

THE NEEDS AND EXPECTATIONS OF STAFF AND STUDENTS LIVING WITH HIV AND AIDS IN A SOUTH AFRICAN RURAL-BASED UNIVERSITY

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ABSTRACT

HIV and Aids are making an impact in institutions of higher education. Studies have revealed that though few students and staff have been recorded as suffering from HIV/Aids, more have become ill and some have died in ways that signal the impact of HIV/Aids. Universities can contribute to addressing the needs and expectations of staff and students living with HIV and Aids. The purpose of this study was to explore and describe the preparedness of a South African rural-based university in addressing the needs and expectations of staff and students living with HIV and Aids. A qualitative study design was followed, with one South African rural-based university as the case setting. Qualitative interviews were conducted stemming from the central research question, 'How is the university addressing the needs and expectations of staff and students living with HIV and Aids?' Following an open coding method of data analysis, three themes emerged relating to how the needs and expectations of staff and students living with HIV and Aids were addressed: persistence stigma and discrimination, limited assurance to confidentiality, and inadequate treatment, care and support. Recommendations were made for improvement of service delivery to address the needs and expectations of staff and students living with HIV and Aids and further research should be conducted on a large scale to determine other needs and expectations of staff and students living with HIV and Aids at other South African rural-based universities and how they are addressed.

Keywords: expectations, needs, preparedness, rural-based university, staff and students living with HIV and Aids

INTRODUCTION AND BACKGROUND INFORMATION

South Africa has the highest number of people living with HIV and Aids (UNAIDS, 2011:7). The number of People Living with HIV and Aids (PLWHA) is on the rise. In 2008 there were 5.2 million (10.6% of the population) PLWHA in South Africa as compared to 2012 when approximately 6.4 million (12.2%) were infected. This indicates an increase of 1.2 million within a period of four years (Shisana et al, 2014:xxiv).

Although studies indicate that the HIV/Aids prevalence in the higher education sector is lower than in the general population, HIV prevalence is still a problem (HEAIDS, 2013:6). The results of the 2008–2009 Higher Education HIV/Aids Programme (HEAIDS) survey carried out in order to understand the threat posed by the HIV/Aids pandemic in the universities in South Africa, shows the highest HIV prevalence rate of 12.2% among service staff, followed by 4.4% among administrative staff, and 3.4% among students. Academic staff were found to have the lowest overall HIV prevalence of 1.5% (HEAIDS, 2010:105). According Phaswana-Mafuya and Peltzer (2006:153–154) HIV/Aids leads to loss of skilled workers and reduced throughput for skilled graduates. This also leads to the reduction in the throughput in higher education institutions, which affects future funding by the Department of Education. This state of affairs compromises the value of education and the worth of institutions of higher education.

PLWHA have special needs and expectations in order for them to live healthy and productive lives. Meeting such needs and expectations is considered the responsibility of all sectors where there are PLWHA in order to sustain the health and wellness of this population (SANAC, 2011:11). As there are staff and students living with HIV and Aids in higher education institutions, these institutions also have the responsibility to ensure that their systems and services remain responsive to the needs and expectations of PLWHA, including: reducing HIV and TB-related stigma and discrimination, reduction of mortality and disability associated with HIV and TB, ensuring accessibility to treatment care and support, and ensuring that the rights of staff and students living with HIV and Aids (SSLWHA) are respected (SANAC, 2011:15). Adequate preparedness for addressing the needs and expectations of SSLWHA will lead to improved quality of life. Improved quality of life of SSLWHA will ensure that staff members remain productive and students remain healthy. The researcher is of the opinion that addressing these needs and expectations may have a positive effect in higher education institutions by increasing the throughput rate of all students, regardless of their HIV status. This may also improve the quality of life of SSLWHA in South African higher education institutions.

