PATIENTS' EXPERIENCES OF COMPREHENSIVE ANTI-RETROVIAL TREATMENT RENDERED BY PROFESSIONAL NURSES AT SELECTED PRIMARY HEALTHCARE CLINICS IN THE EASTERN PROVINCE OF SOUTH AFRICA

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ABSTRACT

Studies indicate that once persons living with AIDS (PLWAs) enter the healthcare system, they run the risk of receiving inadequate care because of being stigmatised by healthcare providers (Bos, Schaalma & Pryor, 2008:450). The purpose of the study was to determine how PLWAs experienced their treatment by professional nurses at primary health care (PHC) clinics in one metropolitan area in South Africa.

The study adopted a qualitative, explorative, descriptive and contextual research design. Purposive sampling was used to select ten participants who fitted the selection criteria from selected public primary healthcare (PHC) clinics in the Nelson Mandela Bay Municipality. In-depth unstructured interviews were transcribed verbatim by an independent person. An independent coder assisted with the data analysis.

PLWAs had fewer negative than positive experiences at the participating PHC clinics. Negative experiences included stigma-related encounters and distrust of the lay health counsellors. Positive experiences generally related to the PLWAs' satisfaction with the services received.

Based on the findings of the study, guidelines were developed for professional nurses to render more user-friendly comprehensive ART services.

Keywords: comprehensive ART management, HIV/AIDS stigmatisation, lay HIV/AIDS counsellors, persons living with HIV-AIDS (PLWAs), primary health care (PHC)

INTRODUCTION AND BACKGROUND INFORMATION

South Africa has the highest number of persons living with HIV globally (UNAIDS, 2011:7). In 2008, the South African National Annual Anonymous Antenatal Survey on pregnant women estimated that a total of 5.3 million individuals were living with HIV (UNAIDS, 2011:7). More than 17.5% of South Africa's adult population is infected with HIV. South Africa's national HIV-prevalence rate amongst pregnant women was 29.3%, while the Nelson Mandela Bay Municipality reported a rate of 29.0% (Department of Health (DoH), 2007).

In November 2004, the South African Cabinet approved the 'Operational Plan for Comprehensive HIV-AIDS Care, Management and Treatment for South Africa', which was developed by the National Department of Health (DoH, 2004:1). This plan was necessary because HIV infection progresses from a prolonged asymptomatic stage, during which the person's well-being can be maintained, until a stage is reached where anti-retroviral therapy (ART) becomes a critical part of the care and treatment strategy (DoH, 2003:54). ART prolongs and improves the quality of life of PLWAs. The development of an effective ART programme is a critical component of the larger comprehensive plan to care for PLWAs.

People infected with HIV should have access to care and support services meeting their changing needs over the course of their lives (DoH, 2003:54). ART services should be comprehensive, providing treatment, care and support for the patients. Education on prevention of re-infection and further spread of HIV are important aspects of a comprehensive ART programme (DoH, 2010:44). Treatment involves prophylactic medicines for opportunistic infections and full-blown AIDSto delay the progression of HIV-infection (AbdoolKarim & AbdoolKarim, 2010:529). The concept "care" involves services to stabilise and/or improve the health of individuals infected with and affected by HIV/AIDS, while "support" involves interventions to stabilise and/or improve community and social systems affected by the epidemic (AbdoolKarim & AbdoolKarim, 2010:381). South Africa's government adopted a continuum of care approach, integrated from primary to tertiary levels, and from pre-diagnosis to palliative care (DoH, 2004:1).

To make ART services more accessible, these services have been incorporated into the local district hospitals and into certain PHC clinics. The HIV/AIDS care and treatment programme intends to integrate care and treatment with prevention efforts such as HIV counselling and testing (HCT), prevention of mother-to-child-transmission (PMTCT) and tuberculosis (TB) control. However, studies indicate that once PLWAs enter the healthcare system, they run the risk of receiving inadequate care because of being stigmatised by healthcare providers. Stigma can also interfere with ART adherence and increase the stress levels of PLWAs, which can aggravate the progression of AIDS (Bos, Schaalma & Pryor, 2008:450). HIV/AIDS-related stigma in sub-Saharan Africa (SSA)

presents a serious challenge to the understanding, mitigation and prevention of HIV (Lorentzen & Morris, 2003, in Deacon, 2005:8).

