Article

Experiences of Patients and Registered Nurses regarding the Antiretroviral Therapy Programme

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Abstract

The purpose of this study was to explore and to describe the experiences of nurses and HIV-positive patients regarding the antiretroviral therapy (ART) programme in primary healthcare (PHC) settings in Lesotho. A descriptive qualitative design was used to collect data which were analysed using a constant comparative analysis. Purposive sampling was used to select participants who participated in focus group discussions. Five themes and 19 sub-themes emerged from the data analysis, namely the ART programme, ART service delivery, unavailability of antiretrovirals (ARVs), staff providing ART services, and satisfaction with ART. The results showed that many HIV-positive individuals accessed ART in PHC settings. Nurses symptomatically managed patients, while patients used alternative healthcare providers owing to inadequate resources and malfunctioning equipment. Even though the nurses were proficient in ART service provision, they were few resulting in work overload and provision of inadequate services. The time taken to provide ART services was dependent on conditions of service providers, the number of patients and the availability of basic utilities such as water. Follow-up care was inadequate for HIV-positive individuals who worked in South Africa. Multiple testing was evident owing to the lack of adequate counselling and untoward incentives. ARVs purported hunger, while stigma was still evident. Conclusively, to ensure effective delivery of ART, retention in care is vital. PHC facilities must therefore be equipped adequately with sustainable equipment, and have scaled-up routine monitoring and evaluation for the effective implementation of the ART programme.

Keywords: antiretroviral therapy services; challenges of ART; experiences regarding ART; HIV/AIDS programme; Lesotho; primary healthcare

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Introduction

In Lesotho, most patients receive healthcare in primary healthcare (PHC) settings which are managed by nurses, an initiative permitted by the Government of Lesotho due to the scarcity of medical doctors. PHC is driven by a political philosophy emphasising a radical change in the design and content of conventional healthcare services and necessitating an approach allowing people to receive services which enable them to lead social, economic and productive lives (Obioha and Molale 2011, 73). With the integration of HIV/AIDS services into the PHC system, resources concentrated within HIV care were extended to a broader patient population without diminishing patients' perceived satisfaction levels (Odeny et al. 2013, 6).

The success of ART depends on early diagnosis, appropriate ART, high levels of viral suppression, management of toxicities, and adherence to treatment. Views on the ART programme are crucial to understanding the mindsets of nurses and patients concerning the ART programme. In a study by Chiegil, Zungu, and Jooste (2014, 373) the recipients of care were satisfied with uninterrupted ART drug supplies, polite treatment, volunteerism of support group members and quality counselling services. Patel et al. (2012, 111) reported that participants agreed that ART was beneficial as their health improved although factors such as commuting long distances, long waiting times and repeated recalls to the facility, posed as obstacles to access ART services.

Service providers' perspectives on ART included challenges with adverse effects of medications, patients' distrust that ART would be beneficial and their lack of trust in the government facility (Patel et al. 2012, 110–111). Tabatabai et al. (2014, 1, 8) cited various reasons for treatment interruptions including travel costs, treatment fatigue and healthcare provider-related reasons, such as the lack of treatment supporters, health booklets and poor provider-patient relationships.

Anecdotal evidence identified various ART implementation challenges including insufficient human resources, the lack of equipment, and inadequate ART supplies. This study, therefore, sought to explore and describe the experiences of nurses and patients concerning the ART programme in PHC settings in Lesotho.

Problem Statement

Evidence of experiences of either healthcare providers or patients regarding the implementation processes of the ART programme remains limited, especially in resource-limited countries. Anecdotally it has been reported that patients are unable to go through complete blood testing, wait in long queues for services, fail to collect their medications owing to employment commitments, or are lost in follow-up care. Tedious paperwork during the provision of services and staff overload due to inadequate human resource allocations have also been reported to affect service provision. This study,

therefore, sought to explore and describe the experiences of patients and nurses regarding the implementation of the ART programme.

Aim of the study

The aim of this study was to explore and describe the experiences of nurses and patients concerning the ART programme in PHC settings in Lesotho.

Research Question

What are the experiences of HIV-positive patients and nurses regarding the ART programme in PHC settings in Lesotho?

Methodology

An explorative descriptive qualitative design was used as it allowed understanding of experiences of HIV-positive patients and registered nurses regarding the ART programme. The study population included individuals who were HIV-positive and who sought ART services, and nurses who provided ART services in PHC settings. The non-probability sampling method using a purposive sampling technique was used to recruit the study sample who participated in four focus group discussions.