PROBLEM STATEMENT

A South African Rural-Based University (SARBU) offered treatment, care and support for SSLWHA as suggested by the South African National Aids Council (2011:48). However, statistics recorded by the HIV/Aids unit of this SARBU during 2004–2011 indicated that there was an increase in the number of students and staff visiting this unit for HIV counselling and testing who tested positive. The recorded statistics indicate that there were 12 in 2004 and 54 students and staff who tested positive in 2011 (Anon, nd). Although statistics are not available since the majority of PLWHA may have used hospitals and private practitioners for treatment, this SARBU HIV/Aids unit reported

an increase in HIV/Aids-related deaths of students and staff, which according to the researcher is not supposed to happen as antiretroviral therapy is readily available to all on campus of this SARBU. This made the researcher wonder if this SARBU was addressing the basic needs and expectations of all PLWHA which is considered a health and wellness strategy by the South African National Aids Council (2011:47). This study answers the research question below.

RESEARCH QUESTION

What are the needs and expectations of SSLWHA in a SARBU?

PURPOSE OF THE STUDY

The purpose of this study was to explore and describe the needs and expectations of SSLWHA in a SARBU.

Definitions of key concepts

Expectation is a belief that something will happen because it is likely (Hornby, 2010:513), which in this case is what SSLWHA believe the university should do.

Need is something which is required because it is very important or essential (Hornby, 2010:987).

A South African rural-based university (SARBU) in the context of this study is a historically black university developed during the apartheid era in the former homelands (Nkomo, 2007:235).

Staff and students living with HIV/Aids (SSLWHA) is any member of staff (academic or otherwise) or student who is HIV positive.

RESEARCH DESIGN AND METHODOLOGY

The research design employed by the researcher was a qualitative, exploratory, descriptive study as this helped the researcher to explore and describe the needs and expectations of SSLWHA in a SARBU.

Contextual details

The study was conducted at a SARBU, which was founded in the 1980s to cater for the tertiary education needs of the newly formed homeland. This SARBU is situated

in one of the poorest provinces of South Africa. It had a population of 10 368 students and 735 staff members. Most of the students at the SARBU came from poor families in that province and other poor provinces of South Africa. However, the university also accommodates students from other sub-Saharan African countries. The university has an HIV/Aids unit which is responsible for implementing the HIV/Aids programme on campus. It also had a Campus Health and Wellness Unit (CHWU) where SSLWHA were referred for the management of opportunistic infections.

Population and sample

Participants were selected following purposive sampling procedures, based on being HIV positive or involved in the management of SSLWHA on campus. Nine participants were chosen, comprising a CHWU staff member, three health promoters (PLWHA who were employed on campus to live openly with HIV to promote HIV counselling and testing and positive living with HIV, which included counselling and support of other SSLWHA) from the HIV/Aids unit, and five SSLWHA (three students and two staff members) participated. Except for the staff from the CHWU and the health promoters who work in the HIV/Aids unit with the researcher, other participants were recruited by the researcher during visits to the HIV/Aids unit for ongoing counselling and support. The sample size was determined by data saturation.

Data collection

Data were collected between March and May 2012. The interviews were conducted by the researcher who was also a staff member of the SARBU. Unstructured, in-depth, face-to-face interviews were conducted in the HIV/Aids unit to ensure confidentiality. All nine interviews were audio-recorded with permission from each participant. Each interview was initiated from the following broad central question: 'How prepared is the SARBU to address the needs and expectations of SSLWHA?' Through probing, more questions regarding how the needs and expectations of SSLWHA were addressed were asked. This was done in order to encourage the participants to elaborate on their statements and to clarify some information or to identify emotions around the topic. Field notes focusing on methodological, personal, non-verbal cues and theoretical aspects were also taken during the interviews to enhance trustworthiness. Each interview lasted for 45 to 60 minutes.

