

End-user centeredness in antiretroviral therapy services in Nigerian public health facilities

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Abstract

Objective: To describe the perception of end users with regard to end-user centeredness in antiretroviral therapy (ART) service provision in Nigerian public health facilities.

Design: A qualitative design was followed.

Subjects and setting: Unstructured focus group discussions were conducted with end users (n = 64) in six locations across the six different geopolitical zones of Nigeria.

Outcome measures: Data were analysed using the framework approach and Weft QDA® version 1.0.1. qualitative data analysis software.

Results: The results focused on end users' participation in their care, ranging from understanding their diagnosis, choosing from available treatment options and places, and caring for their colleagues and themselves.

Conclusion: End-user focused ART service provision positions end users to play key roles in decision-making with regard to their care. The findings of this study will be useful for nurses and other healthcare workers when promoting end-user centeredness in ART service provision.

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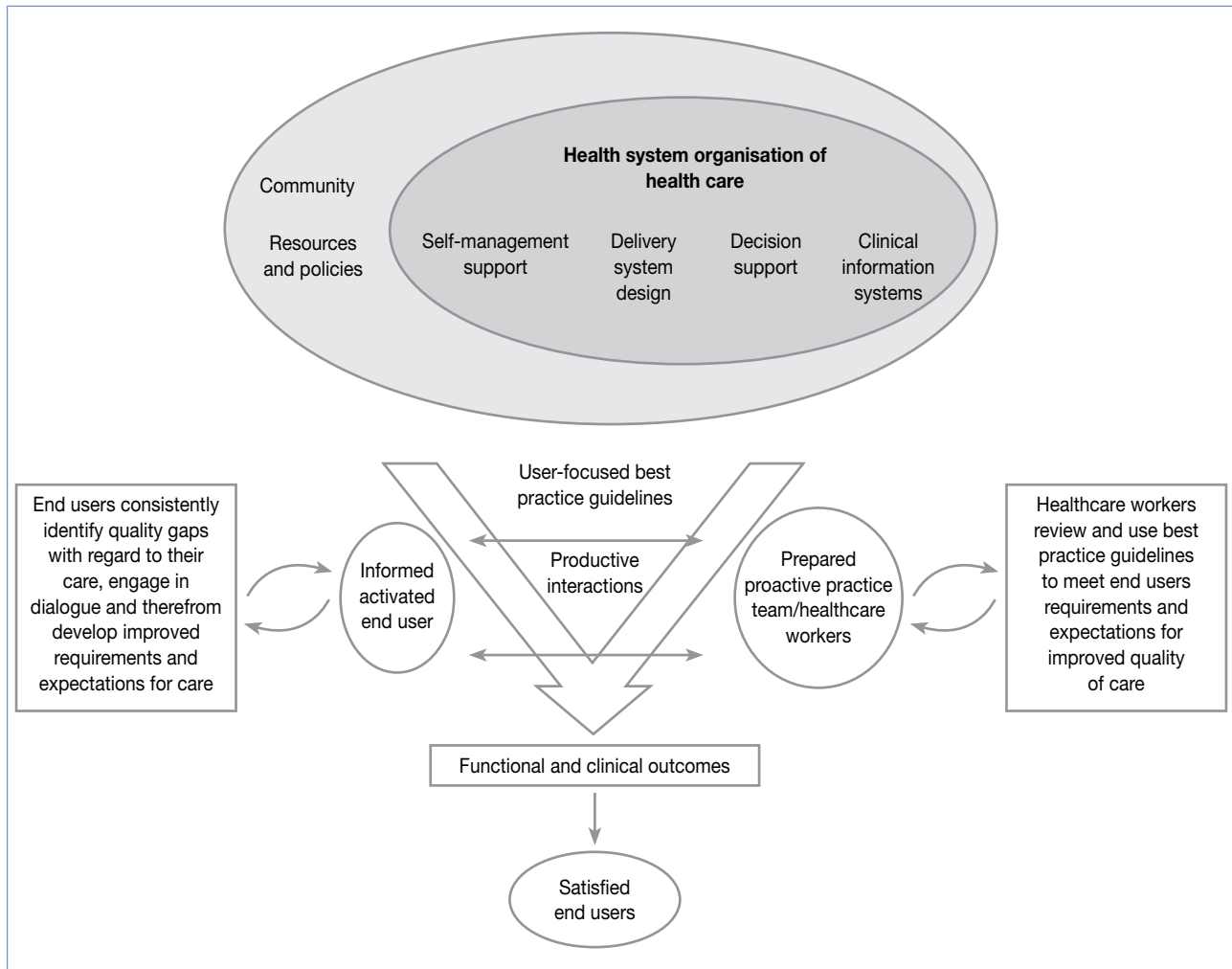
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Introduction

