on what she might change in her life, if she could go back, Patsy a 52-year-old trans women, diagnosed for 24 years, said,

You know, I have to say that, there does feel like there's some value in my life, the work I do. For more than me. So, it feels like my visibility matters, at this particular time in history. I'm not over-blowing my importance . . . but at the moment it's quite important to be me and be visible. And all, everything's that happened in my life, not having a womb, being diagnosed at the end of year one, I mean in a way there's a kind of poetic beauty to that. You know, which is uncomfortable, which is, which seems spiteful, but actually there's a quiet poetic beauty that enabled me to become good at advocacy.

Being visible enables personal connection with other women living with HIV. In their narratives, women described finding meaningful connection and emotional, practical and psychological support in the community of people living with HIV. In part, the meaning and value of this community was found in the opportunities it provided to help others, by sharing experiences, passing on knowledge, and collectively making change.

### *Resilience*

Coping with 'survivor conflict', HIV and other aspects of life was enabled and informed by assets, including community belonging, acceptance of HIV, 'sense of coherence' and 'resistance resources'. A 'sense of coherence' is defined as the extent to which an individual feels they can manage their life, their life is meaningful and they are equipped to face challenges.<sup>32</sup> Resistance resources are the tools or circumstances individuals have that support their resilience, including coping strategies, beliefs, social support, and economic security.<sup>32</sup>

In their life stories, women described tools and resources that support them to live, cope and adapt to HIV, in different ways. These included faith, strength, purpose and independence as well as the experience of having grown through difficulties. There were significant differences in participants' socio-economic status and resources, with immigration particularly key in determining women's experiences, due to poverty and the lack of agency associated with insecure immigration status. The extent to which participants felt or described a 'sense of coherence' was informed by their acceptance of their HIV status, perceived

ability to plan for the future, capacity to manage health and health status, and sense of control over their own lives and choices.

Women's stories included loss, violence, poverty and bereavements that impacted their lives, wellbeing and coping. How women responded to and accommodated these challenges is important to understand, in particular to inform better support. Community played an important role for many women in coming through these difficult experiences. Women credited community and a sense of belonging and social, emotional and practical support with allowing them to process their HIV diagnosis and learn to live well with HIV, as well as providing wider support in their lives. This community is a vital asset for women ageing well with HIV.

## Discussion

Speaking at the 2018 annual conference of the British Sociological Association, the academic Professor Akwugo Emejulu described the 'epistemic injustice' that shapes who gets to speak, to be heard and to produce knowledge. Emejulu described how women of colour participating in activism against austerity struggled to break out of the frame of victimhood and 'otherness', an exclusionary frame that enacted the 'violence of invisibility' against those excluded from epistemic production. A similar violence is enacted against women living and ageing with HIV when they are excluded from the dominant narrative about HIV, from advocacy, from active roles in research, and in their personal lives when stigma and discrimination close doors and create barriers.

Visibility as a deliberate act, on a continuum from interpersonal relationships through to public platforms, is a counter to the violence of invisibility and a claiming of agency and voice. It is also a form of advocacy, which Emejulu and Bassel<sup>30</sup> describe as women who are invisible and made 'other' coming together through a shared sense of 'care' which opens up space for advocacy and for collective action:<sup>30</sup>

For these activists, we can think about care as both a praxis – theory informed action – and as prefiguration – a process of becoming and creating new political subjectivities. To understand care as praxis is to recognize how *caring about Others* is a radical act. *To care about Others* requires the development of a political imagination that takes seriously the lived experiences of the most marginalized. (p. 114)

Emejulu and Bassel<sup>30</sup> suggest that this process of becoming makes possible collective and political action and solidarity. The findings presented in this article indicate the breadth and complexity of women's experiences as they grow older with HIV, navigating challenges, supporting others and persisting in the face of loss and difficulty. Throughout the narratives that women shared, the

principle of 'care for others' underpinned the collective and communitarian experiences of women living and ageing with HIV and their participation in advocacy. To form personal connections with others sharing a stigmatized or marginalized identity is to reject stigma, both internal and external, as a collective act of mutual care. To love someone *like you* is to assert that *someone like you* is entitled, deserving, worthy of love. This care for others involves 'rejecting neoliberal, racist, sexist, xenophobic, homophobic, ableist frameworks that govern [their] everyday lives' (p. 115).<sup>30</sup>

The 'care' that women described includes but goes beyond empathy and concern. Through caring for others, and for themselves, women who experience exclusion and dehumanization claim their own agency and value and engage in a political process of activism, in defining new ways of being and collective action based on solidarity.