Measures to ensure trustworthiness

Strategies described in literature to ensure trustworthiness were applied (Polit & Beck, 2012:723–725). Credibility was established through prolonged and varied engagement in the HIV/Aids field, reflexivity and the triangulation of data, using an independent

coder, peer evaluation and through the researcher's experience in the HIV/Aids field. To ensure dependability, raw data were given to an independent coder. The coding process was evaluated at different phases by an independent coder from the SARBU and an international university which had a partnership with SARBU. Neutrality was ensured through the strategy of conformability. This was attained by keeping a reflexive diary throughout the data collection process as well as analysis as the researcher was also an employee of the SARBU responsible for ensuring that the needs and expectations of SSLWHA were met. The reflective diary assisted the researcher to bracket her own preconceptions and biases regarding the research problem. An audit trail was ensured whereby all the records pertaining to the study were meticulously kept for continuous referrals and use by independent coders. Data were coded and recoded several times and compared with the themes and categories of the independent coders. Inconsistencies were discussed to reach consensus. Direct quotations from participants' interviews were used to ensure authenticity.

Ethical measures

Ethical aspects were adhered to throughout the research process. Ethical clearance was granted by the SARBU's Health, Safety and Research Ethics Committee. The participants were fully informed about the purpose of the research and their voluntary participation was obtained. Individual participants gave written consent. The participants' right to confidentiality was maintained by not using names of either the participants or the institution. The audio-recorded information was only reviewed and transcribed by the author. The responses of different interviewees were discussed without using identities or positions on campus to reduce the risk of being identified and possible stigma and discrimination for those SSLWHA whose status were still confidential.

ANALYSIS AND DISCUSSION OF RESULTS

Data analysis was conducted following the steps described by Tesch (in Creswell, 2009:125). Content analysis was used in the process of transforming raw data into categories and themes substantiated by participants' verbatim statements. Three themes emerged as the needs and expectations of SSLWHA from the SARBU: (1) addressing issues of stigmatisation and discrimination; (2) maintenance of confidentiality; and (3) treatment, care and support.

Addressing issues of stigma and discrimination

Stigma and discrimination were of major concern for PLWHA. The fear of this made most of the population reluctant to use health-care facilities. The SARBU had established a health promoters programme to reduce the stigma related to HIV/Aids

(SANAC, 2011:36). These seemed to have a positive impact as the participants from the CHWU mentioned that SSLWHA at the SARBU were not discriminated against or stigmatised as they were treated in the same manner as all other patients visiting the CHWU: ‘We manage HIV positive students as any other student who is coming to the CHWU. We don’t have any segregation like: “This is a special treatment for staff or student living with HIV and Aids”.’ The finding attests to the findings of Ricks, Jackson and Van der Marwitz (2012:42) who note that PLWHA are not discriminated against by health-care professionals.

However, participants living with HIV and Aids had a different view. Their view was that SSLWHA experienced stigma and discrimination on campus from different university members, including those who worked at the CHWU:

Some people at the CHWU discriminate when an HIV positive person visit the unit for treatment especially those who have opportunistic infections which make it obvious that the person may be infected with HIV. This makes some of us to be reluctant to go to the CHWU even when we are not feeling well.

Stigma and discrimination by health-care workers negatively affected the use of health-care services by PLWHA. This is in line with the findings of Bos, Schaalma and Pryor (2008:450).

Other SSLWHA assumed that stigma and discrimination were related to the sociocultural environment, especially the ‘rurality’ (rural nature) of the university where people had limited understanding about other causes of HIV. They usually blamed women who were infected for being promiscuous and also held them responsible for infecting men. These viewpoints pose a challenge to ensuring that HIV/Aids information addresses sociocultural issues in order to successfully challenge the stigma and discrimination at a SARBU.

Maintenance of confidentiality

Confidentiality about their HIV status is one of the most important needs of PLWHA. They expected that health-care providers and whoever else is entrusted with their HIV status would not disclose this to any other person without their consent. The findings of this study show differing views of participants regarding the maintenance of confidentiality regarding their status as SSLWHA. The participant from the CHWU indicated that confidentiality of SSLWHA was respected at the SARBU:

When the HIV/Aids coordinator refer people to this side (Campus Health clinic), we do not ask for their status, but treat them like any other person. We only wait for students to voluntarily disclose their status’ So we try by all means to maintain confidentiality.

