

# An Exploration of Perceptions on Quality of Life, Stigma and Resilience Experienced by Long-Time HIV Survivors in Rural Eastern Uganda

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## Abstract

The aim of our study was to determine experiences faced by individuals living with HIV over ten years in rural Eastern Uganda villages, their coping mechanisms and factors influencing their wellbeing. A focus group interview (n=9) was conducted in the Mbale district. Overall, three key themes emerged from the interview: 1) stigma, 2) support network and 3) (dis)empowerment. The discovery of having contracted HIV, that initially had a negative impact on the lives of the participants, seemed to have been a driving force on the empowering changes during the years. This qualitative study identified that with the relevant support and gaining financial independence, individuals, especially women, who experienced the shock, despair and disempowerment of being told that they were HIV positive were not only able to survive and carry-on living but were able to find a different freedom, independence and role within their families and close community.

**Keywords:** empowerment; HIV; stigma; support network; Uganda; well-being.

## Background

Globally, HIV and AIDS are a major public health issue [1]. Although a reduction in new HIV infections and deaths has been observed, Sub-Saharan Africa (SSA) remains one of the most affected regions with an estimated 70% of people of all ages living with HIV [1, 2]. Women and girls account for 25% of all new HIV infection cases despite comprising only 10% of the population [3]. In Uganda, the number of new HIV infections reduced by 62% from 140,000 in 2013 to 53,000 in 2019 [3, 4]; however, HIV/AIDS remains the third cause of death and disability (DALYs) [5]. In addition, living with HIV/AIDS is challenging for both the countries and the people living with the infection (PLHA), as they often suffer serious socioeconomic and psychological consequences [6].

Since 2004, when antiretroviral therapy (ART) was initially rolled out in Uganda [7], the country has been progressing towards reaching 90-90-90 testing and treatment targets [3]. The latter aims at having 90% of people living with HIV to know their status, 90% of these to be on ART and 90% of those receiving ART to be virally suppressed [8]. However, several factors namely poverty, lack of social support, living in rural areas, family disintegration, stigma, weak healthcare systems, drug side-effects and disclosure of HIV status have been cited as impacting on ART adherence [8, 9, 10, 11, 12, 13]. Indeed, HIV is highly stigmatized, compromising both treatment and prevention in resource-limited settings [14, 15, 16]. Stigma and discrimination are negatively affecting

HIV test-seeking behaviour, serostatus disclosure, care-seeking behaviour on diagnosis and quality of care provided to HIV-positive patients as well as affecting preventative behaviours (e.g. condom use) [17]. Stigmatization can lead to prejudicial thoughts, behaviours and/or actions on the part of governments, communities, employers, health care providers, co-workers, friends and families [17, 18].

In a review by Pantelic and colleagues of interventions aimed at reducing self-stigma experienced by people living with HIV in low- and middle-income countries, progress on self-stigma reduction in interventions that included ART provision, economic strengthening and social empowerment was observed [19]. However, interventions aimed to improve health awareness, stigma coping and behavioural change reported superficial changes in attitudes [19]. In addition, stigma reduction interventions failed to address social norms which shape individuals' attitudes and behaviours questioning the long-term implications [20]. Yet few evidence-based interventions on how to address stigma exist, as well as limited evidence on what it takes to change attitudes in the long term [17, 19, 20, 21, 22].

Different programmes and organizations in Uganda have been working to help the affected through network building, community mobilization, mass media awareness campaigns, factual knowledge transfer as well as providing basic care and support

to people infected with HIV through quality referrals

and regular follow-ups for ART adherence [23, 24]. However, studies aimed to assess quality of life and wellbeing among HIV outpatients are still limited [17, 25]. A review by Bhatta et al. (2017), aimed to assess the effect of social and behavioural interventions in improving the quality of life of HIV infected people receiving ART, concluded that social and behavioural interventions are likely to have a low or moderate impact on quality of life [25]. Thus, the aim of this study was to determine experiences faced by individuals living with HIV for 10 years or longer in rural Eastern Uganda villages, their coping mechanisms and factors that influence their wellbeing.

## Methodology

A qualitative approach was deemed the most appropriate way of exploring perceptions, challenges, and practices on a vulnerable group of

participants. Indeed, the participants were able to express their thoughts and share personal experiences. Within this social context, the participants were also able to respond to the views and comments of their peers [26].