End-user centeredness is a core component of quality health care.¹ It is defined as health care that establishes a partnership or shared decision-making among practitioners, end users and their families to ensure that decisions respect end users' needs. Also, end users have the education and support they need to make decisions to participate in their own care. Shared decision-making is a process in which end users are encouraged to participate in selecting appropriate treatment or management options.² Shared decision-making is appropriate whenever there is more than one reasonable course of action as no single option is best for everyone. Knowing about the various available treatment options and having a say in these is more important to most end users than having a choice as to where to be treated.³ To maximise impact, it is important for antiretroviral therapy (ART) programmes to recognise end-user decisions with regard to various treatment options.⁴ Despite a widespread view among healthcare workers that the right to end-user

choice is relevant only in urban centres, a King's Fund study found that end users living in rural areas were both more likely to be offered choice and more likely to travel to a non-local provider.²

Evidence is growing that engaging end users in treatment decisions and managing their health care can lead to more appropriate and cost-effective use of health services and better health outcomes.^{1,3} The end user-centered approach encourages end users to comply with treatment guidelines and reduce the underuse or overuse of medical care.¹ It also reduces misdiagnosis by healthcare workers. Although some studies have shown that being end-user centered reduces medical costs and the use of health service resources, others have shown that end-user centeredness increases provider costs, especially in the short term. End users want an explanation about their symptoms, treatment or investigations.³ Many have ideas about what is wrong and what may have caused it, but they do not always articulate these. Information provided to end users



ART: antiretroviral therapy

Figure 1: Adapted Wagner's Chronic Care Model⁷

about self-care was the most important predictor of overall satisfaction in end users.⁵ Failure to engage with end-users' agenda can lead to misunderstandings, dissatisfaction and poor outcomes.³

Theoretical framework of the study

The Chronic Care Model (CCM) was used as the theoretical framework for this study (Figure 1). The CCM consists of multiple "enablers" of good quality care, that once implemented, improves the quality of ART services.⁶ The enablers have characteristic features which address the healthcare processes, structures and mean values of the health facility. The model also has features that focus on the multiple dimensions of end users at the same time. Lastly, the CCM assumes a dynamic relationship between improved performance and the implementation of interventions based on the model's enablers.⁶

For instance, in respect of continuous quality improvement to meet end users' expectations, keeping the quality standards consistently high requires continuous cycles

of participatory planning, diagnosis, implementation, evaluation and end-user feedback, and further planning.

Problem statement

Overstretched ART programmes in Nigerian public health facilities and inadequate human resources could hamper the attainment of end-user centeredness in ART service provision. Against this background, this paper sought to address the research question: "What are the perceptions of end users concerning end-user centeredness in ART service provision in Nigerian public health facilities?" The results of this study contributed to the development of end-user-focused recommendations to nurses and other healthcare workers with regard to the delivery of quality ART service provision in Nigeria.

Method

The study was conducted in six secondary-level public health facilities, commonly known as general hospitals in Nigeria, and which provide ART services in Nigeria. These health facilities were selected from the following states: Anambra

(south-east zone), Edo (south-south zone), Lagos (south-west zone), Sokoto (north-west zone) and Yobe (north-east zone) states; and the Federal Capital Territory (north-central zone) of Nigeria. The selection of public health facilities from the six different geopolitical zones of Nigeria was carried out to depict the lived experiences of participants from different settings (to enhance the richness of the collected data). A qualitative, descriptive and explorative research design was used in this study. A research design was preferred in this study because it provides an accurate and real-life reflection of the experiences and characteristics of the end users who participated in the research.