Similar findings, namely that confidentiality is maintained well by health-care providers, are reported by Ricks, Jackson and Van der Marwitz (2012:33).

However, the health promoters from the HIV/Aids unit thought that confidentiality was not maintained at all, due to infrastructural challenges. The following is how one participant described the lack of confidentiality:

The structure used as HIV/Aids unit is not suitable for maintenance of confidentiality as people are pre counselled for HIV test in the office of Health Promoter and proceed to the office of HIV/Aids coordinator for HIV testing. After HIV testing they go back to the HP office for post-test counselling passing through people who are seated in the waiting room. Those people can easily read the facial expression of people tested and conclude about their HIV status. And when a person is transferred from the HIV/Aids unit to the CHWU for treatment, it is obvious to other clinic staff that such person is HIV positive. So there is no confidentiality.

The lack of confidentiality related to infrastructure is not unique to the SARBU. It is a common challenge in Africa, especially in public health-care facilities which are mostly overcrowded and overused (Deacon, 2005: 77).

Treatment, care and support

Treatment, care and support are key pillars to sustaining the health and wellness of PLWHA (SANAC, 2011:15). The study indicates that although SSLWHA were given support, it did not seem that there was adequate planning to provide comprehensive treatment, care and support. Treatment, care and support were discussed with participants and focussed on the monitoring of CD4 cell counts, treatment of opportunistic infections and antiretroviral treatments, consultation fees for HIV/Aids care services, nutritional support and psychosocial support, and limited educators' knowledge of how to deal with students living with HIV and Aids.

Monitoring of CD4 cell count

The CD4 cell count determines the immune status of PLWHA. It is also used as a determining factor for initiating antiretroviral treatment or changing the antiretroviral treatment regime (WHO, 2014:48). SSLWHA cannot be managed properly without monitoring their CD4 cell counts. The university monitored the CD4 counts of SSLWHA at regular intervals as indicated by one of the participants: 'From my personal point of view, they [HIV/Aids unit personnel] are doing well as they are performing regular CD4 counts for SSLWHA. They will also phone you if you miss your appointment date'. This is in line with the South African National Aids Council's (2011:49) health and

wellness package which includes conducting regular CD4 count tests. However, the value of regular CD4 count tests for people who are stable on antiretroviral treatment is questioned (WHO, 2014:48).

Management of opportunistic infections

Opportunistic infections are infections and malignancies that affect PLWHA ‘because they take advantage of the opportunity offered by a weakened immune system’ (Van Dyk, 2008:5). The participants interviewed reported poor treatment of SSLWHA by some of the staff members at the CHWU when seeking treatment for opportunistic infections. Their feelings were expressed with deeply emotional responses:

If a person is known to be HIV positive and go to the clinic, some staff member will just give you treatment without examining you. If you are not still sick and go back for consultation again, they will just give you the same treatment until you request to be referred to the hospital.

According to the participants it seemed as if SSLWHA did not receive adequate treatment and care with regard to prophylaxis and treatment for opportunistic infections which is in contrast to the literature (HEAIDS, 2010:115). Transferring patients for the management of minor opportunistic infections is against the recommendations by the South African National Aids Council (2011:48), emphasising that opportunistic infection medication should be made available at primary care level.

Lack of antiretroviral treatment on campus

Antiretroviral treatment suppresses the multiplication of HIV thus giving the body a chance to improve its immune system. Antiretroviral treatment not only benefits PLWHA, but also reduces the chances of transmitting HIV to others (WHO, 2014:86). This makes it necessary for health-care service providers to provide antiretroviral treatment to all legible SSLWHA. The research results indicate that the university did not offer antiretroviral treatment, but referred patients to the nearest hospital or health centre for antiretroviral treatment. Not offering antiretroviral treatment in the CHWU is in contrast with the South African National Aids Council’s (2011: 48) recommendation that all primary care, antenatal, TB and mobile outreach health facilities must become fully functional nurse-initiated antiretroviral treatment centres.

