

Silenced Voices- the experiences of women living with HIV in the UK who are subject to domestic abuse

Lynda Shentall, Doctoral Candidate

Supervisory Team

Director of Studies Dr Khatidja Chantler

Dr Rachel Robbins
Dr Ali Roy

Introduction

Very early stages of data analysis

Overview

1 case study

Learning for the future

Sophia 

Silenced Voices

Background, the area is under researched in the UK, much global research but this is not generalizable to the UK

Therefore the intersection is poorly understood, as are the health and social impacts.

Reviewed studies at the intersection found high levels of domestic abuse among women living with HIV, between 52-89%. Current UK statistics estimate that 27% of women will experience domestic abuse in their lifetime

There is no in depth research at the intersection

Dhairyan R, Tariq S, Scourse R and Coyne KM, (2013) Intimate partner violence in women living with HIV attending an inner city clinic in the UK: prevalence and associated factors. HIV Medicine 2013, 14 303 -310

Hutchinson J. and Perry, G. (2012) Gender Based Violence. Violence as a cause or consequence of HIV for Women in England. A feasibility Study regarding a potential national investigation.

<http://sophiaforum.net/index.php/2013/02/14/house-of-lords-sophia-forum-report-on-gbv-hiv-launched/>

Silenced Voices

- Much HIV research tends to focus on men, medication and is quantitative.
- Domestic abuse research has undertaken much in depth research but women living with HIV have not been a feature of this research.
- This research aims to give in-depth insight into the intersection of HIV and domestic abuse
- The research may be relevant to other areas, such as women subject to immigration control and women with disabilities.

Aims of the research

Based on the literature review and the identified gaps in the literature the aims of the research are;

- To explore what the significance of an HIV diagnosis might be in the experience of domestic abuse.
- To explore the impact of disclosure/ non disclosure of HIV and/or domestic abuse on the woman and her family.
- To explore specific health and social impacts of domestic abuse for women living with HIV
- To identify perceived helpful support strategies for women in order to begin to formulate accessible and relevant service responses.

Methods

- Recruitment took place at the HIV clinics at the Hathersage Centre at Manchester Royal Infirmary. 494/1894 patients are women.
- Clinical setting chosen.
- Ethical approval granted for 10 -15 face to face in depth interviews. Approval for Arabic and French interpreters to be used.
- The ethics approval journey was a long one.
- Recruitment was purposive
- I sat in the clinic twice a week for about 8 months of last year
- Recruitment was not as difficult as might be expected.

Methods

- Interviews semi – structured and a narrative approach was taken.
- I had contact with a number of other women where interviews did not ultimately take place.
- Interviewees – voucher and travel costs
- All interviews audio recorded, NHS ethics committee would not allow member checking of the interview transcripts
- Transcription, I am doing all of the transcription myself, this brings me close to the data and means that I am fully immersed in it.

Overview to date

Fourteen women have been interviewed, each once and no interpreters were used. Interviews ranged in length from 30 minutes to two hours

Though there was ethical approval to meet participants elsewhere all interviews were in the hospital setting.

All of the women interviewed were black; 13 were African from 9 different countries. They were aged between 24 and 53 and 11 of the women were mothers.

The women discussed a diverse experience of domestic abuse.

Each individual interview yielded rich data and insight into the subject area.

This study presents the experiences of a highly marginalised group who have not been evaluated in this way before.

Data analysis, using the voice relational method of Gilligan and Brown

With this method the transcripts are read four times, this lends itself also to the intersectional nature of oppression in the lives of the women interviewed

Polyvocal, reading for

- Narrative
- Self
- Relationships
- Culture

Brown, L. M. & Gilligan, C. (1993) Meeting at the Crossroads: Women's Psychology and Girls' Development. *Feminism and Psychology* 3(1) 11-35
February 1993.

Joyce – *to be honest with you*

- 34 year old woman from a South African country. She has two children.
- Joyce came to the UK about 9 years before the interview, aged 25, on a student visa. She met her partner in the UK, age 26, shortly before a planned trip to Canada. He was African, from a different country. When in Canada he begged her to return to the UK to be with him, which she did. Once back in the UK he became increasingly controlling. He took her passport and she was locked in their house and not allowed to go anywhere at all unless with him. Even then they rarely went anywhere at all.
- Joyce's visa expired. She had no social contact and intermittent contact with her family back home. She fell pregnant with their first child and her partner would not allow her to access ante natal care.

Joyce – *to be honest with you*

- Joyce presented at a hospital in labour and was diagnosed HIV positive 5 years ago. Joyce had her first baby, a caesarean section and an HIV diagnosis within a few hours. Once discharged she was again not allowed much medical care. Her partner tested negative.
- He began moving them to hotels and campsites. She fell pregnant again and presented at a different hospital, in labour, having had no antenatal care. During this hospital stay she disclosed her partners behaviour but then retracted. With the second child there was more attendance at health care but always with her partner present.
- Health care staff tell Joyce she is lucky ... to have her partner ...she says it makes her want to cry when they say this

Joyce – *to be honest with you*

- After being in this situation four years, Joyce is allowed to go to one hospital appointment alone and discloses her partner's behavior, subsequently, several days later, she is helped to leave by the police and social services.
- She initially tries to retract what she has says but social services are clear that the children will be taken into care if she decides to stay and she leaves.
- After leaving she recounts reacclimatising and finding it difficult to walk or leave her accommodation.

Joyce the narrative

- Captivity, also an escape narrative. Some very atmospheric narration of the captivity, *he wanted to hold me to my weakness,*
- *Then when this thing came in (meaning the HIV) aaaaah he became powerful, he became strong*
- Rapunzel / Room, Emma Donohue
- Primo Levi *he was training me to accept*
- A measured and non sensationalized narration

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Joyce – presentation of self

- This is a happy, joyful, interview, Joyce laughs often in the interview and at times she whoops with laughter, for example when describing her defiance of her partner, *It became a habit, whatever he said, I would just oppose him, even if it is true*
- Acceptance
- Controlled, understated and matter of a fact narration. There is no recounting of regret or injustice, rather an acceptance of what has happened. *I would rather choose life*
- Joyce is also accepting of her HIV status, though not open *you just pray that it does not come to you but at the same time you know that if this thing comes to you how you are going to handle it*
- Joyce seems very much focused in the present

Joyce – relationships

Professionals *You are lucky, why do they always mention this word lucky?*

Joyce's children *it was my children, really, that saved me because if it wasn't for them then I would have accepted my life with him*

The partner, a shadowy but omnipresent figure *he is there, laughing, passing jokes and they would think that he is a good person but they don't know (laughs)*

Mother and sister at home

Joyce's has two close friends from her time in the refuge.

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Joyce, culture

- Joyce describes her unfettered childhood and contrasts it with her children whilst they were captive
- I wondered if the process of captivity had erased some of Joyce's sense of self and culture
- The importance of the refuge
- Dichotomy of acceptance and resistance, resisted moving back to Africa
- She talks of her plans to visit her home country with her children once she has passports

Tentative findings from all 14 interviews

- Far more data analysis to be done.
- Women living with HIV in the UK experience high levels of abuse
- The type of abuse experienced is diverse and wide ranging
- Intersecting oppressions is significant
- Immigration is a factor
- Domestic servitude and trafficking featured in the lives of several of the women
- Poverty in the UK and Africa was a factor
- Many of the women discussed their strong faith

Learning so far

- It was relatively easy to recruit to the study, being within the clinic was important
- When to interview, when not stopping interviews
- Vouchers and bus fare, incentives?
- Women want to tell their narratives

Thanks to my supervisory team, the women living with HIV who have participated in the research and many other people along the way.

Questions / discussion