This resonates with the stories women told of belonging as a radical act of rejecting social stigma and claiming shared identity and experiences through community, and through that, supporting other women and making wider change. Participants often described HIV community as important, as it provided a space in which they could be honest, safe and understood. For some, this was specific to women living with HIV, while others found community with men living with HIV also.

This community emerged in structured settings such as support groups, but also through other services for people living with HIV like choirs and meal services, which were valued for providing a different way to experience community. Community could also be found online, and through connections on social media.

A range of factors influenced women's sense of belonging to an HIV community. Time since diagnosis appeared to have an impact, in particular as those more recently diagnosed often described more reliance on HIV support groups and formal services, while longer-term diagnosed women often described moving from accessing to providing support. However, this is an imperfect measure to use, as Sara, a 55-year-old white British woman diagnosed for 28 years, continued to regularly attend and value a support group, while Alice, diagnosed for 8 years, sought to inform and educate others by becoming an 'expert patient'. Instead, the role and form of community women described as accessing and valuing was influenced by a broad range of factors, including other forms of capital such as immigration status, employment and economic position.

Engaging with and being a visible member of an HIV-related community informed women's sense of coherence and was described as a vital resistance resource. It enabled women to persist in the face of difficulty and acted as a site of care, both given and received. The value of being visible, of belonging to and contributing to a shared community and shared identity, was indicated by women in this study as an important part of living and ageing well with HIV.

## Conclusion

Women living with HIV described feeling left out of prevailing narratives about HIV, and experiencing intersecting stigma and discrimination based on HIV status, sex, gender, race and other identities. The violence of this enforced invisibility was recognized and rejected by the women living with HIV who participated in this study, through caring for other women living with HIV as a collective and radical act. Women recognized the value and impact of their own visibility, whether as advocates on a public platform, or as an individual reassuring a woman newly diagnosed with HIV that living well was possible. The feminist tenet that 'the personal is political' resonated throughout these narratives, in which care and solidarity formed a political subjectivity.

Every woman described her feeling of being supported as consisting in also providing support, a mutual exchange in which community members contribute as well as receive, and in doing so create a shared identity and belonging. This resonates with the work of Emejulu and Bassel<sup>30</sup> on the politics of becoming, described earlier in this article, where through care for others who share a status that is stigmatized, a collective political subjectivity is developed as a refusal of the dominant hierarchy.

The concept of 'community' was relevant to women in this study, and is defined through personal communities with HIV community at the centre, formed through shared identity and experiences. Women's conceptions of 'community' differed, including persisting and newly emerging connections and connections that changed over time. HIV community was important in many women's personal communities, and belonging to an HIV community, connections to other people living with HIV and peer support were understood as forms of activism. Even women who did describe participating in typical advocacy activities such as media engagement and public speaking, including Alice, Patsy and Yvette, described not just their motivations but the activities themselves as being for support to and connection with other people living with HIV.

As the HIV response becomes increasingly biomedicalised, the space for collective and community responses becomes more contested.<sup>33</sup> In this study, women defined their experiences not as patients within a biomedical paradigm, but as part of a collective and community. It has been argued that the shared experience of HIV stigma is insufficient to form community bonds.<sup>34</sup> In their narratives, women defined belonging to an HIV community as more than a response to stigma, but also as a shared identity and community of care. At diagnosis, women may seek HIV community due to fears of stigma, but they also seek the support and advice of those with shared experience, and find friendship, mutual support and ways of adopting and adapting an HIV subjectivity that refutes

stigma and embraces shared identity. Women did not describe their experiences as patients or clients, or exhibit gratitude, as other studies have found,<sup>35</sup> instead they articulated their desire for better drugs, fewer side effects, reduced stigma and improved experiences for women living with HIV. This suggests an activist, collective form of citizenship.

Outside of funding of specific support services, no participant talked about political decisions, national policy, budget priorities or any of the macro systems or actors normally understood as relevant to advocacy. Instead, these women situated their advocacy within their own lives. By living well, telling their story and supporting others, they were rejecting the stigma society attached to them and, in doing so, undermining its foundations. When who you are is stigmatized, being who you are is a radical act. The personal is political.

## Acknowledgements

The author expresses sincere appreciation and gratitude to all the women living with HIV who participated in each stage of this research, as workshop participants, life story interviewees and in the participatory literature review and data analysis. All research is a collective endeavour and belongs to those who bring their stories to it – thank you for sharing your stories with me. The author also thanks the supervisors who supported this PhD research: Peter Keogh, Elizabeth West, John Smith, and Claire Monks.

## Author contribution

**Jacqui Stevenson:** Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing.

## Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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