STATEMENT OF THE RESEARCH PROBLEM

In 2001, the healthcare sector was identified as the place where one is most likely to be stigmatised, followed by the family, community and church (HDN & Swedish International Development Agency, 2001:1102). A pilot project in the Eastern Cape Province of South Africa revealed that serious impediments can arise from stigmatisation and discrimination of PLWAs (Mitchell, Kelly, Potgieter & Moon, 2009:79). People might thus remain scared to use HIV testing or treatment services for fear of stigmatisation. The researchers wanted to find out how PLWAs experienced their treatment by professional nurses at selected PHC clinics in the Nelson Mandela Bay Municipality, the centre of major hospitals and ART clinics in the Eastern Cape Province

PURPOSE OF THESTUDYAND RESEARCH QUESTIONS

The purpose of the study was to explore and describe the experiences of PLWAs with regard to their treatment by professional nurses at selected PHC clinics in the Nelson Mandela Bay Municipality, in order to develop guidelines for enhancing the quality of ART services, based on the research findings. The research question that underpinned this study was: What are the experiences of PLWAs regarding the comprehensive ART management received from registered nurses at selected PHC clinics?

Definitions of keyconcepts

Comprehensive ART management encompasses the universal access to a comprehensive package of HIV treatment, including ART, integration of HIV and TB care and treatment, counselling, support, prophylaxis, treatment of opportunistic infections and appropriate referrals (WHO, 2003:3).

Persons living with HIV/AIDS (PLWAs) imply that these persons have tested positive for HIV and are living with HIV-infection and/or full-blown AIDS.

Primary health care (PHC) clinic refers to clinics rendering ART comprehensive management in the public sector in the Nelson Mandela Bay Municipality.

Stigmatisation refers to a situation where society categorises individuals into certain groups, and the labelled person is subjected to status loss (Jacoby, 2005:171).

RESEARCH METHODOLOGY

A qualitative, explorative, descriptive and contextual study was conducted at eight selected PHC clinics in the Nelson Mandela Bay Municipality. The research population comprised ART patients at these eight participating clinics. The criteria for inclusion in the sample were that the person had to receive ART at the clinic for at least three months, irrespective of adherence factors, and be able to express him/herself adequately in English.

In-depth interviews were conducted posing one broad question to each participant: 'Tell me about your experience of attending this ART clinic'. Probes and follow-up questions were used. Interviews lasted 40-45 minutes and data saturation was reached after 10 interviews.

The researcher informed the registered nurse manager of the clinic about the project and presented the letter granting permission from the manager of the organisation concerned. Interviews were conducted during January 2007. At some clinics the designated interview room was private and quiet, but at others there were occasional interruptions and background noise due to on-going renovations at the clinic. One researcher approached the patients as they left the consulting rooms, informed them about the research and requested their participation. The interviews were recorded and thereafter transcribed by an independent person. The researcher and an independent coder analysed the field notes and the data independently, to develop independent themes and categories, which were later compared and contrasted and discussed until consensus had been reached. Coding was done according to Tesch's guidelines (Creswell, 2003:192) to reduce the data into themes and categories. One pre-test interview was done prior to conducting the actual interviews.

Trustworthiness

Guba's model (Holloway & Wheeler, 2002:254) was used to ensure trustworthiness:

Dependability was met by describing the context of the study in detail to account for any changes in the design created through increased understanding of the phenomenon.

Credibility means that the findings are compatible with the perceptions of the participants. Credibility in this study was attained by utilising reflexivity, peer review and an independent coder.

Transferability was achieved by providing a dense description of the research process and of the findings in order to increase the probability that the findings have similar meanings in similar situations.

Confirmability was attained by maintaining an audit trail whereby all the records pertaining to the study were meticulously kept for continuous referrals (Holloway & Wheeler, 2002:255). An independent coder and reflexivity enhanced confirmability. A consensus discussion took place between the coder and the researcher to agree on themes and categories.

Ethical considerations

Ethical approval was obtained from the Nelson Mandela Metropolitan University (NMMU) Research Ethics Committee (Human). Permission was also granted by the relevant manager before entering any clinic and from each clinic's nurse manager to approach patients outside the consulting rooms. Informed consent was obtained from each participant after explaining the purpose of the study and they were assured of confidentiality and anonymity. Voluntary participation was maintained. Participants were protected from harm byutilising the principles of beneficence, human dignity and justice (Polit & Hungler, 2001:130). The principle of beneficence was ensured by developing good rapport with the participants and emphasising that they could withdraw at any time if the interview became distressing. Participants were fully informed about the study and promised counselling should the need arise. Participants were given the right to decide for themselves whether they wanted to participate or not. Purposive sampling ensured that the participants were selected fairly and non-discriminately. Sensitivity and respect for the beliefs, habits and lifestyles of people from different cultures were maintained throughout the study.