The study population comprised end users of ART services who met the following inclusion criteria: receiving ART in a government-designated centre in a public health facility in Nigeria, being at least 18 years old, attending the ART programme for at least six months on a continuous basis, and being willing to provide written consent to participate in the study. The researcher purposively approached participants who met the eligibility criteria for inclusion in the focus groups, and who also provided written informed consent to participate. The purposive sampling technique was the preferred approach for this study because it enabled the selection of the most readily available end users for the study.⁸

Unstructured focus group interviews were conducted in six groups of 8-12 each ($n = 64$), in settings that were familiar to the participants.

The major question contained in the prepared focus groups was followed by probing questions, guided by the information elicited during the focus groups.⁹ The researcher took control of the focus groups to facilitate discussions within the scope of the study. The researcher also allowed participants to freely share their perceptions concerning the quality of ART service provision in the public health facility. A focus group notetaker assisted in taking detailed notes and managing the audio tape recorder. The researcher also took brief descriptive summaries that included thoughts and feelings about the focus group interviews, descriptions of the participants and sketches of their sitting arrangements. This information was used as part of an audit trail in support of the confirmability of the study findings, and for triangulation with the notetakers' briefs in data analysis. Each focus group lasted 60-90 minutes, was conducted in English, except in the north-east and north-west regions, where the focus groups were conducted in Hausa, and then translated into English after transcription. Hausa was preferred in these locations because the selected participants could not communicate fluently in English. Participants were asked to share their personal experiences when presenting for ART services at the public health facilities in Nigeria. The researcher explored the attitudes of healthcare workers to

end users and end users' participation in decisions regarding their care, including their choice of treatment regimen. The researcher left when he was satisfied that the data had maximally highlighted the experience and explained the key concepts. He also ensured that the objectives had been suitably reflected in the data, that the research question had been satisfactorily answered, and that there was no new forthcoming information, insight or knowledge, indicating data saturation.

Data analysis

To address issues of trustworthiness pertaining to the qualitative research, the researcher used both manual and electronic software methods of data analysis. The framework approach (manual method) was used in this study.¹⁰ The five stages of data analysis used therein include familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation. Once the themes and subthemes were identified, the analysis was repeated again using Weft® qualitative data analysis version 1.0.1 to validate the results obtained using the framework approach.

Trustworthiness

The researcher took steps to ensure the trustworthiness of the study. Trustworthiness is the extent to which a research study is worth paying attention and taking note of, and the extent to which others are convinced that the findings are to be trusted.¹¹ Credibility standards involve performing specific activities which increase the trustworthiness of the reported findings.¹² In this study, the researcher engaged with the research, established valid and meaningful relationships with the participants, and was open to deeper meanings that unfolded during the research process. The researcher interacted with experienced research colleagues in the workplace who provided guidance for research design, data collection and data analysis for the purposes of the review and consensus on how to proceed. The researcher shared the transcripts with the respondents for review and correction of the researcher's interpretation of the meaning of the data.

Transferability

The study report provided discussions on the nature of the participants, their reported experiences and obtained data, and the researcher's observations during the study, methods of data analysis and the interpretation of the research findings. The researcher also made references to the raw data, kept available for any interested persons (researchers) to cross-check or verify. Therefore, this detailed information potentially rendered opportunities to interest others so that the extent to which the study findings could be generaliseable or transferable could be gauged.¹²

Dependability

The researcher engaged a consultant to conduct independent data collection and analysis at one of the study sites. The data and analyses were then checked for comparability and similarity, and discrepancies resolved through “member checking” with the participants.¹²

Confirmability

The researcher used audit trails, in which approaches to data collection, decisions about which data to collect and the interpretation of data were carefully documented so that another knowledgeable researcher would reach the same conclusions about the data. This also served to protect the human subjects, as required by institutional review boards.^{12,13}

Ethical considerations

Ethical approval to undertake the study was obtained from the Department of Health Studies Ethics and Research Committee at the University of South Africa (UNISA) (ethical clearance certificate number 3675-728-4) and from the National Health Research Ethics Committee (NHREC) (ethical approval number NHREC/01/01/2007-12/05/2011), Federal Ministry of Health, Abuja, Nigeria. The approval ensured that the research proposal was fully scrutinised, adding credibility to the quality of the study. Ethical issues were also explained and participants assured that they could withdraw from the study at any time, or refuse to answer any question with no penalties. Participants were informed that the focus groups would be tape recorded once their permission was obtained, and that the researcher would take notes during the interview. Participants in this study signed consent forms and agreed to participate therein.

