

Exploring reaction to HIV infection among older adults in Ga-Rankuwa, South Africa: Narratives of older people responding to HIV infection at the point of diagnosis.

Abstract

There is an increase in prevalence of HIV infection among older adults in South Africa. Due to focus on traditionally known HIV high risk groups this new emerging social group is being missed by public health practitioners. This paper was set to explore the reaction to HIV infection among older adults at the point of diagnosis. This study used a qualitative exploratory design that included a purposive sample of older HIV-infected men and women currently receiving HIV healthcare services from a treatment centre. The researcher recruited 12 participants, Seven women and five men who met the study's inclusion criteria. Face to face interviews were used to collect data. A thematic approach was used to analyse data. The study found that reaction of older adults following HIV diagnosis included: Anger and shock, Feeling suicidal, Blaming, Fear of stigma and discrimination, Loss of trust and intimacy, Fear of disclosure to new partners and Denial. There is need for an urgent attention to improve sexual health and HIV services to cater for the needs of older adults.

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Introduction

In South Africa, the prevalence of HIV infection among older adults remains high. Possible reasons for rising HIV prevalence in the older age group in South Africa include increased rate of new infections (1). It is important that people living with HIV are aware of their diagnoses, engage with HIV treatment care, initiate antiretroviral therapy (ART) and consistently adhere to ART to achieve effective viral suppression (1,2). Despite improvement in engagements rates there are still serious gaps evident at every stage along the HIV care continuum (3). The Centers for Disease Control and

Prevention (CDC) estimate that of the 25 million Africans living with HIV, 90% are not appropriately retained in HIV care; 63% are not taking ART; and 70% have detectable HIV viral load (VL) (4). Moreover, racial/ethnic disparities persist in many spheres of health outcomes with black sub-Saharan African communities disproportionately represented in the lower socioeconomic strata and high rates of undiagnosed HIV (5).

The present study focuses on older adults' black heterosexuals diagnosed with HIV infection as part of a larger study that was looking into adherence to ART by the same cohort in a study in Ga-Rankuwa in Gauteng Province. In line with the consistent National HIV behavioural Surveillance system of the CDC, the authors defined high risk heterosexuals as those with social connections in urban areas with elevated rates of socioeconomic deprivation and HIV prevalence (6). Heterosexual sex is the highest common route of HIV transmission in South Africa accounting for almost 60% of newly diagnosed HIV infections among both men and women (7). This has shifted the traditional notion where men who have sex with men have always been classified as a high-risk group and has always topped HIV infection statistics among different social groups (8).

Many people affected by HIV infection tend to present late at treatment centres raising the possibility of spreading the infection before getting treatment. For example, many heterosexual men commence treatment at a point where their CD4 count will be so low prompting faster progression to AIDS than men in other risk categories (9). Furthermore, heterosexual women living with HIV also exhibit delayed entry in care and treatment compared to men with attendant poor outcomes (10). Considering the factors that impeded or promote engagement with HIV treatment services, high risk heterosexual social groups are under studied compared to other groups such as MSM and individuals who inject drugs (11). This is because most public health researchers have focused more on generally known high risk social groups while lacking an accepted definition of heterosexuals as a vulnerable group.

Heterosexual older adults tend to think of HIV/AIDS as a problem not relevant to their age because they no longer worry about pregnancy and men are less likely to use condoms (13). On many occasions' heterosexual see HIV as an issue for known vulnerable groups such as MSM, sex workers and individuals who inject drugs (12). Such a mindset detracts many heterosexuals from engaging in regular HIV testing

uptake prompting shock and disbelief when they are infected by HIV. More importantly to note is the generally upheld notion that associates HIV with high stigma among many communities in the world at large including sub-Saharan African communities (13). This stigma comes along with high discriminatory practices embedded in different cultural practices. The discriminatory practices deter many people from taking regular HIV tests and can lead to distress and denial to early HIV infection.

Getting an HIV infection in later life is often a very hard issue to readily accept based on the notion of “its not for me, but for them” (14). This notion also drives older adults to pre-exclude themselves from any initiatives associated with HIV test and screening, making it difficult for them to engage with treatment and counselling services following HIV diagnosis. Considering the above discussed notions this paper was set to explore reaction to HIV infection among older adults at the point of diagnosis.

Methodology

METHODS

This study used a qualitative exploratory design that included a purposive sample of older HIV-infected men and women currently receiving HIV healthcare services from a treatment centre in a public hospital in Gauteng Province (15). This approach was determined to be appropriate as a means of gaining access to the inner world of older men and women in order to understand the issues affecting their reaction following a positive HIV test. Based on the day and time preferences of participants, interviews were conducted in a private room at the clinic by two research assistants: one female, and one male. The gender preference of interviewers was left to participants to enhance relaxation and sharing of silences during the interview (16).