However, results show that SSLWHA are sceptical about going to the hospital due to overcrowding, which makes them fear that they may be recognised. Participants mentioned that it might be better if antiretroviral treatment was brought into the CHWU for them to collect instead of going to the hospital: ‘I do not feel comfortable to go to the hospital as it is over packed, and one has to spend the whole day to receive the ARVs.

That's why some students end up defaulting treatment'. The reluctance to go to other institutions was also reported by the South African National Aids Council (2011:48) who note that most of the people are lost in the process of referral.

Participants view issues of not having antiretroviral treatment on campus as a lack of commitment by management to SSLWHA: 'The issue of this institution of not offering ARVs is showing that the university management does not consider HIV-positive people'.

Regarding the management of SSLWHA who need antiretroviral treatment, the university referred patients to the nearest hospital and health centres which made some participants feel unsatisfied. This lack of access to treatment for SSLWHA had a negative impact as students or staff sometimes missed a whole day of work to access treatment in hospital, which affects productivity. This is in accordance with HEAIDS (2010:115) noting that most of institutions of higher education do not provide antiretroviral treatment on campus. Not offering antiretroviral treatment goes against the recommendation by South African National Aids Council (2011:48).

Payment of consultation fees for HIV/Aids services

PLWHA are often sick with different opportunistic infections. This requires constant visit to health-care services to seek treatment. Findings from other studies indicate that PLWHA are offered treatment free of charge, which was not the case when SSLWHA visited the CHWU. The issue of payment at CHWU concerned some of the participants as they felt that SSLWHA should be treated free of charge, in a similar way to what the institution did for family planning patients. One participant put it this way: 'I don't think staff and students living with HIV and Aids should pay for treatment of opportunistic infections'.

There were no clear policies and guidelines regarding the payment of consultation fees at the SARBU, as one interviewee mentioned that she sometimes paid if she had money, but sometimes she did not pay consultation fees. The following quotation from an interviewee qualifies these statements: 'If I have to pay every time I go and consult, it is too expensive for me. So I pay only when I have the money'.

Expecting SSLWHA to pay consultation fees at the CHWU may prevent them from seeking visiting the CHWU when they are sick. The situation will also cause those SSLWHA who are eligible to receive antiretroviral treatment to miss the opportunity. As recorded in the previous section, antiretroviral treatment not only reduces morbidity and mortality, but also HIV transmission to negative partners, which means that the spread of HIV will not be curbed if PLWHA do not receive antiretroviral treatment. This will prolong morbidity and also increase the mortality rate.

Inconsistence nutritional support

Proper nutrition is one of the important aspects for PLWHA as it assists in boosting immunity (SANAC, 2011: 50). However, most SSLWHA cannot afford to have a proper meal per day. Hence, the need for additional nutritional support through the provision of food supplements. The university, through the HIV/Aids unit, offered food supplements to SSLWHA, funded by donors and the CHWU budget. The following statement from an interviewee indicates the kind of food supplements supplied: ‘When it comes to the management of HIV, we have an HIV/Aids unit; we get things such as supplements, PVM, food supplies, energy drinks’.

Although a participant mentioned that they were given food supplements, further investigation indicated that there was no consistency in giving the supplements: ‘Food supplements are not always available in the HIV/Aids unit as they are ordered in small quantity. The amount ordered does not reach all the HIV positive people’. Lack of consistency in the provision of nutritional support is against South African National Aids Council (2011: 50) recommendations.

Inadequate psychosocial support of SSLWHA

Living with HIV and Aids may lead to psychological problems as stated by the National Centre in HIV Social Research (2012:11); there is a need for SSLWHA to have some form of psychological support. The support may be through individual counselling based on need or through support groups where SSLWHA who feel comfortable meeting with others in a secure and confidential space to share their experiences. The SARBU offered psychological support to SSLWHA in the form of support groups and ongoing counselling as indicated in the following statement: ‘So for those whom we find that they are infected with HIV, we provide them with on-going counselling and monthly support group meetings where we support each other’.

However, the support group was not attended by all SSLWHA at the university, but only by students. A participant mentioned that only female students attended support groups: ‘In our support group I have never seen a staff member but only female students’.

