GROWING OLDER WITH HIV: WHAT DOES THIS MEAN FOR WOMEN?

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IN THIS PRESENTATION...

- Overview of doctoral research project
- Emerging findings from participatory workshops
- Discussion of the opportunities that feminist, participatory and narrative methodologies offer to address the research gaps for women with HIV
WOMEN’S EXPERIENCES OF AGEING WITH HIV: PERSONAL, CLINICAL AND SOCIAL CARE RESPONSES TO THE CHALLENGE OF AGEING WITH HIV IN THE UK

Research in four phases:

1) Literature review
2) Participatory creative workshops
3) Policy review and stakeholder interviews
4) Life story interviews
WOMEN, AGEING AND HIV – WHAT DO WE KNOW?

• “I’m just wrong for HIV: female, 60s, middle class. Some people can’t deal with it.”

• 66 year old woman living with HIV in an interview in the Guardian
PARTICIPATORY WORKSHOPS

- Three workshops held, with support for recruitment and hosting by third sector organisations: Food Chain, NAZ and AHPN
- Organisations shared recruitment materials directly with service users.
- Workshops at Food Chain and AHPN were exclusively participants recruited through links with those organisations
- NAZ workshop was mixed: NAZ service users and participants recruited externally, primarily through UKCAB posting
WORKSHOP STRUCTURE

• Introductions, ground rules, purpose of research
• Initial discussions: what does ageing mean, positive and negative aspects of ageing with HIV
• Body mapping
• Narrative feedback on body maps
• Additional discussion points: what services do women living with HIV need, how do women meet their own needs, where do you access support, what are the main issues this research should explore
DEMOGRAPHICS

- 18 participants
- 13 were aged 50-60, 4 aged 60-70, and 1 aged 70-80
- 15 Black African, 3 White British
- 15 migrated to the UK, 3 UK-born
- Of the 15 who had migrated, 12 were born in East and Southern Africa, 1 in West and Central Africa
- 15 described themselves as single, 1 as married and 2 as widowed
- 10 described themselves as having a disability, 5 no disability (1 did not answer, 1 responded ‘sometimes’
DEMOGRAPHICS – LENGTH OF DIAGNOSIS
FINDINGS

- Multiple themes emerging from the workshops, defined by participants’ contributions
- Not yet fully developed...
- Sharing a few key themes that came up
FINDINGS - ISOLATION

- 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. [Fo2]

- So you are now lonely, you are now fearing death. You start feeling my heart, and oh maybe, maybe tonight I'm dying, because loneliness, most of the people here they live on their own, loneliness is, is sickening. For me its loneliness, I just get up, I don't feel I'm worth living. Loneliness is very bitter. [Ao2]
FINDINGS – CHALLENGES OF AGEING

- The last one is other ailments, things like abnormal smears, cervical cancers and personally like me I think I've been living with a type of cancer for 16 years now. [F01]

- You get agitated easily because you just think you are now 50, what's the next stage? [F05]

- For me you forget things easily [F05]

- For me I can't even sleep on the bed, I have to sleep on the floor... I don't know, it's easier for me to go to toilet. [A03]
FSNDINGS - MENOPAUSE

- It's like you are more likely to have your menopause early [Fo4]
- when I started on medication I was getting into my menopause so I didn't know who hits who. Was it HIV or my menopause? [No2]
- When I getting menopause, things are, I can't even sleep, too much hot. When I add on the stress which I have on my HIV, on the top of that the, the menopause, is also a problem. [Ao2]
• ... I'm very conscious of what goes in my body and to actually put these medications in my body. The first day I took it I just couldn't stop crying. I thought, all this shit going in me. But of course then I had to say 'but if I don't take these I'm going to die eventually, a nasty death. [No5]

• I'm 70 years old and I was diagnosed approximately 19/20 years ago. I've been on medication for all of those years with the exception of the first year. And kept reasonably well, kept reasonably healthy and quite happy and quite fit, and it's only been over the last sort of two years that my health has started to deteriorate a bit which is really concerning me. I am concerned about the long-term effects of medication [agreement]. I was taken into hospital in November and diagnosed with kidney failure which was apparently due to Tenofivir, long-term use of Tenofivir, so I was taken off Tenofivir immediately and I've been put onto another combination which is a temporary combination while my kidneys. [No3]
FINDINGS - RELATIONSHIPS