As they came for their statistical reporting meeting, the researcher introduced the study and invited the nurses to take part in the study. Sample one comprised two nurse clinicians and three registered nurse midwives of which one was male and four were female, while sample two had three registered female nurses. Their ages ranged from 27 to 62 years and their experience of providing ART services ranged from 2 to 11 years.

As they came in for their regular ART services, the HIV-positive individuals were introduced to the study and requested to participate. Sample three comprised seven HIV-positive individuals, two males, and five females, while sample four comprised four HIV-positive individuals, two males and two females. Their ages ranged from 23 to 55 years and they had started taking ARVs from 2005 to 2015.

Data Collection

The data were collected from August to October 2015. The researcher developed guides for the focus group discussions. A pretest focus group discussion with nurses was done and the results were included in the study. The focus group discussions took 60 to 90 minutes and had a maximum of 13 questions. The focus group discussions with nurses were conducted in English while those with HIV-positive individuals were conducted in Sesotho. Permission to record the discussions was sought from all participants and it was granted. A digital voice recorder was used and field notes were taken to document non-verbal communication. The audio recordings were transcribed verbatim.

Trustworthiness

To ensure credibility, sufficient time during data collection was invested to ensure an in-depth understanding of the participants' experiences. Participants' demeanour and behaviours were recorded and the interview context was described in detail. To ensure dependability, a digital recorder was used and the data were transcribed verbatim to enable accurate capturing of the discussions. Probing was used to allow the researcher to record information that was true from the participants. The researcher also returned to the participants to verify their responses. To ensure confirmability, a code book was developed and used consistently during the coding process. A third independent co-coder was used during the development of themes. To ensure transferability, a detailed vivid description of the research context, the people who participated in the study, experiences and processes which were observed during the inquiry was given, and four focus groups discussions were conducted using the same research context.

Ethical Considerations

The benchmarks for ethical research from Emanuel et al. (2004, 930–936) were used to guide the ethical principles in this study and include collaborative partnership, social value, scientific validity, fair selection of study population, favourable risk-benefit ratio, independent review, informed consent and respect for recruited participants and study communities.

Ethical clearance was obtained from the Higher Degrees Committee from the University of South Africa (RECID-012714-039). Permission to conduct the study was sought from the Ministry of Health in Lesotho (RECID136-2014) and its partners, and it was granted. The participants voluntarily decided to participate in the study and provided written consent. A confidentiality agreement was completed to ensure that all information discussed during the focus groups was not shared. The participants could ask questions, refuse to provide information and/or withdraw from the study. The facilities' managers provided private rooms where the focus group interviews were conducted. All the information provided was kept in strict confidence and only used for purposes of the study. The information collected was not used against the participants in their employment status or when seeking healthcare services. The participants were encouraged to disclose any feelings of insecurity during the course of the discussions and were allowed to discontinue the discussions if they felt uncomfortable. There were no implicit or explicit threats for refusing to participate and no rewards for participation. Results from this study provided suggestions for better implementation of the ART programme.

Data Analysis

The constant comparison analysis (Leech and Onwuegbuzie 2007, 565) was used during the data analysis. The researcher listened to recorded interviews and transcribed verbatim. The data were initially coded into small data units. Axial coding was then

used to develop categories, followed by selective coding to arrange the categories into themes. A co-coder confirmed the coding and theme development processes and outcomes.

Results

Table 1 shows themes that emerged from the data analysis. A total of five themes and 19 sub-themes emerged from the data analysis.

Table 1: Emerging themes

Themes	Sub-themes
ART programme	Beneficial programme Demanding programme
ART service delivery	Variety of ART services Routine ART services Inadequate ART resources Malfunctioning equipment Alternative healthcare providers Symptomatic management of patients Employment commitments hamper monitoring of patients Inadequate ART documentation Waiting times at ART facilities Remuneration Inadequate ART counselling Untoward incentives
Unavailability of ARVs	
Staff providing ART services	Proficiency of staff Inadequate staff More staff necessary
Satisfaction with ART services	ART evokes hunger Stigma related to ART

Theme One: The ART Programme

This theme describes the ART programme as helpful and busy.

A Beneficial Programme

The ART programme was described as providing beneficial services as it resulted in patients' better health:

> We get the services well. It's a programme that has really helped us to survive.

Demanding Programme

The nurses explained that the ART programme's demands were great as many patients sought these services:

> Hectic, heavy, busy. It keeps us on our toes. It`s a hectic programme. There are too many patients.