## Sample

The sample comprised of both women and men born and bred in Eastern Uganda in the Mbale district (Figure 1). Individuals aged  $\geq 18$  years who had been diagnosed and lived with HIV for a period of 10 years or longer, were invited to take part by the Mbale Coalition Against Poverty (Mbale CAP) staff. The interpreting support was provided by a community worker employed by the organisation. Nine participants, 8 women and 1 man, agreed to take part in the focus group. In accordance with the current literature on focus group size, a sample size number between 8 and 12 is considered feasible [27].



Fig. 1: Map of Uganda

## Data collection and analysis

A semi-structured focus group interview was conducted with the participants in April 2018. A topic guide was developed from emergent themes found within previous studies [28]. The questions were peer-reviewed by experts from disciplines of public and global health. Minor amendments were then made to the order, syntax and wording of the questions.

The setting of the focus group interview was outside the house of one of the participants. Informed consent and permission to record were both obtained prior to the commencement of the focus group. The interview lasted approximately one hour and thirty

minutes. The focus group interview was conducted by both a facilitator (TF) and a moderator (HO). The facilitator asked the questions and was able to clarify, paraphrase and reflect-back what was discussed. The moderator made notes on the dynamics of the group and salient issues raised. The questions and answers were translated from Lugisu (local dialect) to English by the interpreter. The narrative data were transcribed verbatim. Nvivo was used in the analysis of the data in which nodes and sub-nodes were allocated. This process was undertaken independently by both the authors. Inter-rater reliability was then established in which a consensus was reached on the main themes.

## Ethics

The study followed the Helsinki Protocol [29] and ethical approval was obtained from the University of South Wales (USW) Faculty Research Ethics Committee. The main ethical principles of informed consent, confidentiality, anonymity and data protection were maintained. Participants had been approached in advance of the day of the focus group and informed of the aim of the study, whilst consent was given on the day of the focus group.

## Results

Eight women and one man of different ages (20 - 60 years old), all residents in the rural villages in the Mbale district took part in the focus group interview.

The themes generated from the data analysis highlighted the challenges, coping mechanisms and support experienced by the participants. It showed the journey, highs and lows, experienced by long-time HIV survivors born and bred in rural Eastern Uganda. The main themes can be grouped under three headings. The first theme, stigma, described the disapproval detected and experienced by the participants. The second theme described the support networks that helped the participants on their journey, while the third focussed on the shift from dis-empowerment to empowerment in which the illness experienced by the participants helped them to re-build a new life. Three sub-themes running through each of the themes were: family, community and HIV support groups as shown in Figure 2.

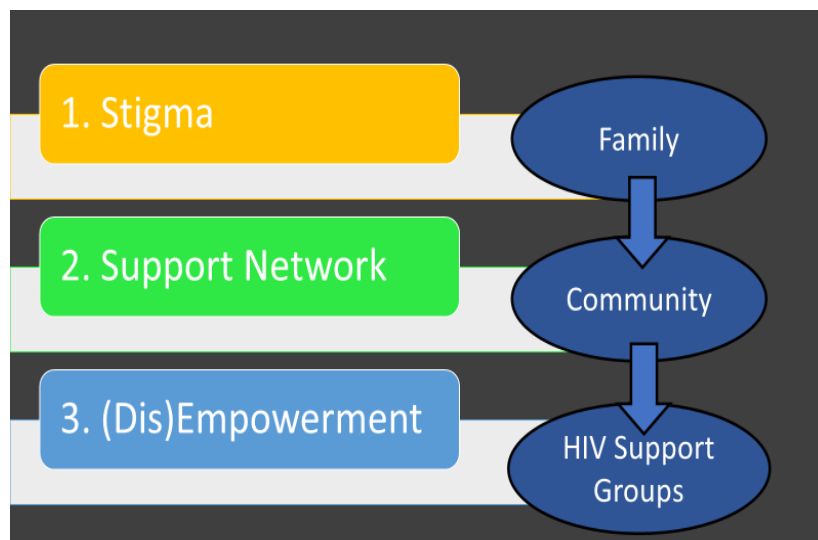


Fig.2: Themes and sub-themes.

### 1. Stigma

Although the majority of participants identified the husbands and partners as the source of infection (of themselves and their children) and often received a formal diagnosis after the death of the spouses, the first condemnation observed and experienced came from members of the family.

‘At first the relationships were worse; they looked at me as a disgrace ...’ (P3)

The community was also blamed for perpetrating stigma, as suffered by the brother of one of the participants.

‘I had a brother who was HIV positive so when he was a young father, when they (people) identified (that he was HIV positive) people pointing at him: he is sick, he is sick (people were pointing at him and saying that he is sick). He decided to commit suicide and left the children, so people fear to be identified

in public’ (P2)

The stigma experienced was identified as a barrier that stopped people from being tested or accessing the hospital for the medicines as well as living a full life.

‘I did not accept it very quickly; because of the stigma ...’ (P6)

‘But after being tested, they gave me the results. I had a sleepless night, I couldn’t sleep. I couldn’t imagine. I was just having nightmares.’ (P9)

‘They fear because people point at them, the fingers, you are sick, being sick ... so they do not want to be identified. They want to take (the antiretroviral medicines) in secret’ (P5)

### 2. Support Networks

The participants identified three sources of support. Even though relatives were blamed, they were also identified as a source of assistance. Participants

shared their personal stories:

'before I was tested, there was one of my cousin's children who came from the village who said we love you so much we want to take you for testing. Then I provoked the child by saying. I'm an old person why do you want to make a decision for me? Let me die. I don't want to go to be tested. I don't want to ...' (P4)

'At first people use to tell us that when you start on these antiretrovirals. They are very expensive; you have to pay a lot of money so I thought it's better not to start on those drugs as they are very expensive, and I cannot afford. But my father encouraged me so much to take these drugs so I can live for sometimes.' (P1)

The AIDS Support Organisation (TASO) was also identified as an important source of help for older and younger people who test positive.

'...the nurses told me that you are HIV positive. Then they introduced me to TASO the AIDS information centre for support. The AIDS support organisation which gives the antiretroviral to clients who have HIV.' (P8)

'There is a group in TASO which have the youth, so they have different appointments. They meet youth, the boys, the girls and interact and share how the drug is helping them. What they are going through their challenges they are having ...' (P7)

Finally, the religious groups, friends and their close community were identified as an invaluable source of care.

'They gave us medicines and we came back. I started to feel some strength but not very strong. When I used to take that medicine, I needed something to eat. When I continued to take the medicine, I would take the medicine, I became weak, I became dizzy. Then I started again worrying how I am going to continue with these drugs, which they make me very weak and dizzy. (Name of the friend) ... use to come and check on me. She was also sick but she use to come and visit me.' (P4)

'Even if we have drugs but we did not have people who care for us, giving us some support, we'd die.' (P3)

### 3. (Dis-) Empowerment

The discovery of having contracted HIV that initially had a negative impact on the lives of the participants seemed to have been a driving force on the empowering changes that the participants reported in the discussion. These changes were not only limited to advocating at community level for routine HIV testing or encouraging the use of ART among those found positive but also engaging their peers in

other preventative behaviours.

'I don't feel any stigma. I am also like now standing out to testify to my to other youth who are not yet tested. I encourage them to go and be tested. They know they have HIV status. I encourage those who have found out HIV to go on the drugs to live a safe life to live a positive life so I am moving preaching the gospel about HIV plus those who do not have, they should prevent it plus those who don't have should be tested, and taking the drugs ...' (P7)

'I have many friends. For some of my friends I try to give them condoms to prevent them from contracting the ... I give them condoms. I advise them the way to use them and I always tell them not to have sex without condoms.' (P9)

In addition, they managed to re-build their lives, found new ways to earn money which lead to a more independent life.