ANALYSIS AND DISCUSSION OF RESEARCH RESULTS

Biographic data

Out of ten participants, six were females; eight were African and two were coloured; three lived in townships in Uitenhage and seven lived in Port Elizabeth. Only two participants were employed. The findings of the study emanated in one central theme and two sub-themes reflecting the experiences of PLWAs with regard to the treatment received from professional nurses at ART clinics. A literature control was conducted to contextualise the research findings.

PLWAs' negative experiences at ART clinics

The participants' negative experiences related to a lack of resources and long waiting times at the ART clinics.

Lack of resources

The lack of human resourcesis evidentfrom the following quotes:

"Everything is good, there's only one problem, the government must hire more staff because there's only one lady here...not enough nurses, the delivery is slow".

"They can organise more doctors here, there is only one doctor, if you are very sick you must wait until the doctor comes – at least there should be two or three doctors".

The overall shortage of healthcare personnel is a chronic national and international healthcare problem affecting both the public and the private health sectors. A WHO report estimated that 4 million healthcare workers are needed to combat the 'chronic shortage' globally (Capazorio, 2006:10).

The lack of physical resources experienced by the PLWAs was related to clinics in need of repairs to handle their clients. A few participants indicated that the clinics were not consumer-friendly and that there was no outside shelter while waiting for the clinics to open. Combined with a compromised immune system, PLWAs have the added stress of trying to stay warm in cold conditions, which puts them at further risk of ill health.

Participants also reported a shortage of HIV-related literature at the clinics, as illustrated by one participant who said:

"The pamphlets here are very rare. They must recognise, it is not all of us that have education about HIV."

Pamphlets and other literature should be available for patients to take home with them to reinforce what they had been told at the clinic. There should be adequate supplies of appropriate health education materials in the local languages at ART clinics (DoH, 2000:1-89).

Long waiting times at the clinic

Long waiting times at clinics caused frustration, anger and helplessness among the participants. They needed to be helped promptly, especially when they were ill.

"The queue; it is too long – sometimes they will start to work very late while you come early, early- you will be sitting there, waking up very early in the morning, sometimes they start late only 9:00 while you were queuing 5:00, people will be standing outside, we are sick."

In a study conducted on service-related barriers to voluntary counselling and testing (VCT), Van Dyk and Van Dyk (2003:4) contended that large patient turnover rates and low counsellor-to-patient ratios caused concern in South Africa. For example, the

average number of patients consulted for VCT at a rural district hospital in the Eastern Cape is six per hour, averaging only 10.0 minutes per client. Professional nurses need to explain to the patients that adequate counselling, with regard to ART adherence, cannot be rushed, hence the reason for the long waiting times.

Lack of professionalism amongst some professional nurses

The participants were fearful of reporting missed doses of ARVs or of fetching their ARVs later than their scheduled appointments, by stating:

"They mustn't shout at us...then you'd be scared to come."

However, one participant indicated that the professional nurse should be a bit harsh, so that patients would listen to her:

"I don't blame the nurse, I'm wrong; she must do it because I give her a hard time...I must get a little bit scared."

Nursing is a helping profession because nurses care about, and for human beings (Mellish, Brink & Paton, 2004:9). When nurses practise in an ethical manner they adhere to ethical principles like autonomy, beneficence, justice, veracity, fidelity, confidentiality and privacy. Despite the fact the ethical and legal framework of nursing practice is defined in the Nursing Act (no 33 of 2005), the ethical conduct of nurses does not always meet the standards set by these ethical principles.

Negative attitudes of nurses towards HIV-positive patients could occur because of ignorance, high mortality rates associated with the disease and the stigmatisation of PLWAs. This might negatively influence the quality of care rendered to HIV-positive patients (Deetlefs, Greeff & Koen, 2003:24).

Bos, Schaalma and Pryor (2008:450) noted that healthcare workers' negative attitudes towards PLWHAs influenced patients' access and use of healthcare facilities and also their ART adherence levels. These authors further stated that patients fearing nurses' attitudes had to overcome their pain, anxiety and doubts, because their lives depended on the close cooperation with nurses.

