



Challenges of Antiretroviral Therapy Among Children in Free State Province, South Africa

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Abstract

Background/Aim: Antiretroviral therapy (ART) is an important intervention for survival among children in Sub Saharan Africa where HIV infection rates are comparatively high. Only few studies have explored issues relating to paediatric ART initiation and maintenance. This study was conducted to explore the perceptions and experiences of trained professional nurses regarding paediatric ART.

Methods: Six focus group discussions (FGDs) were conducted among trained professional nurses in selected health facilities in Free State Province, South Africa. Verbatim transcripts were analysed with a thematic approach.

Results: The participants of this study reported counselling as an important component of paediatric ART in health facilities. The problem of non-disclosure, migration, incomplete records from referral health facilities, inadequate health workforce and difficulty in record keeping were cited as barriers against paediatric ART.

Conclusion: This study showed that initiation and adherence to antiretroviral therapy among eligible children faces a significant challenge.

Key words: Children; Antiretroviral; Therapy; Challenges; Problems.

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ARTICLE INFO

Received: 10 August 2022

Revision received: 2 September 2022

Accepted: 2 September 2022

Introduction

Globally, an estimated 2.1 million children are living with HIV and almost 9 in 10 are in Sub-Saharan Africa.¹ While about 160,000 new HIV infections occurred in 2016, an estimated 120,000 deaths due to AIDS were recorded among children.² The introduction of antiretroviral therapy (ART) has been associated with significant changes in the natural course of HIV infection including improved clinical status and increased longevity.³ Furthermore, ART has also been associated with improved clinical states of children living with HIV. A prospective study reported a decline in the incidence of AIDS- and non-AIDS-defining illnesses among children.⁴ However, less than half of children living with HIV are currently accessing ART worldwide.^{5,6}

In Sub-Saharan Africa where the impact of HIV-infection is very significant, studies have shown that transportation and supplementary food costs, poor attitudes of health workers, fear of stigma and discrimination are barriers to uptake of ART and adherence to therapy.^{7,8} However, most of the studies on ART were conducted among adults. While knowledge of the barriers and facilitators of treatment access may help in addressing concerns and optimising health care delivery services, there is paucity of studies on the uptake of paediatric ART in health care settings. The objective of this was to explore and describe issues relating to initiation of HIV-infected children on Antiretroviral Therapy (ART) and identify enablers as well as barriers to ART initiation among eligible children in Free State Province, South Africa.

Methods

The present study was part of a study whose findings have been described elsewhere.⁹ The present study was conducted out in the three sub-districts of Manguang metropolitan district (Thaba Nchu, Botshabelo and Bloemfontein) of Free State Province. The prevalence of HIV infection among children aged 0-4 and 5-14 years in this province were 1.7 % and 2.7 %, respectively.¹⁰ The study was conducted among purposively-selected participants who were nurse-initiated management of antiretroviral therapy - NIMART-trained professional nurses.

A qualitative approach using focus group discussion (FGD) was adopted as a data collection method suitable for exploring and describing perceptions, attitudes and practices about health and social issues. Two sessions of FGD were held in each of the three sub districts of Mangaung and data collection took place over a period of three days. The conduct of FGD sessions were led by the principal author and demographic sheets were used for profiling of the characteristics of the participants. The interview guide included open-ended questions regarding the practice of initiation and maintenance on ART among eligible children in their respective health facilities, their experiences about paediatric ART and, recommendations for improvement in ART services in the province. Interview questions were followed with prompts to gain an in-depth understanding of participants' experiences, thoughts, and perceptions. Each FGD session lasted about one hour.

Audio recordings were transcribed by professional transcribers. Audio recordings were replayed and corrections made to transcriptions where appropriate. Field notes were also triangulated with transcriptions from audio recordings.

Based on emerging topics, data coding was done and verbatim transcripts were analysed with a thematic approach. Data were analysed using Atlas.ti version 7 software.¹¹

Validity and reliability

The lead facilitator is experienced in qualitative research methods and familiar with policy discourses in health systems and all efforts were made to ensure objectivity in this research. All original data were re-assessed after analysis to ensure any concept or information had not been missed. Findings were also shared with participants for validation.