'I have changed because at first I was in their hands (relatives), they cared for me and bought my food but now that I've started working for my own, it has changed. I take care of my family and the relationship is good.' (P1)

'We try to sell some second-hand clothes, others sell tomatoes, others sell charcoal, cabbage, she has a sewing machine, she has a cow and takes it out to the grass, She has somewhere where she cooks chapattis and people buy.' (P3)

'Because when I was taking the drugs, I was thinking about death but now I met people who love me, who care for me. Now life has started to come, I was going to die. I believe in good things.' (P8)

'...I buy something what I want to eat, I eat. So, life is going well. I am taking the money and, in the evening, when tired I am going to sleep.' (P4)

## Discussion

This study aimed to explore the experiences faced by individuals living with HIV over 10 years in rural Uganda, their coping mechanisms and factors influencing their wellbeing. Three key themes emerged from the analysis: 1) stigma, 2) support network and 3) (dis)empowerment. Although participants had fallen victim to having contracted the virus from their partners/husbands or during pregnancy as a result of maternal-foetal transmission, fear to be tested as well as disclosing their positive serostatus was experienced by everyone along with an initial rejection from their close relatives and the community at large. Similar to other studies [8, 30, 31, 32, 33], stigma has been identified as one of the main barriers that stopped

people from being tested as well as revealing their status because of fear of being accused and ostracised. This is especially true among women who do not only bear a greater burden but may be subjected to social and economic vulnerability in comparison to men [28, 33, 34]. In fact, according to the latest Uganda population-based HIV impact assessment [35] incidence and prevalence of HIV were highest amongst women (15 - 64 years old). In addition, accessing HIV services in rural areas has been identified as facing several barriers e.g. difficulties in reaching clinics, lack of social and financial support along with stigma, that may limit the use of these facilities [8]. Indeed, viral load suppression (VLS) in the Ugandan Mid-Eastern region, where our participants resided, was estimated at 53% which is below the national population level at around 60% and far below the UNAIDS targets [2, 35].

Similar to other studies, social networks namely family members, friends, religious groups, health care providers e.g. nurses and HIV support groups, were identified as key in providing the support required to help face such a major challenge and shift in their personal lives [28, 30, 34]. In addition, the majority of our participants were women who have been identified as having a larger and more diverse social network made up of relatives, friends, church worshippers that may lead to greater support in comparison to men [34, 36]. However, participants reported that the role of friends, the church and congregants and TASO, the NGO that offers HIV counselling and medical services to people infected and affected by HIV/AIDS, were crucial in the shift from despair to hope that the participants experienced. In addition, our findings are consistent with other studies that have identified the preventative role carried out by individuals affected by HIV in which the victims became advocates for HIV testing, ART and HIV prevention supporting behaviours to prevent transmission [30, 37, 38]. This is a sign of empowerment and the ability to regain not only their health but also recovering their self-esteem, sense of worth and dignity.

Along with the shift from disempowerment to empowerment due to their advocacy role, the greatest change that our participants reported was in relation to the role they had, especially women, within their families and their community. Women, particularly in rural Uganda, carry out most of the unpaid care and domestic work with limited opportunities for income generation [39]. Although this is culturally accepted by both women and men, it places women in a subordinate, dependent role [39]. However, our participants identified a shift in which the key change seemed to be the ability to earn and make independent decisions. The increased financial independence also affected the acceptance

by their close relatives, that was experienced by our participants. The participants did not present themselves as victims of the infection, they presented themselves as independent individuals whom, with the support of their relatives, friends, church leaders, worshippers, TASO and health care providers, were able to gain a greater quality of life and recognition in the community. Similar findings were reported in other studies [19, 40, 41, 42]. Hence, the discovery of the HIV infection that had initially created a negative impact on the lives of the participants, seemed to have been a driving force on the empowering changes during the years.

This qualitative study reports the experiences of a group of individuals who have lived with HIV for over 10 years in rural eastern Uganda. Most of the participants were women, the man who shared his experience was the youngest in the group. Although he had lived with HIV for all his life, engaging a wider sample of participants, including older men may have provided a different insight. Additionally, the results of this study are a reflection of the perceptions and experiences of a specific group of respondents and cannot be generalised to include other HIV survivors, women or men, and especially not individuals living in other parts of the country. However, the engagement of women who live in rural, isolated areas of Uganda, who may be underrepresented, especially women who have managed to survive HIV since ART was rolled out in Uganda in 2004, represent a different voice, experience and a message of hope that is important to remember.

## Conclusion

Notwithstanding the limitation discussed, this qualitative study identified that with the relevant support and the gaining of financial independence, individuals, especially women, who experienced shock, despair and disempowerment of being told that they were HIV positive, were not only able to survive and carry on living but were able to find a different freedom, independence and role within their families and close community.

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