The tape recordings, verbatim transcriptions and observation notes relating to this study were kept under lock and key by the researcher. Only the researcher had access to these data until the research report was accepted by UNISA in 2012. The researcher also took steps to protect the rights of the participants and the relevant institutions to the study, and to ensure the scientific integrity of the research.¹²

Results

Participants' demographic data

Sixty-four participants were interviewed during six focus group discussions, held in six locations, representing different geopolitical zones in Nigeria. The majority of the participants (71.88%, $n = 46$) were female and 28.13% of the participants were male ($n = 18$). Most participants owned their own businesses (32.81%, $n = 21$), and the occupation of 31.25% ($n = 20$) was categorised as “other”. (This comprised participants who stated that they did nothing for a living, or had lost their jobs owing to ill health).

Most participants were within the age range of 31-40 years (51.56%, $n = 33$). 23.44% were aged 21-30 years ($n = 15$). Most participants had attained Ordinary level (O'level) qualifications (29.69%, $n = 19$), and had been involved in the ART programme for 2-3 years (50%, $n = 32$).

Focus group discussions

Four themes emanated from the analysis of qualitative data obtained from the focused group discussions. These included:

- ART services to meet the participants' requirement of end-user centeredness.
- Participants' perceived success using the ART services.
- ART services that prevented participants from meeting their needs (dissatisfaction with the services).
- Participants' suggestions as to how to improve the quality of ART service provision.

This paper focuses on end-user centeredness. Therefore, the results presented in this paper are based on the theme of the perceptions of end-user centeredness in ART service provision in Nigerian public health facilities. Other themes that did not relate to end-user centeredness are beyond the scope of this paper. Therefore, they will be presented and discussed in a separate paper.

To present the findings on end-user centeredness, applicable direct quotes are supplied that substantiate the relevant results. Relevant literature was used to validate the findings of the current study.

Results emanated from the focus group discussions that ART service provision in Nigerian public health facilities is perceived as follows.

Courtesy treatment provided by the healthcare workers reinforced end users' confidence in the public health facilities. One participant said: “I enjoy the treatment of the doctors. The doctors, they are too good, and the nurses, the people they are working. They are too good. I enjoy the hospital because they take care of me. When I came here, I was very lean. I didn't know I'll be like this now. So, I enjoy their treatment and the drugs given to us, I enjoyed it”.

Participants expressed confidence in the quality of the counselling services in the public health facilities: “In fact, their counselling here is good. They tell you the importance of what you are about to start and tell you you shouldn't stop taking them (antiretroviral drugs)”.

A participant expressed her view on the level of trust and freedom among people living with human immunodeficiency virus (HIV): “Somebody who is positive will be more at home when handled by an HIV-positive person. Somebody will meet somebody who is HIV-positive and say: ‘Even me, I am positive. That same person will say: ‘Are you positive?’”

He'll say: 'Are you truly positive?' And I say: 'Yes!' Because I know. I am an adherence counsellor, so I know people who come in. I know how they feel when I tell them I am also positive. They come down well".

A participant recounted his experience of the courtesy of nurses in the ART clinic, which he described as very bad: "The nurses, they call matron or something like that. The way they shout about people having this virus. It is as if you are no more a living person. They will see you and say: 'Was it me who gave you the sickness?' They are not even telling us that there will still be life. That is why I always ask. Maybe they don't know how someone in this problem feels. In fact, they are very harsh. It may be that the person's mouth has an odour, or your ear may be having a problem, not able to hear something clear. Something like that. They'll be shouting at you, that's my own experience. These are not even exaggerations. That is how they did it to me and up until now, that's how they are treating patients, especially new patients there. My own (experience) is easier. The way they handle them (new end users) is very, very bad. Their services are very poor".

Participants perceived that changes in health facility leadership might have contributed to weak responsiveness to their demands: "Based on my own observations, the administration is not giving us enough support. The support we are expecting will give us space where we can meet as a support group. If we have a problem with the hospital, we should take the case to the administration, and they should give us a forum to tackle the case".

Another said: "Most of the challenges we started having is that they transferred the doctors and [managing director (MD)] who recognised the support group. So, immediately with these people gone, we started having problems. Even our current (MD) now, he doesn't recognise the support group".

End users who had complaints to file against healthcare workers were unaware of the procedure to do so (inadequate processes with regards to complaints management): "At a point, after waiting (to be tested in the laboratory) for so much hour, some of them will be asked to (go and) come again. It is not obtainable outside Nigeria what is being done here. Sometimes, I used to hear that there are certain mistakes that the doctor will do and the patient will sue that doctor, but that cannot happen here. I have heard cases of a doctor throwing away a patient's folder, probably because he was annoyed and he knows that nothing will happen. And if, just like my sister said, I wish to know if she has been denied the right to collect her drug on the appointment day, what does she do? Or what (will happen to) the person who refused (to give the drug)?"

Analysis of the food discussion groups showed that participants expected health facilities to continuously improve quality and processes to meet the changing requirements and expectations of end users. End users continuously demanded more sophisticated care: "We want them to be doing viral load for us. Viral load, they are not doing it here. We want them to be doing it for us".

Participants wanted internal processes to be improved to increase end users' satisfaction with the services: "Let the pharmacist, the doctor, the counsellor... just put them closer, so it should be a bigger place. Or let them appoint someone to carry the folders to the pharmacy, not the patient carrying their folders".

Another said: "What should be done is simply let the CD4 count machine be made functional. If it becomes functional, if it starts working, well maybe you have two or three CD4 count machines there. You come anytime you are scheduled to. But the issue is if it is not functioning, people are packed up and are told: 'Without your CD4 count at the next appointment, no drug', or something of that nature.

Participants wanted measures to be instituted to prevent the extortion of end users by syndicates: "What I am suggesting is to advise the person that is doing it (extorting money from patients) to stop doing it. Because they will not bribe to do it. It is so difficult because some people will wake up very early to make sure, but when they come here, they'll be told that their time has passed. So, my suggestion is to approach the person that is doing it so that the person will stop doing it".

End users demanded automation of recordkeeping systems to enhance the easy storage and retrieval of data: "For the patient management and monitoring, we were saying about the personnel. The only difficulty will be new clients. You'll just ask for the card number and click on the Lafiya Management Information System, an electronic medical record, to access records for existing clients".

Participants demanded segmentation of record-retrieval terminals according to age: "Sometimes, you may see a mother who just gave birth maybe one week ago. Maybe she come to see the doctor. She'll come with the baby, the newborn baby. In a place where adults stay, and you don't know whether there's somebody who has tuberculosis around there. And not even that, when that person reach there, that they'll even attend to that person. They'll tell her to go and wait until when it is her turn, before they'll bring out the folder. So, I'm suggesting they separate the paediatric folders from the adults. Keep them in the place where they see children, so that when you come for children, you just go straight there. They will remove the folder and see you there".

Participants demanded gainful employment of persons living with HIV: "Some of our members are not doing anything. Most people, the reason why they just collapse at last is they take their drugs, and don't eat fine. Some cannot afford two square meals a day. So if there is anything, like there were some people who came here to rehabilitate people. Maybe, if there can be anything like that".

End users wanted support in the form of a microcredit scheme to support group members: "At (another support group), they lend them Nigerian Naira (N) 40 000. At the end of the month, they pay back N 2 000. They give them 20 months to pay back everything".

Participants requested uninterrupted, affordable or free supplies of basic care kits: "They (people living with HIV) used to come and ask that they need a water purifier, whether we have or not. If we don't have, we tell them we don't have. They are telling me that they used to, but at N 150-N 200 outside, but some of them do not have the money to buy".

Another said: "The issue of basic care kit, like a water purifier. Some used to buy, but many of us cannot afford that N 150 to buy".

Participants required assistance in the form of food and food supplements: "We need assistance in the areas of food and food supplements", and "Maybe, if we can have some multivitamin drugs and antibiotics", and "Like we used to go, one support group, last Saturday of the month. If you finish the support group, they give us rice, milk, beans and immune boosters, but here they don't give us anything. That's why they (people with HIV) don't come here".

