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## Full Length Article

# Accessing antiretroviral therapy for children: Caregivers' voices



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## ARTICLE INFO

## Article history:

Received 12 May 2015

Accepted 3 March 2016

Available online 1 September 2016

## Keywords:

Antiretroviral therapy

HIV-Positive children

Primary health care clinics

Caregivers

## ABSTRACT

Despite efforts to scale up access to antiretroviral therapy (ART), particularly at primary health care (PHC) facilities, antiretroviral therapy (ART) continues to be out of reach for many human immunodeficiency virus (HIV)-positive children in sub-Saharan Africa. In resource limited settings decentralisation of ART is required to scale up access to essential medication. Traditionally, paediatric HIV care has been provided in tertiary care facilities which have better human and material resources, but limited accessibility in terms of distance for caregivers of HIV-positive children. The focus of this article is on the experiences of caregivers whilst accessing ART for HIV-positive children at PHC (decentralised care) facilities in Nelson Mandela Bay (NMB) in the Eastern Cape, South Africa. A qualitative, explorative, descriptive and contextual research design was used. The target population comprised caregivers of HIV-positive children. Data were collected by means of in-depth individual interviews, which were thematically analysed. Guba's model was used to ensure trustworthiness. Barriers to accessing ART at PHC clinics for HIV-positive children included personal issues, negative experiences, lack of support and finance, stigma and discrimination. The researchers recommend standardised programmes be developed and implemented in PHC clinics to assist in providing treatment, care and support for HIV-positive children.

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## 1. Introduction

'No child should die due to lack of access to treatment' (UNAIDS, 2011). In order to achieve the vision of zero AIDS-

related deaths proposed by the World Health Organisation (WHO), everyone living with human immunodeficiency virus (HIV) needs to have access to life-saving medication in the form of antiretroviral therapy (ART) (WHO, 2013). Approximately 260,000 (712 per day), children were newly infected

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Peer review under responsibility of Johannesburg University.

<http://dx.doi.org/10.1016/j.hsag.2016.03.001>

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with HIV during 2012, bringing the total number of children living with HIV to 3,3 million, 91% of whom live in sub-Saharan Africa (Elizabeth Glaser Pediatric Foundation, 2014 & UNICEF, 2013). Only 34% of the above mentioned children received ART in 2012 (UNICEF, 2013). The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2011) highlights the need to adopt a holistic approach that builds on the country's existing maternal and new-born health platform in order to ensure the optimal impact of ART, care and support for HIV-positive children, particularly at the primary health care (PHC) level.

An impacting factor on morbidity and mortality rates in HIV-positive children in developing countries is under nutrition, caused mostly by lack of food in the household. In resource poor settings, such as where this study was done, food insecurity exacerbates lack of adherence to ART, which furthermore accelerates the progression of HIV infection to AIDS (Ivers et al., 2009). Early and intensive dietary interventions should be a fundamental part of the case management of HIV-infected individuals, especially children (Duggal, Chugh, & Duggal, 2012). The previous statements concur with reports of the levels of stunting, underweight and wasting in children in Africa (36% in 2011), which significantly increases under-five mortality rates in South Africa (UNICEF-WHO-World Bank, 2012).

The challenges to paediatric HIV care and treatment in South Africa are therefore multifaceted and further include lack of sufficiently trained healthcare professionals, inadequate facilities, drug regimens that are too complicated for caregivers to understand, particularly those who are illiterate; and lack of paediatric drug formulations (Meyers et al., 2007). Additional difficulties include the complexity of early infant diagnosis, lack of funds and personal/family challenges related to the caregivers (Fayorsey et al., 2013). Decentralisation of ART from tertiary sites – usually meaning a centrally placed hospital – to PHC clinics is essential for HIV-positive children in order to bring treatment closer to where children live (Rabie, 2009). Brichard and Van Der Linden (2009) advise that early HIV diagnosis, followed by immediate commencement of ART in infants who are HIV-positive, can reduce infant mortality by 76% and HIV progression by 75%. Once children begin treatment, the next obstacle is increasing retention on ART. Optimal adherence rates to ART are essential to suppress viral replication, which in the case of HIV-infected children has to be done by motivated caregivers (Vreeman et al., 2010).

### 1.1. Statement of problem

HIV-positive infants and children are being lost to follow-up after diagnosis, and before referral for ART, owing to the centralisation (at tertiary hospitals) of ART services (Morsheimer, Dramowski, Rabie, & Cotton, 2014). Hospitals are out of reach of most HIV-positive children due to the inability of their caregivers to travel the distance requisite to accessing treatment. Therefore decentralisation of ART services at PHC level is essential to improve the acquisition of ART for HIV-positive children (Rabie, 2009). The researchers noted that larger numbers of children in Nelson Mandela Bay (NMB) were being treated at public hospitals than at the clinics

selected for this study, with raw data statistics indicating that 12,592 children access ART at hospitals in NMB as opposed to the 479 children accessing ART at the six purposively sampled PHC clinics used in this study (District Health Information Systems, 2010).