POPULATION AND SAMPLING

Recruitment was achieved with the assistance of healthcare professionals treating older persons at an AIDS treatment centre in a public hospital in Gauteng Province. In the first instance, the researchers wrote a letter to the head of the treatment centre asking the centre to invite their patients to take part in the research. The head of the treatment centre, a senior professional nurse, then approached older HIV-positive individuals and requested their permission for referral to the researchers who had experience in collecting qualitative data. The researcher determined whether the

referred patients met the study’s inclusion criteria, informed them about the study, and obtained their written consent to participate. Only those patients who had expressed their willingness to take part in the research had their names forwarded to the researchers to organise and schedule an interview. The population of this study was purposively selected to include older persons (male and female) as they would best contribute the information needed for the study (17). The researcher recruited 12 participants (see Table 1); Seven women and five men met the study’s inclusion criteria. Participants had to be over the age of 50 at the time of being diagnosed with HIV and had been on ART for at least six months. Participants who had only recently been diagnosed, that is, within a period of less than six months, were excluded because of the possible emotional impact of discovering that they were HIV-positive (18). A saturation point was realised after interviewing 12 research participants.

Participants

Overall, older PLWHA were more likely to be married or cohabiting, although some had never married. All females were unemployed or retired, whilst males were unemployed or currently working part-time, and with little formal education; one male had a high school diploma. Only one participant had been recently diagnosed with HIV, while the participant who had known his positive status for the longest period had been diagnosed 15 years earlier (see Table 1).

Table 1: Participants’ demographic data

Participant	Gender	Age	Marital status	Education	Employment	Number of years diagnosed
1	Female	53	Widowed	Lower primary	Unemployed	6 months
2	Female	55	Divorced	Lower primary	Unemployed	5 years
3	Female	56	Widowed	Lower primary	Unemployed	8 years
4	Female	69	Never married	Lower primary	Unemployed	11 years
5	Male	53	Cohabiting	Primary education	Unemployed	7 years
6	Male	54	Never married	Secondary education	Unemployed	6 years
7	Male	56	Never married	High School	Unemployed	6 years

8	Male	59	Married	Primary education	Self-employed	15 years
9	Female	62	Cohabiting	Primary Education	unemployed	7 years
10	Female	63	Widowed	Primary education	Unemployed	10 years
11	Female	67	Widowed	Lower primary	Unemployed	9 years
12	Male	72	Married	Secondary Education	Part-time employment	13 years

DATA COLLECTION

Data were collected using face-to-face interviews. After obtaining informed consent from participants and furnishing them with an information sheet, face-to-face interviews were conducted by two experienced gender-segregated research assistants who were not involved in the main study procedures to limit biases (19). Interviews were conducted in the African languages preferred by participants. A semi-structured interview guide included open-ended, exploratory questions and additional follow-up probing questions that allowed participants to discuss the topics that were relevant to their experience (20). Domains of inquiry included issues of emotions, stigma, and disclosure. Data saturation was reached following twenty interviews, when no new categories or themes emerged.

DATA ANALYSIS

A thematic analysis was then conducted on the data in order to identify themes (21). Thematic analysis was conducted by the authors and a co-coder (an expert in qualitative research) who read the transcripts independently and jointly reviewed emerging themes in order to reach consensus on the interpretation of the data. The data were then analysed manually to identify emerging themes and subthemes that reflected the participants experiences following HIV diagnosis. This was followed by developing a code list that was used to establish themes.

ETHICAL CONSIDERATIONS

The study protocol was reviewed and approved by the Sefako Makgatho University Research Committee (**Ethics number: SMUREC/H/132/2017:IR**). Informed written consent was obtained after the study was explained to potential participants, including potential risks and benefits. The research participants were also given an information

sheet. Participants were also informed of the voluntary nature of the study and their ability from the study at any time or not to answer specific questions. Standard precautions were undertaken to assure the confidentiality of the data. All interviews were conducted in a private room within the HIV clinic or at the university, depending on the participants' preference. Codes were used in place of participants' names. Only the researcher and interviewers had access to the data.

Results

Following analysis of data collected several themes with regards to reaction of older adults following HIV diagnosis emerged, and included: Anger and shock, Feeling suicidal, Blaming, Fear of stigma and discrimination, Loss of trust and intimacy, Fear of disclosure to new partners and Denial.

Anger and shock

Participants narrated anger and shock following their diagnosis of HIV. They were angry that they were HIV positive and shocked that they will have a back lash from the community.

“When I got home, I told my family that I’m HIV positive and I’m going to kill myself..... I felt so angry with myself for not listening to health promotion messages” (male 55 years).

