I did not deserve this: The trauma of being diagnosed with HIV/AIDS for Zimbabwean Women

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Zimbabwe has one of the highest HIV infection rates in the world

- Total population 13 mil
- Estimated 1.3 mil people living with HIV/AIDS in 2007
- 680,000 women infected compared to 500,000 men
- 60% ARV coverage in 2010
- Peak prevalence rate of 29% in 1999
- Prevalence down to 14.2% in 2009 (in 15-49 year age group)

(Ministry of Health & Child Welfare, 2010)
Research questions, study design

1. What is the lived experience of being diagnosed & living with HIV on a daily basis for Zimbabwean women?

2. What are the meanings of being diagnosed and living with HIV/AIDS?

Study Design:
van Manen (1984, 1997)’s phenomenology - for data collection, analysis and interpretation of meaning
Sample

- Purposive sample of volunteer HIV+ women living in Harare, Zimbabwe
  - > 18yr and participating in the DART trial at UZCRC
  - Had known their HIV status for at least 12 months
  - Fluent in and able to read and write in Shona,
  - Participants recruited through an announcement at a support group meeting

- Sample size determined by data saturation
Study Setting: UZCRC
Protection of Human Subjects and Data Collection

Protection of Human Subjects
- IRBs, Consent in Shona
- Research assistant did preliminary screening, researcher obtained informed consent
- Used code names

Data collection:
- Demographic questionnaire
- Interview guide
- Tape recorded interviews in Shona, Journaling, recording verbal/nonverbal behaviors, personal thoughts
- Data transcribed verbatim, checked for accuracy, linguist translations
- Checked translations for accuracy
Data Analysis

 Phenomenological reflection
  – Read and re-read the transcripts- identified commonalities across cases
  – Data categorized into meaning units
  – Isolating thematic statements

 Phenomenological writing and rewriting
 Thematic analysis to uncover themes and dimensions
Study Participants

- 17 HIV + women,
- 29 to 54 yrs old, mean 40.7
- 4 to 20 yrs since diagnosis; Mean 6.6 yrs
- 11 widows; 2 married; 2 single; 2 divorced
- 13 mothers
  - 1 has an HIV+ child

Education
- 2 college educated school teachers; 6 high school graduates; 9 > 7yr education <11 yrs

Employment
- 2 school teachers, 3 housemaids, 8 informal traders, 4 were unemployed
Theme 1: Living with Suspicion of HIV/AIDS & Dimensions

Living with Suspicion of HIV/AIDS
- The meaning of women’s being diagnosed with HIV including their noticing symptoms, deferring testing until symptoms could no longer be ignored and seeking testing as factual confirmation of what they already believed

Dimensions
- Noticing symptoms
- Seeking testing as confirmation
Noticing Symptoms

Rosemary: ..... what was being said that there would be swelling behind the ear, so I checked at the back of my ear and found a swelling. I used to listen to the TV and hear it talked about… they would say if you develop this or that…..So I started examining myself, weight and complexion, and thinking about the fact that I was constantly falling ill, and being picky with food. I also started examining my husband and I started scrutinizing here (pointing at the neck), checking if it was healthy. I suspected and left it at that. When I was two months pregnant, my lips started turning red, and I really began to suspect….but when I left the hospital I went home and stayed.
Seeking HIV Testing as confirmation

**Rufaro**: I had seen how ill my husband was before he died… it seemed he had HIV. I had fallen ill, although I suspected it… when I went for tests, I had resigned to knowing my status and I suspected that I was positive, I was going for testing wishing to confirm whether what I suspected was true… I wanted to get tested because I suspected I had the virus … I wanted to know my status.
Theme 2: Sensing the engulfing anguish of an HIV/AIDS diagnosis & Dimensions

The physical and psychological torment experienced when women were diagnosed with HIV/AIDS

Dimensions
- Being-toward-death
- Concerning self with “what will happen to my children when I die?”
- Suffering illness
- Thinking about the injustice of being infected with HIV
Maidei: In my mind I thought I was dying...to me I was dying, so I started telling my mother what had happened... that I was nothing; I had no future...at that time I didn’t think that I would survive again or even get to six months alive, even a year. I only assumed that this was my death. I thought if one is said to be positive, they would die immediately after; since people are dying of AIDS so it meant I was also dying. I rushed to my mother to tell her that I was destroyed; I am dying as you see me here...I now have the virus, look this virus that you hear about in other families...the very disease you were talking about is not in other families only, ...it’s already in your family, I’m also dying of it.
Concerning self with “what will happen to my children when I die”

Julia: *I was now thinking about the family and wondering what would happen to my children, I have children. That is what bothered me most as a person who has children; you begin to ask how your children will remain, who will look after them? What will they do? Now that I have the virus what will happen to the children if I die… I was in pain wondering what I was going to do with those who were still growing, who was going to look after them*
Anna: I was losing weight, and having problems with food, and had thrush, I was always at the doctor, I would get some cream and would apply it, but after some time the thrush would come back, and I would go back…it comes and disappears, ..... then I came here, they took blood tests and CD4 counts.....I was examined by doctors Jar and Pascal and they were asking me if I had been admitted before; I said I had not, my CD4 count was 2. They asked me to go and stand up and I stood up and weighed 38kgs, my natural weight was 49kgs, such that if I walked and was tripped by a stump, or if somebody pushed me I would fall,.......when I used to go to bed before I started taking the pills, one would think there was something pricking on the bed…but there was nothing like that, but just that there was no flesh on the body and you just could not sleep. You would get up and sit, the whole body was just a bundle of pain…I lost appetite for everything.
Thinking About the Injustice of Being Infected

Nyasha: *My husband gave me the disease because he brought girlfriends… it was him who brought the disease, I said to him look what you have done, I wept continuously for 3 days saying I was a virgin when I got married, having preserved myself but look at what you have done… in the beginning I never imagined I would contract this disease….. I thought I was safe since I was a virgin when I got married, I was well-behaved, married well, I never suspected that I could become HIV positive… just hearing that someone was infected we thought they were prostitutes that is why they had it.*
So What?

This study sheds light to the trauma of being diagnosed with HIV/AIDS, and has implications for Nursing Practice, Education and Government Policy

- Nurses need to understand where the woman is in the disease trajectory, then design interventions based on the specific needs of each client
- The clients are traumatized and require the care of highly educated nurses who understand not only the disease process, but also the issues of gender and culture that are embedded in the women’s experiences
- Hodge-podge of testing sites and groups need uniform standards for counselors
Study Limitations

- Study was nested in a clinical trial
- Interviews were conducted in Shona then translated into English
- The researcher’s familiarity with the culture
- The researcher conducted only one interview, as she was unable to do member checks
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References:

