

CASE STUDY

Person living with HIV becomes a community care-giver: A case study

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ABSTRACT

The prevalence of HIV in the province of KwaZulu-Natal, South Africa is 16.9%. Although the Department of Health (DOH) has increased the workforce in an attempt to address the burden of disease, there are many people who are unable to access these services. This has resulted in the emergence of informal care-givers for those living with HIV. This case study explores the challenges faced by a voluntary health care-giver. This care-giver was diagnosed with HIV approximately 20 years ago. She made an effort to learn about the disease by attending lectures informally, and subsequently, courses in basic counselling and peer education. Among the challenges faced by people with HIV/AIDS, are accessing services at local hospitals where the waiting times are very long and patient-practitioner interaction is sub-optimal. Difficulties are also experienced in receiving Anti retro virals (ARVs). Palliative care is also necessary. Besides the challenges with access to care and treatment, issues with stigma are also pervasive and contribute to decisions to seek care and impede HIV prevention initiatives. She is educating people to remove the stigma surrounding HIV, educating them about transmission, counselling people living with HIV and providing informal care to them. This study highlights the need for satellite or mobile clinics and also emphasises that nurses need to be more sympathetic when treating people living with HIV. We conclude that people living with HIV can serve an important role to educate and assist others. Training should be provided to these community care-givers.

Key Words: HIV, Caregiver, Motivational speaker, Living with HIV

1. INTRODUCTION

The epicentre of the HIV pandemic is the province of KwaZulu-Natal in South Africa where 16.9% of the population are infected with HIV. In addition, the highest prevalence in metropolitan areas, is in the eThekweni municipal area within this province.^[1] The South African National Department of Health (DOH) made the reduction in new HIV infections part of a National Strategic Plan in 2007.^[2] This policy has resulted in reducing the progression of HIV to AIDS, by scaling up access to antiretroviral therapy (ART).

However, there has still been an increase in HIV infections.^[3] One of the main strategies is to educate people about the importance of voluntary counselling and testing as well as to dispel myths and stigma around the disease, particularly to those in low socioeconomic regions due to their high risk for infection.^[2]

In line with the National Strategic Plan, a large number of community health workers have been employed by the health sector so that they may promote voluntary testing and counselling of HIV, and also promote the uptake of ART.^[4,5]

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While the DOH has increased the workforce in an attempt to prevent new HIV infections, and address the burden of the disease among those infected, there are still many people who are unable to access these health services.^[6] This has resulted in the emergence of a large number of informal caregivers within communities.^[7] These informal care-givers carry a substantial part of the burden of caring for people living with HIV, often providing educational services and the emotional support to those in need, on a volunteer basis.^[6,8]

These volunteers are essential for the health and well-being of communities, particularly those that have challenges in accessing health resources.^[7] This case study explores factors that may drive a person living with HIV to provide voluntary health care services.

2. METHOD

This report focuses on an interview conducted with a health care volunteer who resides within a low income, urban community in Durban, South Africa. This interview was part of a larger study conducted in 2013, where health data was collected from women living in the community.^[9,10] Permission to conduct the study was obtained from the Institutional Review Board at Virginia Commonwealth University (VCU) and the Institutional Research Ethics Committee of the Durban University of Technology (IREC 056/13). Following written informed consent, the interview was conducted in English by one of the authors (KP). The interview was audio recorded and transcribed. To protect the identity of the interviewee, her name has been changed, and she is referred to hereunder as Ms. Jones. Key themes were extrapolated and summarized using principles of content analysis.

3. THE INTERVIEW

3.1 The study setting

Ms. Jones has been a resident of her community for over 40 years and she explained that the infrastructure within the community has diminished over time. Initially, the homes were set aside for white, working class families, but with the transition of South Africa into the post-apartheid era, the previously white, working class population was slowly desegregated. The housing was then earmarked for families of low socioeconomic status, or those in whom one or more members had a disability. The change of socioeconomic status has negatively impacted the level of education and access to resources within the community.

3.2 Diagnosis and education of HIV

Ms. Jones was diagnosed as HIV positive approximately 20 years ago. She was infected by a boyfriend who knew that he had HIV, without telling her about his status. He also in-

fectured several other women. Ms. Jones could not, at the time, afford ARVs. At that stage, in the 1990's, there were no drug trials in South Africa. A new programme, for the roll out of ARVs, was introduced at a local tertiary hospital, which paid half the cost, with the other half required to be paid by the patient. She received a sponsorship, for her portion of the cost, through a church group where she previously gave a motivational talk on HIV. That was the only way she could afford medication at the time. She remained on the program for two years, after which her CD4 count was raised. She then dropped out of the program and asked the church group to sponsor someone else in her place.

After being diagnosed with HIV, she wanted to know what was going to happen to her and therefore made an effort to learn about the disease. She went to the Medical School which is within walking distance from her home. She approached a professor, who she knew from her treatment program, to enquire about HIV in the first year nursing curriculum. She was subsequently given permission to attend the lectures at no cost, without being registered for the course. After this initial training, she went into the medical wards at the hospital and spoke to patients about their illness. This was followed by her enrolling for short courses on HIV, to improve her knowledge about the disease. She subsequently registered for courses in basic counselling and peer education and now holds certificates for these.

3.3 Treatment and care

Ms. Jones detailed the numerous obstacles that the members of this community face in reaching care. For example, although there is a hospital within walking distance from the residential area, due to municipal zoning, these residents have to use a hospital that is some distance away and are thus forced to travel to that site. For many, this is not possible as they do not have money for travel expenses. In addition, many of the residents are elders. The waiting times at government hospitals are also of concern since each hospital must service a large number of people. She reported that people often wait for over 12 hours for a consultation and that the patient-practitioner interaction requires improvement. Since the patient numbers are large, the hospital staff are unable to give the personal attention that patients need. The interviewee stated that palliative care is required in order to change people's misconceptions and helplessness. An additional problem is that, due to lack of knowledge, many are unaware of the symptoms of HIV, and therefore miss opportunities for care.

Ms. Jones explained that difficulties are also experienced in receiving ARVs. Often ARVs are only given to those people who can guarantee the providers that they will take them

consistently, and thus, many who do require the ARVs, are not given the medication. The underlying problem is that sufficient amounts of ARVs are not available and hospital dispensaries often run out of ARVs. Patients who may have waited in a long queue for almost the entire day are then told to either come back, or sometimes only given about a quarter of the required medication and asked to return for the remainder at a later date. They then have to travel the long distance again and spend an added day in a long queue waiting once again for medication that they should have received previously. For those who are unemployed, it means finding the money for transport from limited resources and for those who are employed (usually in menial labour), it will only be possible to return for the medication if allowed by the employer.

The volume of patients that nursing staff have to treat is usually very high as hospitals are usually short staffed. As a result, nurses often do not treat patients with dignity. The patients then lose faith in the system. She highlights that nursing staff therefore need to be empathetic towards patients. Ms. Jones suggested that communities should have access to satellite or mobile clinics that can be present in different neighbourhoods on certain days of the week. This will assist people who are unable to travel to a hospital that may be far away. It will provide the community with medical support without the required infrastructure for an on-site clinic, and will also be less costly. These satellite clinics will also allow for more personalised and efficient care, which will hopefully result in people coming in regularly for their medication, which is currently not the case.

3.4 Stigma

While there are many challenges with access to care and treatment, issues with stigma are pervasive. These affect decisions to seek treatment, and also impede HIV prevention initiatives. Ms Jones indicated that people with HIV are seen as a disgrace to the family and as a result they do not disclose their status; as the interviewee mentioned, it "... causes people not to say anything - to keep quiet, because they don't get welcomed with their disclosure." Gossiping about people living with HIV is also rife. As the community is so small, everyone knows about everyone else and people appear to be relieved when someone from another family contracts HIV. "Neighbourly jealousy that goes around here, for instance, there will be one family whose daughter becomes HIV positive, then there will be gossiping and one family will say: 'yeah you see she was always talking about my daughter but look what happens to her daughter, now her daughter has got AIDS.' Then the next minute their daughter has got AIDS and then they say yeah you see they pushed my daughter

down and they had a lot to say about my daughter now she's got it."

Education to remove stigma

Ms. Jones now uses what she has learned to help people with HIV live a better life. She began educating others through motivational speaking two years subsequent to her diagnosis, almost two decades ago. She wants people to view the disease differently in order to remove the stigma around HIV. She says, "People living with HIV have their identities tied to the disease as opposed to just a person suffering from a disease." She mentions that she once went to a prayer meeting at a neighbour's home and was introduced as: "This is Ms. Jones and Ms. Jones has AIDS. That is what happens to you when you have sex outside marriage." She understood that this was not intentionally meant to be hurtful. However, she felt that these types of attitudes need to change and she explains, "... people don't realise that that person is not the person with AIDS, but a person that is dealing with a chronic illness. You don't go around saying meet Jane, she has breast cancer." She believes the disease is seen differently to other chronic illnesses, because people feel that those living with HIV are responsible for contracting the disease. To reduce stigma, Ms. Jones believes that people need to see someone who is HIV positive as a person with a chronic disease who needs compassion and care.

3.5 Educating the community

Her introduction at the prayer meeting led her to correcting the difference between HIV and AIDS. She mentions that these terms are often used interchangeably. This has led to her educating people that a person living with HIV does not have AIDS if his/her viral load is low, the CD4 count is high and other opportunistic infections are not present, as it was in her case.

One of the ways she proposed progress was by "tackling HIV as a chronic illness, likening it to diabetes, hypertension and cancer". The level of education requires "wellness programmes" on many chronic illnesses, including HIV. In addition, this would allow the community to be open about diseases with which they have been diagnosed. The stigma attached to an "HIV programme" would not be present at a "wellness programme".

Since she has been a resident in the community for over 40 years, she feels responsible for the community and is involved in community engagement and education. She spoke about the effort made to create awareness of HIV in schools in the surrounding areas. She said that listening to someone who is not an authoritative figure in students' daily lives, gives a different approach to their usual education, and that

listening to the experience of a person who is living with HIV increases their level of engagement. This also helps to reduce the stigma that still surrounds HIV. A person who is open about her personal experience receives a different response from school children and community members alike, helping to reduce HIV stigma. Her openness, was part of the reason for receiving medication and this shows that those living with the disease will not necessarily be condemned. Her story demonstrates that instead of stigma there can be a positive response to people living with HIV if they are open about their status.

Ms. Jones would like to run monthly programs on HIV so that people can get a better understanding of the disease. She would particularly like to target the youth by hosting movies and slide shows on HIV and then get them to talk about it, as they are in the most vulnerable age group for contracting HIV.

3.6 Transmission of HIV

New HIV infections are most common in the age group of 15-24 years, yet when she speaks to young people who are sexually active, they admit to not using condoms regularly. They claim to have used condoms initially in their relationship but after about 2-3 months they stopped because they felt pressured to trust their partners. These young girls admit to having arguments with their boyfriends and then breaking up, only to get back together at a later stage. They are aware that in the interim period, the boyfriend had other sexual partners yet they do not insist on the boyfriend using condoms when they subsequently date each other again.

She also emphasised that young people in the area often believed that marriage protects one from HIV, but that in reality this was not so, as even marriage partners were often promiscuous. She also noted that people did not know that HIV could be transmitted via infected donor blood and that an infected person could subsequently transmit it to a spouse.