Discrimination and stigma experienced at clinics

Some respondents reported various forms of discrimination such as withholding treatment because of having an HIV-related symptom, or being forced to use contraception, as illustrated by the following quotes:

"Uhh, the nurses are quite good, but there is one time that I felt bad. I had some pimples on my buttocks and when I reported it to the sister she told me you are HIV-positive, as if it is right to grow these pimples."

"I don't think it is right for them to force us to take an injection[contraceptive]."

Although PLWAs experienced some stigmatisation from professional nurses, these were reportedly not as negative as those portrayed in a report by Sonjica (2006:5). This report portrayed patients' visits to the ART clinics as 'nightmares' because some professional nurses were insensitive and unprofessional. The article stated that one of the PLWAs described the treatment received from the clinics as being 'painful.'

The PLWAs' reported primary fear, when approaching a clinic was the possibility that the disclosure of their positive HIV status to healthcare staff would not remain confidential, and would result in various forms of stigma (Greeff, Phetlhu, Makaoe, Dlamini, Holzemer, Naidoo, Kohi, Uys & Chirwa, 2008:315). Such fears might be validated as a study by Deetlefs et al. (2003:29) confirmed that the attitudes of nurses towards PLWAs were largely negative.

A longitudinal study in South Africa by Maughan-Brown (2010:372) suggests that stigma has in fact increased over time among young adults. This trend appears to be reflected by participants in this study who continued to experience stigma.

Institutional discrimination was identified by participants who described being allocated separate areas in the clinic and given folders that looked different from those of other patients, making their HIV status known:

'When we are sitting there on these chairs they know, I'm sure, that that space is for HIV, you know, they just look and walk."

Separate facilities and colour-coded folders serve to visibly mark a person as having HIV, exposing him or her to other forms of stigma. Van Dyk and Van Dyk, (2003:4) reported that it is common practice in hospitals and clinics to demarcate a special room for HIV counselling. This might help to reduce stigma when people realise how widespread the problem is. However, some people might feel uncomfortable about coming to HIV/AIDS clinics for VCT and ART in such a stigmatised climate while other patients might resent the special status of PLWAs.

Participants' perception that lay health counsellors were not trustworthy

Volunteer lay health counsellors are part of a national programme, including categories of volunteers collectively known as Community Care Workers (CCWs). The participants

indicated that they were uncomfortable sharing information with the CCWs. They also felt that the volunteers should not do home visits because they lived in the same communities as the PLWAs, and might not treat their information confidentially. Some PLWAs experienced the volunteers as being untrustworthy who failed to treat their information with confidentiality:

"One day there was a volunteer here, she was the one who gossips...she comes here and looks at my folder and then is going to the street and tell the people..."

Van Dyk and Van Dyk (2003:4) stated that one of the major challenges for the South African health services is to change the image of its counsellors to that of trustworthy people. Confidentiality must be emphasised in training programmes. Community members might be unable to distinguish between professional nurses and the lay health counsellors at their healthcare facilities, and unethical behaviour by the latter could tarnish the image of the nursing profession. The PLWAs wished that professional nurses should do the home visits rather than the volunteers.

PLWAs'positive experiences at ART clinics

Nurses' conduct

Many participants indicated that, prior to their first ART clinic visit, they were fearful because of rumours about professional nurses' conduct. However, their fears were usually unfounded as indicated by the following statements:

"The people they were telling me that the nurses treat the patients badly, but I discovered that I was in good hands actually."

Confidentiality maintained by professional nurses

No participant reported any breach of confidentiality by a professional nurse and stated:

"We experience that our status are being kept confidential."

"I never had an experience that someone (professional nurse) did not keep confidentiality, no problem."

Although this is encouraging for the nursing services in the Nelson Mandela Bay Municipality, it does not seem to be the case elsewhere. Literature, regarding the issue of confidentiality, states that public healthcare services in Africa, which are often overburdened, generally fail to provide confidential treatment (Deacon, 2005:77).

Professional nurses' and doctors'care and support

The participants expressed praise and appreciation for the professional nurses and doctors at the ART clinics. Reportedly these patients experienced care, empathy and encouragement from professional nurses and doctors in a non-discriminatory way that made them feel happy and good, as revealed by the following quotations:

"The sisters, the doctors, everyone cares about us – to me I am very happy about that."