It was felt that healthcare workers should ensure that end users presenting at health facilities benefit from a full assessment of their current health status, and receive counselling, if needed: "Like when I leave my house, and come to the hospital for a check-up. I know that I am coming to collect drugs, but because it is a check-up, I expect that all formal medical questions should be asked and tested. Like when I go, most times, when it is time to go into the doctor's room, I'll say: 'I want to check my blood pressure'. He'll say: 'Must you check your blood pressure?' I'll say: 'I want to check. I want to know what my blood pressure is and I want to know my weight.' Even though I am fat, I want to know my weight. If there's a way I can reduce it, if it'll have an influence on me".

End users would like there to be strengthening of linkages with other groups and organisations in the community to promote a complementary service: "There is a manual (referral directory) which contains all of the organisations, all those volunteer and donor organisations. Like myself, there are people who we linked through that manual (referral directory) and they support us with materials".

Participants wanted end user volunteers to be recognised by their fellow colleagues, and capacity building and motivational programmes to be designed to meet their task requirements and expectations: "Projects should assist support groups to access gatekeepers and assist in advocacy efforts to improve their visibility and the welfare of people living with HIV".

Lastly, it was requested that HIV/acquired immune deficiency syndrome should be incorporated into regular health services, and end users encouraged to regularly attend clinics: "Let the clinic days be from Monday to Friday. Now, they only do three times a week. If the clinic day is held from Monday to Friday, it will help in addressing some of these problems (the congestion of patients and long waiting times on clinic days)".

Discussion

The following key findings relating to end-user centeredness emerged from this study. The courtesy service provided by doctors, nurses and other health workers served as a source of encouragement for people living with HIV. However, there were also instances of perceived increasing incidences of failure to treat end users with courtesy and which related to the inadequate capacity of health workers and to staff burnout. In such cases, health facilities should recognise people living with HIV as volunteers, and designed capacity building and motivational programmes to meet task requirements and volunteers' expectations. Participants reported that empathising with end users during counselling improved their quality of life. Therefore, health facilities should ensure that end users presenting at health facilities benefit from a full assessment of their current health status, and are counselled on emerging clinical manifestations that need medical attention. Health facilities should recognise that people living with HIV appreciate interacting with their peers, and create opportunities for such interaction as part of the continuum of care process. Additionally, health facilities providing ART services should develop linkages with relevant facilities to obtain specialised diagnostic services, and accept referred end users and laboratory results from such facilities. Although the health facilities continuously improved quality and processes to meet the changing requirements and expectations of end users, weak responsiveness to the needs of end users by the health facility leadership and inadequate processes and procedures to manage end users' complaints were still evident.

Courtesy treatment by the healthcare workers develops confidence in end users and empowers them to want to take on more self-care roles. This element pertains to self-management support in the CCM. This principle requires that healthcare workers should set a tone of collaboration

with chronic end users and encourage their participation in setting goals and enhancing treatment.^{7,14} The majority of end users were critical about staff behaviour, and wanted to be seen and treated as fellow human beings.¹⁵ Therefore, health facilities that are known to be unfriendly will lose end users to their competitors.¹⁶

It emerged from this study that empathising with end users while counselling them improved their quality of life. This means that when healthcare workers empathise with end users, they instil confidence and the ability “to do it yourself” in end users. This, in turn, refers to empowering and preparing end users to manage their health and health care,^{7,14} the self-management element of the CCM. A study reported that 95% of end users receiving ART who participated in the study thought that the counselling sessions were good, and indicated knowledge gained and increased hope and the ability to make informed choices.¹⁷⁻²³ In addition to counselling, end users wanted to be assessed and have the assessment results properly communicated to them. This relates to strengthening internal systems to ensure that end users are routinely provided with basic assessments whenever they present for care in health facilities.^{7,14} End users wanted an explanation of their symptoms, treatment or investigation. Many had ideas about what was wrong and what might have caused it, but they did not always articulate it.³ Failure to communicate information about illness and treatment is the most frequent source of end-user dissatisfaction.³ Therefore, doctors and nurses should pay more attention to and take better care of end users.¹⁵ While this may be limited by the current inadequate staff capacity in health facilities, people living with HIV should be empowered to care for their peers and themselves to supplement the health workforce.^{7,14} This relates to self-management support in the CCM, and this empowers end users to make substantial decisions and to carry out personal actions regarding their care. Studies have found that end users who report greater involvement in their medical care are more satisfied with their healthcare workers.²⁴ They also report more understanding, reassurance and perceived control over their illness. Their medical conditions also improve. Another study found that end users who preferred a more active role were less satisfied when their nurses and physicians did not support their preferences.²⁴ While ART helps volunteer workers to regain the capacity to work, other economic support is needed to enable them and their households to re-establish their livelihoods, especially in resource-constrained settings.²⁰