“Honestly, I was shocked and filled with anger knowing how our community views everyone who is HIV positive.... I just felt like taking my life to avoid experiencing nasty things waiting for me” (Female 60 years)

Feeling suicidal

The research participants reported feelings of being suicidal once they were told that they were HIV positive. Some presumed it as death sentence despite the availability of high quality anti-retroviral.

“When the doctor told me that I was HIV positive.....I just felt that I needed to jump over the cliff and leave this life because I just viewed this new situation as a death sentence” (Male, 65 years)

“When the news came to me that I was HIV positive I just said to myself there is no future for meall I need is kill myself before it kills me it is honestly a death sentence” (Female 69 years)

Blaming

Most of the research participants felt that their infection was caused by their partners not them. They expressed feelings of blame and exoneration of themselves from being potentially infecting their partners.

"I started blaming the women who infected me with HIV honestly I regretted why I had an unprotected sexual relationship with her" (male 56 years)

"..... Instead I developed hatred towards women, when I look at a woman, I get angry, I say to myself "this person has made me sick" (Male 59 years)

".....My partner infected me with HIV because he always infected me with sexual transmitted infections it was so embarrassing as we kept on going for treatment at the local clinic" (Female 58 years old)

Fear of stigma and discrimination

The research participants expressed fear of stigma and discrimination due to their new HIV diagnosis. They reported experiences of stigma among people who were HIV positive in their communities and felt that it was also going to happen to them.

"I felt like a big blanket had been cast on me.... I could not imagine living with HIV in my community where everyone will be stigmatizing and discriminating me for being HIV positive.... I knew it and I had seen it happening to others." (Male 67 years).

"I really got worried I had seen how people who were HIV positive were being treated in my community the discrimination the ridicule I could not stand it.... I just felt fear in myself" (Female 60 years)

Loss of trust and intimacy

Upon being informed about their HIV status the research participants reported loss of trust and intimacy. Some stayed for a long time without a partner.

I just felt that I no longer trust anyone and felt loss of intimacy, it took me a long time because I was not comfortable with men anymore, and I felt that they are not fair, like my husband (female, 55years).

When I was told that I was HIV positive I just I immediately lost my trust in women and intimacy..... I stayed for one year without having sex, because I said to myself women are the ones who infected me, so I must give myself a break. (Male 63 years)

Yes, I have decided that I no longer need a man in my life, I'm not interested, I thought my husband who passed away in November was the one because he was older than me, but he was not faithful to me; and then I decided to retire (Female, 68 years)

Fear of disclosure to new partners

The research participants found it difficult to disclose their HIV status to new partners for fear of losing them. They reported being in dilemma over their new relationships and HIV status.

"I was really in dilemma I felt that if I disclose that I am HIV positive my new partner will desert meon the other hand I was afraid that if he discovers it he will report

me to the police for not disclosing...honestly it was one of the most difficult time of my life” (Female 59 years)

“I was torn in between.... I just felt like keeping quiet about my HIV status knowing the stigma and discrimination of our community but my other thought was fearful of being reported once my partner found that I did not disclose to her my HIV status... It was really a hard time to make a decision” (Male 69 years).

Denial.

As a coping mechanism and prevention of stigma and discrimination, upon being told about their positive HIV status the research participants reported actively searching for an alternative diagnosis from traditional healers. They reported complete denial of the results from the doctor.

“I asked them not to take me to the hospital but rather to traditional healers. I once heard that if you get sick and they give you an injection you do not get healed. The traditional healer gave me Rooibos tea, I don’t know what did she mix it with, I did not get better and that was it, when I went back for the second time I didn’t find her, she disappeared” (Female, 69 years)

“I could not believe it; how can I be HIV positive of all the people.....I was convinced that the doctor was missing the cause of my illness I straight away went to the “Sangoma” African traditional healer who told me that I was ill because one my forefathers had committed murder and I needed to have a cleansing ceremony which I had but the illness never went away until I went back to the hospital for HIV treatment” (Male 60 years).

“When I was told about my positive HIV status I couldn’t believe it....I started to think about people who didn’t like me in the community and I knew that one of them must have bewitched me.... I had no option but to go to the traditional healer who confirmed my suspicion, but the sickness did not go away until I went back to my doctor for treatment”(male 72 years)

Discussion

This study set out to explore narratives of older adult response to HIV infection at the point of diagnosis. Participants responded differently when they were first informed of their HIV status.