- Another thing, you are not interested in any relationship [F01]
- 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. [N05]
Me I hate my GP, I hate them... they are not knowledgeable about HIV. Today I had a GP appointment this morning. When I was trying to explain about my aches and pains, he said to me, he asked me what I think causes the pain. I said - that's why I've come here, if you can refer me for MRI scan by now go to the hospital. He said to me he has already referred me to pain management, for pain management, but because the pain management they deal with thousands and thousands of patients they are unable to get back so if I have to wait. Imagine waiting when you are in pain... If I go to the GP the GP says don't tell me about HIV because I don't know anything. [F01]

My GP and my consultant they discuss together, they, when I go to the consultant all my test and results and everything, they do something for me, something very good for me to be honest, my GP is very good. [F05]
FINDINGS - SERVICES

- There used to be one but now these days because of the cuts you cannot get funds, funding [Fo2]

- Yes. And so we feel left out. We people with HIV we feel like we don't exist anymore to be honest with you. Our voices are not heard. Because the services like we used to get we don't get it. [Fo4]

- Most of the support groups are closing down, because of the cuts that come from the government, so now we don't know how we are going to end up. [Ao3]
And the other thing which we have not mentioned here is like when you're ageing with HIV there's always a chance to be judged... where we come where we meet, some places you go if they know your status it's difficult. So sometimes you just prefer to be on your own. [F01]

if it was cancer it would be easy to talk about because you know you're going to get sympathy but HIV is a different disease, you know. People don't want to associate with someone who has got HIV. [No2]
FINDINGS – DISCLOSURE AND SUPPORT

• In case I'm now living with HIV at this age, fifty something, and I’ve not disclosed to my children. That is again another challenge... because you risk two things, let me say one thing, rejection or acceptance. You find that they can choose to reject you or accept you. So how would you know that they are going to accept you? [F04]

• I only told my family, my son and my daughter. And they've got someone to discuss it with, you know, I didn't leave them hanging on their own, so they've got partners to discuss it with. And my sister, who has her daughter to discuss it with. I don't feel that I need to tell anyone else. [N05]
FINDINGS - CARE

- We're worried about care homes for people with our disability. In other words they will mistreat you. [Fo5]

- 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. It will be now, people don't want to know, so what more. We are now old, we're now, we are old now, we are getting old, you know. We don't have our own carers, or people who are younger, who are willing to care for us. [Ao6]
FINDINGS – ADDITIONAL CHALLENGES

- Inadequate or inappropriate housing
- Lack of financial resources: the benefit that I get cannot even sustain myself for the duration that it's meant to. So you find that you end up having no food in the house or cutting the meals. [Fo4]
- Work, particularly having to stop working early due to physical needs
- Migration: So being a migrant in a different country is also a challenge, and living with HIV, and being a woman has its own bit as a challenge. [Fo4]
I would feel great if people, you know, think about us. Try to make us happy. Try to make us think that we still have a life ahead. It's like you know people are just neglecting us, we are just at home, now the only happiness which I have is to talk to someone on the phone and nothing more nothing less. We need to be active, we need people who can encourage us, help us to meet all the needs we want so that we can move on. You know it used to happen but it is stopped and the way it has stopped it is so depressing. Everywhere has just stopped like that. They are saying no one is funding. We used to come here for cooking, we used to do things but right now they will give you so many things that if you want you have to go through this and that which we cannot afford to do that. So we are just trapped at home, of which it's very depressed. You know, depression. [Fo2]
FINDINGS
I used to have a big farm for my life. I used to have good shops and big holidays. I used to fly to different countries for holidays with my husband and kids. I used to have posh cars. When I heard the news that I am HIV infected, I was shocked.

The only people who gets me going is church people and UK positive. Besides that, I am a loner with no sense of direction.
REFLECTIONS

• Combining creative and narrative methodologies facilitated greater sharing and situated the ‘ageing’ discussion within the life course

• Some reticence initially about the creative activity but once women got started this dissipated and most participants described it as a good experience

• The body map narrative sharing was often very emotional and participants shared more and more honestly than in open discussion

• Feminist and participatory approaches supported participants to ‘own’ the process, directing their own discussion whilst I played a less active role
THANK YOU!

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