Health facilities should continuously improve quality and processes to meet the changing requirements and expectations of end users. The CCM must be used as a total quality management tool to optimise care of this specific end-user group at operational or process level.²¹ Therefore, it is a convenient framework within which to

address quality and process-related issues. The function of CCM in healthcare organisations relates to creating a culture, organisation and mechanism which promotes safe, high-quality care, including making excellence a priority and pursuing it visibly. It involves continuously reviewing processes (process flow) and redesigning the processes to yield maximum value to improve the efficiency and effectiveness of ART service provision.^{7,14} To attain adequate continuum of care services, linkages with community-based organisations and other complementary services are fundamental to quality care. When advancing the benefits of the CCM, it is important to sustain seamless integrated care during the whole care process.⁶

It emerged from this study that weak responsiveness to the needs of end users by the leadership in health facilities, and lack of adequate processes and procedures to manage end users' complaints, were evident in the health facilities studied. Decision support was an element of CCM that examined leadership and policy issues and was relevant to this finding. Decision support relates to promoting clinical care that is consistent with scientific evidenced and end user preferences. This element related to promoting health facility management and the overall care process, and is consistent with the evidence and end-user preferences.^{7,14} Feedback from end users should form sufficient evidence to enable the leadership of the health facilities to take action. In Zambia, end users go from clinic to clinic, seeking better treatment, aware of the inability of the leadership of the health facilities to address drug shortages. This means they may not be prescribed the most appropriate or effective drugs.²² In other cases, the inadequate capacity of health workers prevented delivery of an explanation of a drug's action in the body, leaving end users to rely on past experience with pharmaceuticals and their own traditional and biomedical knowledge to interpret side-effects and efficacy once they began treatment.²² Health facility leadership should encompass qualities of compassion, empathy and responsiveness to the needs, values and expressed preferences of the end users.¹

A key finding in this study was that the health facilities had inadequate systems for complaints management.²³ Managing complaints requires active participation and coordination between the community and the health facility. The component of the CCM which addresses the link between the health facility and community-based opportunities is called “community resources”. This element involves mobilising community resources so that the community members manage their complaints and meeting the needs of end users who have long-term conditions, such as people living with HIV.^{7,14} The CCM requires that health facilities identify and establish systems and processes that ensure adequate complaints management systems in the health facilities and communities, and that encourage end users to

participate. The system also inculcates role clarification and preventive complaints management through open, clear and transparent communication. End-user centredness should be supported by good provider/end-user communication so that end users' needs and wants are understood and addressed, to enable the latter to understand and participate in their own care. Failure to engage with end users' agenda can lead to misunderstandings, dissatisfaction and poor health outcomes.³

Conclusion

End users' participation in decisions regarding their care is fundamental to ART services and health outcomes generally. End users' participation ranges from understanding their diagnosis, choosing from available options with regard to places and types of care, and caring for their colleagues and themselves.

Limitations

This was a qualitative study. Therefore, its findings cannot be generalised. Additionally, the researcher did not observe the quality of the ART service provision in the public health facilities.

Recommendations

The findings of this study should be applied to nurses and other healthcare workers to promote end-user centeredness in ART service provision. End-user centeredness should be integrated into the general guidelines for ART service provision and implementation monitored to enhance end-user satisfaction.

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Conflict of interest

We declare that we have no financial or personal relationships which may have inappropriately influenced us in writing this paper.

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