



"I was not meant to be here, and I'm still here": a feminist, participatory and assets-based exploration of women's experiences of ageing with HIV in London

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Acknowledgements

This research was a collaborative effort with women living with HIV who contributed their time, experiences and expertise as participants and co-producers, and I would like to acknowledge and thank them for their contributions and support. This research summary was reviewed and co-developed by participants in a dissemination event held in June 2019, and I am grateful for their help and involvement.

About the research

This research looked at the experiences of women aged over 50 who are living with HIV. As HIV treatment has improved, more people are getting older with HIV. This can lead to challenges, such as coping with stigma, menopause or other health conditions, but women are also coping and doing well with HIV. To explore both positive and negative experiences, this research looked at the tools, strengths and strategies that women have and use to be able to live well.

The study started by looking at the existing research on ageing, women and HIV, to find out what is already known, and what needed more research. Women living with HIV participated in this process by discussing how the research that has already been done compared to their own experiences.

The approach used in this study focused on research to make change, or to do 'advocacy'. This model used stories and story-telling to understand women's experiences of ageing with HIV and to make sure that women were both involved in and shaped the research themselves – so it was done with them rather than being done to them or about them.

To carry out the research, a range of different activities and methods were used. This included a creative activity called body mapping, where women were asked to draw themselves and their experiences to help them tell the story of their experiences with HIV. It also included life story interviews, a conversation with a researcher where women were asked to tell the story of their lives and how HIV had been a part of it.

The researcher also spoke to experts including women living with HIV, advocates, HIV doctors and other researchers, and looked at policy documents, to understand how women's experiences of ageing with HIV fit within a bigger picture of medical and social support and policy.

The research found three main themes or ideas: persistence, participation and personal connections, and resilience.

In this context persistence refers to successfully meeting the specific challenges presented by living with HIV. For some women who were diagnosed with HIV or AIDS before the introduction of effective antiretroviral medication, this included being given a terminal diagnosis (being told that they would die because of HIV) and then surviving. This brought many different emotional and psychological challenges. 'Survivor guilt' is a term frequently used to describe how people might feel because they did not die but people they knew did. Women described their experience differently as 'survivor conflict', as they feel no guilt. This was a new concept developed in this research and named by women living with HIV. 'Survivor conflict' is about feeling happy or grateful to have survived but also struggling with feelings of loss around opportunities, plans or relationships that changed because of HIV. Many women used the phrase "I'm Still Here" to describe surviving and getting through challenges, while dealing with these emotions.

Participation and personal connections were important to helping women to live and age well with HIV. Belonging to a community of other women with similar experiences of HIV was an important way of sharing and learning the skills need to survive and thrive.

Resilience is about coping, and the research found support from other women living with HIV helped women to learn how to manage living with HIV effectively. But challenges like not having immigration status or living in poverty in a time of austerity made it hard for some women to cope.

Overall, the research offers new ideas about how to do research and it also reveals some of the priorities, needs and experiences of older women living with HIV.

Recommendations for research and practice

- 1) The experiences of older women living with HIV are under-addressed and under-recognised, and while this study has aimed to fill the gap in literature, there is much work still to be done. In the context of cuts to services and funding, there is an urgent need to ensure that needs are understood but also to explore how individuals and communities are coping, and where this can be better supported. Importantly, this should include community, and not just an individualised understanding of what it means to live and age with HIV.
- 2) The concept of 'survivor conflict' warrants further research, to understand more its resonance to older women living with HIV and how it is experienced. Additionally, understanding more about how women can be supported to cope with 'survivor conflict' would be valuable.
- 3) The impact of side effects, pain and menopause were significant for many women, and additional research to explore both how these are experienced and how women might be better supported to cope with or mitigate them, would be recommended.

- 4) Policy development is needed to ensure that the needs of an ageing HIV cohort are met. Women's specific needs are under-researched, and require further targeted exploration.
- 5) There is an ongoing need for investment in HIV support services and organisations, recognising the vital role these play in providing the framework through which HIV community operates. This research also indicates a need to review and reconsider how this framework of support is provided, with a desire articulated by many older women living with HIV for more informal spaces, open and social activities.
- 6) For women diagnosed prior to access to effective HIV treatment (either pre-1997, or diagnosed in a geographic location without accessible treatment), the burden of 'survivor conflict' is significant, and indicates a need for further, specialised support. There is also a huge amount to learn from these experiences, which are unique in the context of HIV but may have parallels for other health conditions.
- 7) The shock of diagnosis was described in similar terms by women diagnosed at very different stages of the epidemic, indicating the lack of knowledge about HIV and treatment in the wider population, and a need for more support at diagnosis. Involving women living with HIV in providing this support would be invaluable, as demonstrated by the prevalence in women's stories of meeting and being supported by other women living with HIV as the pivotal moment in learning to adapt to HIV.
- 8) This study could have been improved by recruiting more women aged 60 and over, and more women diagnosed recently with HIV, so further research including more women from each group would be beneficial.
- 9) Comparative study with men, in settings outside London (including other UK settings and other countries) and with other health conditions would all potentially be of value.

We Are Still Here – campaign with Sophia Forum

I have partnered with Sophia Forum to develop a campaign based on and building on these research findings. 'We Are Still Here' is launching as a national campaign shaped and led by older women living with HIV, to highlight the issues that affect them and call for greater voice and visibility for their experiences, priorities and needs.

To find out more about the campaign, see <https://sophiaforum.net/index.php/we-are-still-here/>

OLDER WOMEN WITH HIV: OUR JOURNEY



Additional information

To find out more about the research, please see the links below or contact Stevenson.jacqui@gmail.com for copies of any of the publications or any queries.

- *Aging, HIV and the Body: Women's Experiences in Body Talk, Whose Language*, 2019. Editors Jennifer Patterson and Francia Kinchington. Cambridge: Cambridge Scholars.
- 'Survivor conflict' how women adapt to surviving with HIV. Poster presentation, AIDS Impact Conference, London, 2019
- *Reaching the Right People: Reflexive Practice to Support Effective Recruitment, Participation, and Engagement in Research With Communities Affected by Stigma.* (International Journal of Qualitative Methods, 17(1) Dec 2018)
- *Women, ageing and HIV: using participatory literature review to address gaps in the evidence base.* Oral presentation, ASSHH Conference, Amsterdam, 2018.
- *Women ageing with HIV: "I was not meant to be here, and I'm still here." How women have adapted to living long-term with HIV.* Oral presentation, ASSHH Conference, Amsterdam, 2018.
- *How are the needs of women ageing with HIV understood and addressed in HIV policy and practice in the UK?* Oral presentation, ASSHH Conference, Amsterdam, 2018.
- *Women ageing with HIV: "I was not meant to be here, and I'm still here." How women have adapted to living long-term with HIV.* Poster presentation, International AIDS Conference, Amsterdam, 2018.
- *Ageing with HIV: Participatory and creative methods to explore the experience of ageing with a stigmatised condition.* Oral presentation, British Society of Gerontology Conference, 2018.
- *Stigmatised identity and contested communities: women, HIV and belonging.* Oral presentation, British Sociological Association Conference, 2018.
- *Women's experiences of ageing with HIV in London.* (HIV Nursing, 17 (4) Winter 2017)
- *Older women living with HIV in the UK: discrimination and broken confidentiality.* Article, OpenDemocracy, April 2017.
- *Growing older with HIV: what does this mean for women?* ASSHH seminar, London, 2016.
- *Reaching the right participants: reflexive practice to support effective recruitment.* Oral presentation. Qualitative Methods Conference, Glasgow, 2016.