3.7 Helping those living with HIV

The population tends to live in denial about HIV. Many refuse to get tested – “they don’t want to hear about it, until they get sick... then they get TB and then it’s too late”. She recalls that two of her neighbours became very ill and were unable to walk due to their weakness. She remembers carrying them to her car and taking them to a hospice where they died of AIDS a few days later.

Since those incidents, some people do go for testing and if diagnosed with HIV, they approach Ms. Jones for counselling. She is always empathetic towards them, takes them into her confidence and maintains confidentiality. She says that nurses need to provide this sort of “spiritual care” to

those living with HIV/AIDS.

She has written magazine articles on HIV, appeared on television programs and her face appears on government posters and booklets. People have accepted her in her community, despite her status.

3.8 Other social issues

Another social issue in this community, is drug abuse. It plays a role in HIV transmission through the sharing of needles and increasing risky sexual behaviour. Ms. Jones explained that it is one of the biggest problems within this community and that residents have urged her to help them or other members of their families. However, the current counsellors are members of the community who are not properly trained. Furthermore, the residents do not feel they would have absolute confidentiality when talking to someone who is a member of their community. As a result, she has asked for professional counsellors to come in for support. This would also help those, suffering with HIV, who do not wish to disclose their status to people in their community.

Regarding mother to child transmission of HIV, the knowledge is limited as further discussed in previous research within this community.^[9] Ms. Jones personal experience within the community is that mothers wait until they show symptoms before getting tested, and they prefer to live in denial. After finding out their status, they turn to the church in an attempt to “pray it (HIV) away”. Medical treatment is a last resort and, more often than not, it is too late for intervention to save the life of the mother or prevent transmission of HIV to the child. The child usually grows up as an HIV positive orphan. This finding shows that spiritual leaders should be included in educational training and counselling for HIV.

3.9 Qualities required by community care-givers

From the interview it is evident that certain characteristics are essential for both HIV motivational speakers as well as care-givers. They need to be positive about life, be able to speak with conviction, be knowledgeable about HIV and also be able to answer questions. Ms. Jones also said that she often needs to switch off her own emotions when speaking about HIV issues. Her talks often make her think back to the time when she was diagnosed and also to when she lost a loved one to AIDS. She therefore needs to be very careful that she “removes herself from that situation”. The person needs to be quite tough emotionally as often people say or ask very sensitive things. One school boy mentioned “If more people die, more jobs would be created for the rest of us”. She was able to reply by asking how he would feel if that person was his sister. That helped him to see the issue in

a totally different light.

4. CONCLUSION

This interview was with Ms. Jones, a person living with HIV, who has educated herself about the disease, initially in an attempt to learn more about what was possibly going to happen to her and subsequently to educate others. She has used her experience to counsel others about prevention, treatment and living with HIV. As she is open about her status, it has resulted in a positive reaction from those whom she counsels and those to whom she gives motivational talks. This study highlights the need for satellite clinics in the area and also emphasises that nurses and other healthcare professionals need to treat people living with HIV with respect and dignity. There is also a need for more lay people to be recruited and trained to provide basic HIV education and support. We conclude that more people living with HIV can be used to educate and assist others with the disease. This will reduce many stigmas that continue to surround HIV and AIDS. Some form of training should, however, be provided to these “community counsellors”. Changing the mentality of the entire community to reduce stigma, while necessary, would be a long process. The South African DOH would

need to provide infrastructure for these clinics, as well as provide funding for training programs for care-givers. The latter would be relatively inexpensive, but could have a large impact on improving education, prevention, and dispelling stigma in communities. Moreover, it would give some control over what information is being shared: lay care-givers are stepping up to meet a gap in health care services, and yet, there is no way of knowing what information they are sharing in their communities and it could be potentially harmful as shown in our previous study that lay care-givers knew very little about mother to child transmission, despite this being a priority area.^[9]

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare they have no conflicts of interest.

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