Ethical Considerations

Ethical clearance (ECUFS NR 52/2013) for the conduct of the study was obtained on 21 May 2013 from the Research Ethics Committee of the University of Free State (UFS). The conduct of the study conforms to international ethical guidelines. Informed consent was obtained from all participants. Data was anonymised ensure that no sociodemographic variable was able to potentially identify any particular participant and access to the data was restricted only to the members of the research team. No compensation or direct benefits were given to the participants.

Results

Sociodemographic variables

The age of the 47 participants in the study ranged from 38 to 60 years with a median of 50 years. Majority (95.7 %) of them were females. All participants were trained professional nurses with experience in paediatric ART.

Theme and categories

Based on the analysis of the study data, the findings of this study are reported under the following themes:

1. Process of paediatric ART initiation and adherence in health facilities

a. Counselling as an important component of paediatric ART in health facilities

HIV counselling and testing (HCT) is usually followed by the conduct of other tests prior to initiation of patients on ART. A participant stated thus:

"...you can initiate after doing the test, the viral load and CD4 and explain to the mother..."

In addition to HCT and other laboratory tests, participants also explain to their clients the importance of adherence with medications.

"...explain compliance with taking the medicine every day.... you can tell the mother and you can say that your child will be healthy, you can be healthy, just comply and come to the clinic every month for your medicine and everything will be fine..."

Health workers often make comparisons between HIV infection and other chronic diseases to encourage or assist caregivers cope with challenges of adherence with ART among children.

“...So, I try to explain to people that we have to look at HIV the same way that people have to look at diabetes, they have to take the medicine every day. If you have heart disease, you have to take the medicine every day, so you can have a normal life. So, most of the people still have this mind set of if I have HIV, I have to go and apply for a policy for a funeral or whatever because that’s things of the past and you have to change that perception of I am going to die. No, you are not going to die, you stay with me, you come to my clinic and you will have a normal life and you can be healthy. So, that is good news and people start to take it. It’s easier for them to comply...”

b. Tracing of defaulters - an enabler of adherence

Health facilities support adherence with ART by promoting defaulter tracing. A participant explained: .”

“...Within our facility, the patients are coming every month because we have to fill these every month. So on the book list, we have, we are seeing the attendees, and also the data capturer is capturing that this patient was here today, so the following month, on this day, the patient will be/is supposed to be there. So, if the patient is not here, they are doing some follow ups; we are asking people to help us trace the patient and sometimes we are going, or we are phoning from our own cell phones and following up, following up on the patient...”

2. Challenges of ART initiation and adherence among eligible children

a. Caregiver-related problems

i. Problem of non-disclosure

Oftentimes, caregivers do not disclose the HIV status of children to them even when they are old enough to know. This prevents adequate follow up of children on the therapy (Figure 1).

“The main challenge there is that mothers who are on ART, even their children, they don’t know how to tell these kids why they are taking these medicines. But it’s very difficult and they want to always come to the clinic to collect for the kids, they don’t want to bring the children to the clinic.”

Participants explained as follows: “...Children don’t really know why they are taking this medication and if you ask them... you will find out that they

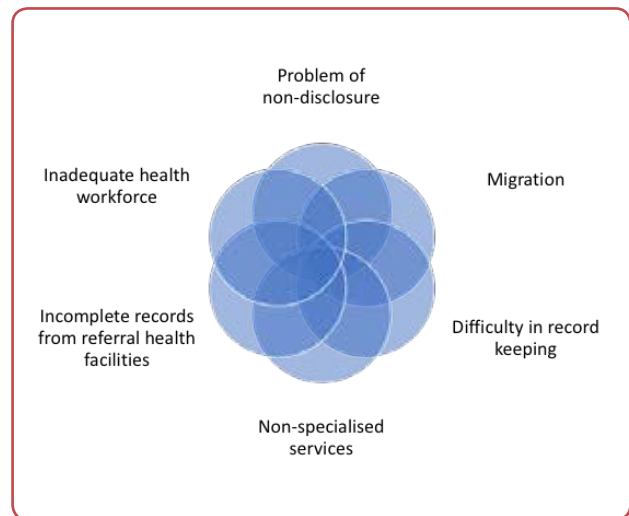


Figure 1: Challenges of antiretroviral therapy (ART) initiation and adherence among eligible children

really are not saying anything to the kids. The kids just know that they are taking these pills, and they don’t know what these are.....and sometimes they don’t want even to take them. So, I think that’s a challenge, because parents are afraid to talk about things to their children; starting from sex and everything, whatever. So HIV is something is like a taboo for parents to talk about with their children.”