Theme Two: ART Service Delivery

This theme describes the experiences of the implementation of the ART programme.

Variety of ART Services

The patients identified available ART services:

> Adherence, counselling, family planning, laboratory monitoring, TB screening, treatment of other ailments, screening of TB and STIs, consultation. We do support sessions. Blood is taken on Wednesdays only. We are also given food for the kids.

Routine ART Services

The nurses explained that ART services were routinely provided every week and that the patients knew the operating times:

> The services are routine as the patients even know the operating times at the facility.
>
> Usually services are for five days but even Saturday and Sunday like prevention of mother to child transmission (PMTCT) we still provide services. PMTCT is given for the whole seven days of the week since the women can come to deliver on weekends and if they have to be initiated immediately, they get the service.

Inadequate ART Resources

The nurses exclaimed that they experienced challenges in monitoring ART patients:

> As planned! We have a major problem. It's very difficult. No! Resources are not adequate at all. Resources are a major challenge.

Malfunctioning Equipment

The machines for checking CD4+ counts and monitoring patients' blood assays were dysfunctional:

> We do not have CD4+ machines to monitor patients. It has been broken for more than a year now.

> But there are patients on zidovudine (AZT) who need to have their haemoglobin (Hb) checked and we are in a dilemma to continue giving the treatment and we do not have a way of checking the Hb. As we know AZT reduces the Hb level.

> Even venereal disease research laboratory test (VDRL) we were doing it ourselves. The slides for this one are not there.

Patients also explained that they did not undergo routine tests owing to the lack of CD4+ machines:

> This is the second year and now even going to the third year without a CD4+ machine.

Use of Alternative Healthcare Providers

The participants sought CD4+ services at other facilities, even though not all received the services:

> They have informed us about the seven clinics on the paper just behind you. Those are the facilities from which CD4+ tests are being done. So an individual personally goes there at their own extra expense.

> The problem with those clinics is they refuse to take blood to check the CD4+. They check CD4+ for the patients they tested. So now we don't know what to do.

Symptomatic Management of Patients

Clinical monitoring of patients was an alternative solution used by nurses as they lacked blood-profiling machines:

> But for others, we just do clinical monitoring. But it is wrong. Sometimes the patient can look fine when the CD4+ count is gone. It is not correct but due to the circumstances that is all we can do.

Employment Commitments Hampered Monitoring of Patients

Persons from Lesotho working in South Africa were inadequately monitored and it was uncertain whether they received treatment while in South Africa:

> Except for patients who are working in South Africa; they usually send their relatives and we always ask them to tell the patients to come for routine tests. They usually do not come. This is not right.

> One gets caught up on whether to continue giving the drugs or not. If I withdraw treatment, maybe this was a good patient taking the medicine properly. If I continue, maybe this patient needs close monitoring. So really it becomes a challenge.

> And when we ask them they say they were getting treatment in RSA but there will be nothing written down as proof.

Inadequate ART Documentation

Incomplete ART registers resulted in inefficient service provision:

> Sometimes we run out of registers and they take a long time before we get them.
>
> Not only registers but also ART cards. And it takes some time to get the cards. The documents are never complete.

Waiting Times at ART Facilities

Patient waiting times depended on the number of patients:

> We get the services on time but it depends on how many patients are in front of the queue before me as on some days there are many patients.

The availability of drinking water at facilities affected time spent at the facilities:

> Like now you see that there is no water and now the vehicle from the hospital has brought water for the nurses. So they had to stop and get the water.

Interruptions from other facilities and persons influenced the time patients spent at ART facilities:

> Sometimes there are disturbances from other agencies, who come to see the registers and hence the nurses stop giving us the services. They will continue seeing patients later.

Remuneration

Poor remuneration for treatment supporters affected ART service provision:

> You will also find that some of us have been lay counsellors and unfortunately the work we do is not appreciated. We are only given a meagre salary of only M700.00. [M700 is equivalent to R700 or approximately US$50]

Inadequate ART Counselling

The nurses attributed multiple HIV testing by patients to result from inadequate counselling:

> That's why it's been wondered why after all our efforts there is no change. In fact, the incidence and prevalence are on the rise. Sometimes the patients do not understand and hence they test many times and they test anywhere.

The patients resorted to multiple HIV tests due to frustrations resulting from the lack of CD4+ machines:

> Some of us who will be desperate to get the CD4+ count done, we end up testing again at the facilities that have such machines. And it means that one is actually recorded twice in the system, even if they are already on ARVs.