Anger and shock following diagnosis of HIV can prevent the affected individual to engage with counselling and treatment services (22). The anger and shock emanated from the perception that they will be blamed by their communities for being HIV positive. Likewise, most of the research participants narrated feelings of anger and shock following their positive diagnosis of HIV. There is need for the sexual health

services to initiate concurrent programmes for HIV health promotion, testing and counselling services to run side by side in communities as a way of encouraging older adults to take up HIV testing while getting support from counselling services. Such a set up can encourage normalisation of testing and easy engagement with treatment services among the older adults (23). There is also need for the central government to roll out some HIV initiatives that are targeted towards older adults who seem to be slipping through the HIV prevention and testing safety net.

Suicidal feelings following HIV diagnosis is not new in the history of HIV infection (24). Such feelings were prevalent in the early 80s and 90s in many low- and middle-income countries where ART was very expensive to acquire. The research participants reported feelings of being suicidal once they were made aware of their HIV positive status. This was also exacerbated by the long-standing belief in communities that being HIV positive is equated to a death sentence (25). It is therefore important that sexual health promotion in communities should include clear information on availability of high quality ART and evidence of living a normal life expectancy following diagnosis of HIV provided the individual is taking ART as instructed by the medical professionals. More importantly resilience among recently diagnosed older adults should be inculcated through health promotion, community support and availability of counselling in communities.

Blaming of HIV positive individuals in communities has been reported in religious and secular organisations among others (26). Such a blame has deterred several HIV positive individuals from taking their ART leading to relapse and subsequent critical illness or death. The research participants blamed their partners for their HIV positive status. This feeling of blame undoubtedly had a lasting impact on relationships of affected partners with possible secondary impact on their health and well-being (27). It is therefore important that health promotion in communities should stress positive life after diagnosis of HIV between partners. The absence of such messages in community health promotion has led to blames and counter blames between partners. More importantly there is need to enlighten the communities on the existence of quality ART that leads to normal life expectancy to detract blame and arguments between partners which may result in negative health outcomes.

Stigma and discrimination towards HIV positive individuals have continued despite a concerted health promotion campaign against it (28). The research participants expressed fear of stigma and discrimination due to their new HIV diagnosis. Such a fear as alluded to earlier on can be a source of relapse and disengagement with treatment services following a positive HIV diagnosis. More inclusive interventions to reduce HIV stigma and discrimination in the communities are needed to accommodate newly diagnosed older adults' individuals in the community (29). Furthermore, the central government should strive to engage community leaders to tap their influence when fighting against HIV stigma and discrimination (30). This initiative is a tested and tried one in many communities and has yielded positive results.

Loss of trust and intimacy is usually experienced by partners who feel that they have been let down by their partners following an unexpected HIV diagnosis (31). The research participants reported loss of trust and intimacy in their partners sometimes leading to divorce or staying for long periods without partners following their HIV diagnosis. It is important that counselling services for couples should run alongside HIV testing centers to provide a one stop center for services (32). This can enable early intervention to prevent loss of intimacy and trust among couples following a positive HIV diagnosis.

Disclosure following HIV infection has always been challenging in many communities (33). This is more difficult in older adults than young couples because of living a long period of their lives without HIV (34). Disclosure or partner notification is a highly challenging issue among couples and potential couples living with HIV as this can cause disputes in the relationship. The research participants found it difficult to disclose their HIV status to new partners for fear of losing them. They reported being in dilemma over their new relationships and HIV status. It is therefore important that new initiatives to get read of HIV stigma should be explored. Such initiatives should be specific to the culture and orientation of the affected individuals.

HIV infection at a later age can lead to lack of assertiveness in disclosing status leading to eventual infection of partner and misunderstandings. (35). This is normally caused by denial of the HIV infection owing to community-based ant-sentiments against the condition. The research participants reported actively searching for an alternative diagnosis from traditional healers to make their condition acceptable in the

community and avoid a backlash that comes with stigma and discrimination (36). There is need to provide informative health promotion and information on the dangers of seeking HIV treatment late. More importantly traditional healers should also be educated around the symptoms of HIV so that they can quickly sign-post the affected individuals to HIV treatment centers without delay.

Implications for professionals working with older adults

It is important for sexual health professionals to investigate the HIV needs of older adults to make sure that they are not missed. More importantly sexual health promotion initiatives targeted at older adults to increase uptake of HIV testing need to be rolled out in communities.

Limitations of the study

This research was conducted in Ga-Rankuwa only and did not include other townships in Gauteng Province. In future a research including all big cities of South Africa is ideal to enhance comparison and possible generalisability. The research was purely qualitative in nature and could not therefore tackled issues that needed quantitative research methods. A research study utilizing mixed research methods in future can provide comprehensive findings covering the ontological and epistemological positions of both research approaches.

Concluding comments

There is need for an urgent attention to improve sexual health and HIV services to cater for the needs of older adults. Health promotion initiatives targeting older adults are needed to prevent negative sexual health and HIV outcomes following HIV diagnosis.

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Conflict of interest

All authors declare no conflict of interest

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