“... that is why the mother end up saying that: You know, I am not ready for my child to know about her status... we also do consider that as a hindrance.... It is even difficult with the mothers...”

“...I remember the one that we have now... She was not taking treatment because she was afraid other children will mock her. She was not taking treatment gradually and surely, she was deteriorating. Now as I’m talking to you, she is bed-ridden with a shunt. She had TB meningitis. Her parents were not even aware that she was not taking treatment. She’s thirteen years old – bed-ridden. She was saying children were discriminating, so she decided not to take the tablets any longer...”

ii. Migration

Majority of the participants view inability to locate caregivers and their children as a major hindrance to paediatric ART:

“...The other challenge is that people are not staying at one place, you get the people starting at this clinic, and then they go to another clinic, say for instance the mother goes to the antenatal clinic at [...] but now the mother is not staying at [...], she is staying at one of the places. Then for immunisation and everything, she will go to another clinic...”

“...Sometimes, the parents are changing addresses. So, sometimes, we fail to initiate in time...”

b. Health system-related problems

i. Incomplete records from referral health facilities

Participants explained that when patients are referred to their facilities without adequate referral documents, initiation or follow up on ART is often hindered:

"If a client is referred from the hospital to the clinic, some of the records are not completed, it is only the profile of the client, the rest has to be done at the clinic."

ii. Inadequate health workforce

Participants cited the issue of few health workers attending to a large number of patients attending health services for several health conditions including paediatric ART as a major barrier to adherence:

"...Because, when you are using one pharmacist assistant, when he's not there, like us in our case now, that sister who's seeing that long queue, is even dispensing ARVs. So it's so difficult and when they lose patience, the patients just go away; they can't stay for long."

"..... that other person who is positive is still going back to the clinic for continuation of care. So shortage is clearly an issue, it's the main issue..."

iii. Non-specialised services

Participants reported that having to offer care to all categories of clients limit their ability to provide quality services to children eligible for ART initiation or maintenance:

"... it's very difficult to attend properly to clients if you are not a person who is dealing with children on a daily basis, so you will find that you will be doing some stuff, like seeing hypertensives or antenatal patients. All of a sudden there is a child, you know, you tend to forget these problems... It is very difficult to follow the protocol correctly and to keep all the statistics correctly... There has to be someone who's responsible for this programme..."

"...The children and adults want to see one sister. Really it is not going to be fair for those clients because sister will be seeing a hypertensive patient and then enter in the register. After that patient comes the child. The child is for immunisation, she is doing that. After that is the IMCI who is sick, after that is the one who is to be initiated. That sister is not really going to manage to do all these things at the same time. It is true she must know all but now to master every program is not going to be possible..."

iv. Difficulty in record keeping

Difficulty in the use of monitoring and evaluation tools was reported as a major barrier to paediatric ART initiation and maintenance:

"We visited one of the clinics, the professional nurse was working alone, initiating, seeing all other patients, the clinic was full. So we assessed the form, this form we fill for initiating, the forms were terrible. We struggled, I think we couldn't get eight files for the patients, the ones we got hold of, all the forms were terrible, so I think that this initiation form is not flexible."

"There is a lot of information which is needed, but you will find that the professional nurse has just left the spaces blank...the forms were all incomplete, some of the information, I think it was impossible for the poor registered nurse to fill in the form, because she was just hurrying to fill in the form and initiate."