Untoward Incentives

The provision of incentives by Ministry of Health (MOH) partners resulted in many patients' repeated HIV testing, as explained by the nurses:

> There are too many partners who screen for HIV and offer incentives to patients. An individual will test again and again as long as they can get something in return.
>
> Even those on ART will test again since they want the incentive. And when we check, we find that this patient is already on ART but they have been recorded as a new HIV patient with that partner.

The patients reiterated:

> Partners helping the MOH, just get into the village and start testing individuals without informing the clinic. And there are some of us who do not understand and test again regardless of being on ART or pre-ART period.

Theme Three: Unavailability of ARVs

The nurses explained that ARVs were sometimes unavailable at their facilities:

> We have stock-outs once in a while, otherwise, they are available.

Patients also explained that unavailable ARVs resulted in interrupted treatment:

> It has happened that there were times when ARVs were few. We were given ARVs for three days and asked to come back after some days, even though others did not. Those who worked in South Africa were even given a supply for three months.

Theme Four: Staff Providing ART Services

This theme refers to the experiences of the nurses regarding their ability and adequacy to provide ART services.

Proficiency of Staff

ART providers were perceived to be confident and competent in the provision of services:

> Confidence is there, enough knowledge and skill are there, competence is there.

However, the nurses felt they needed regular refresher courses to keep up to date with the ART programme:

> Always we need some refresher courses to remind us of what is supposed to be happening.

Inadequate Staff

Inadequate staffing resulted in work overload:

> No, we are not adequately staffed. We are so short-staffed that sometimes we just offer basic services. It is too much. With this supermarket approach, it is very difficult to get all services done properly as we are few.
>
> Mmm, disaster! We are also conducting deliveries and it means more shortage of staff.
>
> The population is fifteen thousand nine hundred and something and we see more than 100 patients per day in total, whilst we are only three.

The patients also indicated that services were interrupted when women had to be assisted during childbirth:

> But I think they are not enough. Because if there is a woman to deliver, they stop helping us so they conduct the delivery.

More Staff Regarded as Necessary

Both nurses and patients confirmed the need for more staff at the facilities:

> We could have an addition of three more nurses because we still have to do other duties. At least if we are four, even five to cater for one who might be on leave.
>
> Again on Mondays and Fridays only two members of staff are on duty as they take turns for off days. At least if they are five, it will really help.

Theme Five: Satisfaction with ART Services

The patients were partially satisfied with ART as it caused hunger and there was still social discrimination.

ART Evokes Hunger

ARVs reportedly aggravated hunger:

> Many patients on ART complain of hunger. The tablets make us feel hungry.
>
> We usually have some packed food. Truly speaking they make us abnormally hungry.

Stigma Related to ART

The patients did not disclose their HIV status to prospective employers as there was fear of stigmatisation:

> When they tell their employers that they are on ART, others are sent away from work. We are now afraid to tell prospective employers that we are HIV-positive as they will not understand that we must collect the drugs every month.

Discussion

In line with previous studies by Nyangu and Mokwena (2015, 70) and Patel et al. 2012, 111), this study shows that ART continues to be the treatment choice for people living with HIV/AIDS (PLWH) as it improves their health significantly. The programme is coupled with many patients, an observation in line with the Joint United Nations Programme on HIV/AIDS (UNAIDS) data which reported that there was an estimated 36.9 million PLWH worldwide, and 21.7 million of them accessed ART in 2017 (UNAIDS 2018).

In this study, various services were routinely offered on a weekly basis. However, there were healthcare provider related challenges, including inadequate resources and malfunctioning equipment which inevitably resulted in the symptomatic management of patients by nurses and the use of alternative ART providers by patients. It was reported that ART documentation was incomplete as sometimes the stock of registers and ART cards ran out. The time it took for ART patients to receive services was influenced by conditions of service providers, the number of patients and the availability of basic utilities. Follow-up care was a challenge especially for the patients who worked in neighbouring South Africa. Discontentment with the remuneration was reported by patients who provided supportive care. Inadequate ART counselling and untoward incentives also contributed to multiple HIV testing by patients as they sought either ART services or to be afforded some kind of reward.