Although the SARBU offered counselling in the form of a support group to some students, it was not adequate which is in contrast to the South African National Aids Council (2011:50) advocating for ongoing counselling regarding nutrition, lifestyle, contraception, conception, social support and pain management. Lack of psychological support may lead to increased stress which may hasten the progression to the Aids stage as stress is also immunosuppressive.

Limited educators' knowledge of to deal with students living with HIV and Aids

Students living with HIV expected that academics would be knowledgeable about dealing with a student who openly lives with HIV or Aids. However, this was not the case with some of the academics at the SARBU as illustrated by the following statement:

It was a bit difficult for some lecturers to talk about HIV/Aids, they didn't know how to address it because I have publicly disclosed my HIV status and they were thinking that if they say something negative, they might offend me.

The failure of academics to address HIV/Aids topics objectively defeats the recommendation of the Department of Basic Education (2011:5) that stresses the extension of HIV/Aids education to young people attending institutions of higher learning.

The failure of a rural-based university to adequately address the needs and expectations of SSLWHA is in contrast with the management model for HIV/Aids in a SARBU which recommend that the university should plan to address the needs and expectations of this population (Mavhandu-Mudzusi & Netshandama 2014:376). The model emphasises: access to antiretroviral treatment on campus in the most cost-effective and user-friendly manner, which is not time-consuming and ensures the maintenance of confidentiality; a policy regarding the consultation payments at the CHWU; continuous nutritional support, including offering at least one meal a day for SSLWHA and ensuring maintenance of confidentiality; addressing stigmatisation and discrimination; and training all educators on dealing with students living with HIV or Aids.

CONCLUSIONS

Results indicate that the SARBU was inadequately prepared for addressing the needs and expectations of SSLWHA, evidenced by persisting stigmatisation and discrimination which was also shown by health-care personnel; lack of confidentiality that was mainly attributed to infrastructural challenge; and inadequate treatment, care and support of SSLWHA. Inadequate treatment, care and support was shown by the failure to offer antiretroviral treatment, the inconsistent supply of nutritional support, inadequate ongoing counselling and expecting SSLWHA to pay consultation fees for the treatment of opportunistic infections.

RECOMMENDATIONS

Participants made several recommendations based on the needs and expectations identified in this study.

Adequate treatment care and support would include offering treatment of opportunistic infections free of charge, an adequate and consistent supply of food supplements, supplying antiretroviral treatment in the CHWU, improving counselling and support services to reach all SSLWHA, and assisting educators with relevant information to address students living with HIV.

Eradicating stigma and discrimination would involve training of all members of staff in the CHWU to accept and assist SSLWHA in a non-discriminatory and non-stigmatising manner.

Ensuring confidentiality can be achieved through the improvement of the infrastructure used for HIV/Aids services and also by offering all treatment on campus instead of referring SSLWHA to overcrowded hospitals.

The author recommends the use of Mavhandu-Mudzusi and Netshandama's (2014) management model for HIV/Aids in a SARBU as it is contextually relevant to the SARBU's situation. Quantitative research should be conducted on a large scale to determine other needs and expectations of SSLWHA at SARBUs and how they are addressed.

LIMITATIONS

Most of the people interviewed were female and some of them were stationed in the HIV/Aids unit and thus co-responsible for rendering services to other staff and students living with HIV and Aids. This may have biased the information given. Secondly, the sample was drawn from a population of students and staff members on campus who were involved in activities related to HIV/Aids. As their knowledge regarding HIV/Aids may be different from other SSLWHA who are not directly involved, their needs may not be representative of the entire university SSLWHA. Finally, the researcher was a member of the university staff, which might have influenced the way participants responded during the interview. These considerations indicate that although the present study identified notable patterns, the explanation of such patterns may require further investigation.

ACKNOWLEDGEMENTS

The author would like to thank the SARBU for granting permission and providing the funding for this study to be conducted, all the persons who participated in the study, and Prof VO Netshandama for her guidance and support.

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