"Inside this clinic the people they've got good hands, open hands and a good smile for me, and the nurses are also talking nicely, they don't shout or anything or talk rude or anything."

"They are friendly, everyone. If I am hungry they send me to the community centre next door – I can get some soup and bread."

Participants expressed their appreciation of the spiritual support that they received from some of the professional nurses. Religious convictions of nurses reportedly play a positive role in their reactions towards HIV-positive patients (Deetlefs et al., 2003:29).

Other participants reported that they were treated effectively for their opportunistic infections:

"I get the attention that I want because if I say I've got chest problem, anything that I ask I am complaining about, they have got medication for that thing."

Other PLWAs' support

The participants indicated that they experienced the support received from their fellow-PLWAs as therapeutic because it gave them hope:

"...when he talked to me, this patient, I felt no, I am not alone and if he could make it I can also make it."

"I support somebody if they tell me ooooh, I'm sick, I don't know what's wrong, then I support them. Sometimes somebody who sits near me supports me also."

The participants expressed an interest in support groups, but indicated that the support group should meet at the clinic because they feared that curious individuals, who simply wanted to see who was HIV-positive, might attend these meetings at other venues. As with any disease, support mechanisms around those infected and affected can mean the difference between coping or failing to do so. Coping skills, as well as stress management, healthy lifestyle practices and counselling issues could be addressed during such meetings.

Counselling and education

All participants indicated that the counselling and education that they received from the lay health counsellors and professional nurses were positive and non-judgemental.

"When you got a problem they are not judgmental, they listen to your problem and give you advice and then when you come next time they ask you is the problem solved."

"I even got their phone numbers, I feel weepy at night, I am so stressed and want to talk to somebody, I just call them about my problem now, that is how they encourage me."

The effort to provide counselling to the PLWAs, calls upon healthcare workers' most human traits and challenges their feelings about sexuality and mortality. The counsellor must convey a hopeful, positive and caring attitude that can be healing, without minimising the painful struggles endured by the patient.

CONCLUSION

All participants had reached a stage of openness and were willing to relate their experiences regarding the treatment they received from professional nurses at the participating ART clinics. Their negative experiences were rooted in a lack of resources, long queues at the clinics, lack of professionalism amongst some professional nurses, various forms of discrimination and stigma and untrustworthiness of lay health counsellors. Although all the participants experienced various forms of discrimination and stigma, no participant experienced a breach of confidentiality by a professional nurse. The participants' positive experiences, concerning the caring and supportive attitude of healthcare staff members exceeded their negative experiences.

RECOMMENDATIONS AND GUIDELINES

Recommendations, based on the findings of this study, apply to nursing practice, education and research.

The possible applications to nursing practice include the provision of healthcare services that are 'friendly' to PLWAs, including VCT and prevention, treatment, care and support services that need to be scaled up. Communication, interaction and listening to patients should be facilitated through reviewing the staffing patterns in line with patient numbers and patient acuity, so that time for emotional support is also calculated when determining staffing needs.

Table 1: Broad guidelines for professional nurses that could enhance the rendering of user-friendly comprehensive ART services

Principal guidelines	Sub-guidelines
Create a therapeutic environment conducive to rendering user- friendly comprehensive ART services	Promote an improved physical environment for PLWAs Promote a therapeutic psychological environment for PLWAs Prevent stigma and discrimination of PLWAs
Ensure that all aspects of comprehensive ART services are integrated	Integrate prevention and education messages for HIV-positive patients Uphold the patient's right to access to treatment Integrate care and support services when rendering ART management
Identify and improve areas for the training and support of lay health counsellors (LHCs) to enhance confidentiality.	Professional nurses should enhance the capacity of lay health counsellors (LHCs) under their supervision Ensure support for LHCs Professional nurses should act as role-models for LHCs.

Recommendations with regard to nursing education include that in-service education programmes and workshops should enhance professional nurses' and volunteers' stigma-reducing skills. The code of ethics and professional conduct, taught in the basic training curricula, should be emphasised and applied to PLWAs.

Quantitative research should determine the extent of stigma encountered by PLWAs at specific clinics, and address the identified factors influencing such experiences.

LIMITATIONS OF THE STUDY

The limited sample size, and the specific nature of the sample and research context (specific clinics), imply that generalisations are not possible. The participants might have been hesitant to disclose any negative experiences because their survival depends on these clinics and on the staff members, especially the nurses and doctors.

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