Retaining patients in care depicts the effectiveness of ART services towards meeting UNAIDS 90–90–90 targets (UNAIDS 2018) and results in viral load suppression (Brown et al. 2016, 2855). However, this remains complex, especially in low- and middle-income countries (Wubshet et al. 2012, 1). Several previous studies have attested to challenges in the provision of ART (Bekker et al. 2014, 110; Mutevedzi and Newell 2014, 1016; Tabatabai et al. 2014, 1), including poor resource allocation, long queues, cleanliness, staff attitudes, treatment interruptions, treatment fatigue and healthcare provider-related reasons, human resource shortages, too few patients receiving ART, too many patients starting treatment late, the lack of equipment, and poor clinical monitoring of patients.

Previously, there were instances when ARVs were unavailable owing to a lack of supply from the main pharmaceutical dispensing authority. Individuals that worked in South

Africa were, however, afforded a three month supply, while those residing locally had to return to check. Treatment interruptions did occur for those who did not return to receive their full course of treatment. This observation is in line with results from a study by Bekker et al. (2014, 109) who reported that ARV stock-outs had negative consequences including treatment interruptions leading to treatment failure and drug resistance requiring a therapy switch to more costly and less tolerable second-line ARVs. Provision of three to four months' ART treatment supply to adherent patients could reduce patients' absence from work time and the burden on overstretched dispensing systems (Bekker et al. 2014, 109).

Staff providing ART services were proficient in their duties, however, they required sustained educational support. Mtshali et al. (2019) explained that perceptions regarding the competency of graduates from pre-service programmes to deal with complex population and healthcare system needs were negative and served as proof for the need for advanced preparation of nurses and midwives. The number of nurses was inadequate to provide effective ART services and more were deemed necessary. This was also explained by Uys and Klopper (2013, 2) who concluded that for the effective running of PHC settings, at least one specialist nurse, five registered nurse midwives, and four enrolled nurses are needed. The participants in this study suggested four or five nurses at PHC facilities. A nurse-mentor driven mentorship programme enabled competent nurse initiation of most ART patients (Green et al. 2014, 1). Crude retention on HIV care was higher in patients who started ART initiated by nurses in rural Lesotho (Labhardt et al. 2013, 1), while using mid- and low-level cadres as substitutes for physicians improved access and sustainability of health services in rural and peri-urban communities in Ethiopia (Assefa et al. 2012, 27).

The patients were partially satisfied with ART as the medication made them feel hungry, an observation in line with a study by Au et al. (2006, 2116) who concluded that the unavailability of adequate nutrition affected long-term adherence to treatment as patients feared to develop too much appetite without enough food to eat. There were associated stigmas especially in work environments, as was reported by Kalichman et al. (2018), that some participants did not take their ART in social settings to avoid stigmatisation. Therefore, behaviours that patients employ to avoid stigma are paramount to interventions that directly improve ART adherence.

Conclusions

As a developing country, Lesotho faces challenges in the implementation of the ART programme. Dysfunctional equipment poses major setbacks for the ART programme resulting in questionable adequate monitoring of patients and retention in care. The patients had to move from one facility to another seeking blood-profile monitoring services and in the process, others resorted to retesting as a way of ensuring they got the service. Care retention was found to be a challenge for patients who worked and resided in neighbouring South Africa and many did not appear at PHC facilities to get their

medication. As Lesotho is completely surrounded by South Africa, aspirations for the two countries to have more bilateral agreements to curb HIV remain.

Paper documentation such as ART registers and cards were not always available, therefore affecting the regular tracking of patients. More nurses trained in ART provision to deal with the increasing number of patients requiring ART are needed to avoid work overload and poor service delivery. Continued education and training of nurses involved in ART remain paramount to the effective delivery of services as information on HIV management is updated.

Multiple testing by patients raises concern for the need to have coordinated efforts between the Government and other partners assisting in the propagation of ART. ARVs were reported to cause excessive hunger and the daunting question is, therefore, the ability of the many patients in ART to meet bodily nutritional requirements. This study proves the need for further public education on avoidance of stigma and discrimination towards HIV-positive individuals.

Recommendations

Retention of patients in ART care can be achieved if there is adequate allocation, maintenance and accessibility of resources, especially blood-profiling machines and tracking tools. There is a need to review the staffing of nurses in PHC facilities to be in line with the growing numbers of patients who seek ART. Regular ART programme monitoring and evaluation are key to ensure implementation remains aligned with care objectives. Public health education is crucial in dealing with issues of multiple testing and avoidance of stigma and discrimination towards HIV-positive individuals.

Limitations of the Study

This study did not seek to ascertain the outcome impacts of the ART programme and more information could have been obtained if the focus group discussions had not been carried out within PHC facilities.

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