3. Strategies for improving paediatric ART initiation and maintenance

Participants also identified possible strategies that may improve the coverage and quality of paediatric ART services as follows:

a. Community education to reduce stigma

Reducing stigma was highlighted as an important step towards improved care for children living with HIV:

"...This issue of stigma, should also be reduced because it is the only one, the possibility of the child to be helped out when necessary, because now, even this morning, somebody read us an item from the newspaper that we are, you know sort of discriminating these people who are HIV positive. Here in [...] you are having caravans where we isolated the people, so if you can just raise the health education of stigma, confidentiality and all that, may be that...will improve..."

"More education maybe on radios or stuff because the problem is like, here, people come from far then they are scared, I don't know, they don't want to go to their clinic where they live because people will see them..."

b. Increase trained workforce

Recruiting and training health workers on paediatric ART is important for improved care among eligible HIV infected children:

"On ARVs training matter, but at the moment we are

unable to go and train because we are short-staffed. So if you get more staff and then they should be trained on ARVs initiation."

"...I think training of nurses will be a priority issue, big priority... Nobody else will say that, the nurse does everything..."

c. Inclusion of HIV/AIDS in Primary School Curriculum

Including items on HIV into primary school education was cited by some participants as a strategy to improve care:

"...School health I think is where it comes in. Like now including it in the primary school curriculum and the school health professional nurses go into schools giving kids information about HIV and AIDS..."

Discussion

This study focused on exploring the perceptions and experiences of trained professional nurses on the practice of initiation and maintenance of eligible children on ART and strategies for improving care for HIV-infected children. The findings of this study are important in that only few qualitative studies exist on issues related to ART among children in Sub Saharan Africa. In the interactions, the study found that caregivers often hide children's own HIV status from them even when they are emotionally mature enough to know; migration of parents/caregivers hinder initiation and maintenance of children on paediatric ART; there is inadequate workforce to adequately cater to the needs of eligible HIV infected children; and community education including introduction of HIV-related topics into primary school curriculum will go a long way towards improving ART among children.

Caregivers' disclosure of infected children's own HIV status to them is an important component of the long term management of paediatric HIV/AIDS. While WHO recommends that children of school age should be informed of their status,¹² findings of this study show that non-disclosure of children's own HIV status limits the capacity of the health workforce to provide quality health care and support to eligible children. This is in keeping with the results of a systematic review which showed the rates of own HIV status disclosure to children as ranging between 0 %

and 69 % in resource-limited settings.¹² The review also reported improved adherence to medication after disclosure.¹³

Migration was a factor cited as a major barrier to paediatric ART in this study. When a caregiver migrates to a new area with their HIV-infected children without updating their contact details in the attending health facility, follow up on treatment and support becomes difficult. Studies have also reported migration as one of the causes of loss to follow up on ART among people living with HIV.¹⁴⁻¹⁶

Inadequate capacity of the health workforce in terms of number of professional nurses compared to patients reported as a major barrier to quality healthcare for HIV infected children in the present study was also observed in similar studies.^{17, 18} Participants in a qualitative study among health workers in Lesotho reported insufficient manpower and increased workload as one of the major difficulties facing health workers responsible for HIV care and support.¹⁹ While ratio of health workers to patients are often low in developing countries, lack of adequate training and poor infrastructure often complicate their tasks.

Community education aimed at reducing stigma was recommended by majority of the study participants as a useful tool for improving paediatric ART. This recommendation is important in that it has been shown that community mobilisation and education was associated with improved care for HIV infected pregnant women and their exposed infants in a study in Uganda.²⁰ Community education is capable of enlightening the public and creating synergies between healthcare facilities and the society towards mobilising for improved care of HIV infected children. Having a primary school curriculum with inclusion of appropriate HIV-related information was also cited as a strategy for improving paediatric ART.

This study provides data about perceptions and experiences of professional nurses regarding initiation and maintenance of HIV-infected children on ART. Participants highlighted enablers as well as barriers to ART among eligible children in the study area. The findings of this study are important as it is one of the few qualitative studies focusing on paediatric ART. However, this study was conducted only among professional nurses. Hence, perspectives of other health care workers were not explored.

Conclusion

This study showed that initiation and adherence to antiretroviral therapy among eligible children faces a significant challenge.

Acknowledgements

None.

Conflict of interest

None.

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