The South African Department of Health (2004) emphasises the need to maintain optimal (95%) adherence to ART. Numerous challenges are experienced by caregivers regarding accessing ART for their HIV-positive children, such as the cost of travelling. Stigma remains a burden, is still widely encountered in many healthcare facilities, and leads to caregivers avoiding their local PHC clinics to access ART. Additional issues are the reported shortage of trained staff, long waiting times and lack of integrated services for HIV-positive children and their caregivers (International Treatment Preparedness Coalition, 2011). The dichotomy between the dire need for, and provision of, ART for children, particularly at decentralised levels such as primary healthcare clinics, initiated the research study. The aim of this study was to explore and describe the experiences of caregivers accessing ART for their HIV-positive children at PHC clinics in NMB, particularly related to the more vulnerable under-five age group.

### 1.2. Contribution to the field

The unique contribution of this article is the voices of the participants as they relate their experiences of accessing ART for their HIV-positive children, which will assist to improve access to ART at PHC clinics in NMB.

## 2. Research design and methods

Qualitative research was chosen because of its ability to provide the 'human' side, emphasising certain significant characteristics of how caregivers experience accessing ART for their children (Streubert & Carpenter, 2011). Descriptive was selected in order to describe the phenomena of interest as accurately as possible and portray how things naturally happen (Rebar, Gersch, MacNee, & McCabe, 2011). Exploration in qualitative research is considered to be inductive, and accomplished by flexible and reflexive methods of data collection and analysis. The researchers sought to understand perception and behaviour from the participants' own experiences, in their own words and in the context in which they live and work (Streubert & Carpenter, 2011). Context is important to augment description and exploration therefore PHC clinics that provide ART services in the NMB in the Eastern Cape were used. The population in NMB comprises 1,152,115 people, of which 25.5% are children under the age of 14 (Statistics South Africa, 2011). The areas in which the PHC clinics are situated are amongst those with extremely low socio-economic circumstances, 58.2% of the population receive at least one grant per household and 70.7% have to utilise public health facilities (Statistics South Africa, 2011).

### 2.1. Population and sampling

The research population comprised of caregivers of HIV-positive children who have to access ART at PHC clinics in

NMB. Fifteen caregivers were interviewed, ranging in age from 25 to 63 years. Fourteen were female and one male, a father, was interviewed. All participants had HIV-positive children who were under school-going age. A criterion-based purposive sampling strategy was used to select the participants (Kumar, 2014). The criteria for inclusion in the study encompassed being a caregiver of an HIV-positive child under the age of six. Furthermore, the caregiver had to be able to communicate in English or be open to the presence of a translator. The participants who matched these criteria were able to provide information-rich data (Polit & Beck, 2012).

## 2.2. Data collection methods

The researchers chose in-depth individual interviews, in which the intent was to openly explore the experiences of caregivers in order to obtain pertinent research data (Rebar et al., 2011). Each recorded interview was between 30 and 60 min in duration, and the researchers engaged with the participants prior to, and following the interview, to discuss and debrief regarding the experiences shared, from which field notes were compiled (Polit & Beck, 2012). The professional nurses at each clinic were used as gatekeepers who assisted the researchers to gain access to the site and ensured the well-being of the participants. All interviews were conducted in the privacy of a room in the clinic. The central open ended question presented to the participants was: *'Tell me how is it for you to receive the antiretroviral treatment for your child at this clinic, which generated rich data from participants.*

Data was collected over a period of four months until data saturation occurred, whereby sufficient data was obtained, or no new themes emerged from the interviews (Creswell, 2014). Field notes provided a detailed record of all the interviews, and enhanced the richness of the data gathered (Polit & Beck, 2012).

## 2.3. Data analysis

The coding process and data analysis were conducted according to Creswell's (2007) 'data analysis spiral'. The data spiral consists of four phases, namely data management, reading and memoing, describing classifying and interpreting and finally visualising and representing the data (Creswell, 2007). The researchers identified units of meaning which were grouped together to form categories, following which themes were developed. Raw data, the transcribed interviews, field notes and the protocol for data analysis were given to two independent coders to analyse, after which a consensus meeting was held between the researchers and independent coders. Literature was used to support the research findings (Green & Thorogood, 2009; Creswell, 2014).

## 2.4. Trustworthiness

In this study credibility was facilitated by the researchers ensuring that their findings were compatible with the perceptions of the participants (Streubert & Carpenter, 2011). Peer review took place through discussing the research process and findings with colleagues, promoters and the independent coders, who all have experience with qualitative research

methods (Streubert & Carpenter, 2011). The credibility of the data was endorsed by incorporating copies of the transcribed interviews into the research report. Triangulation of data gathering methods and sources was verified to ensure accuracy of the data in this study (Polit & Beck, 2012). Transferability, termed the extent to which qualitative findings are meaningful and can be transferred to other settings, was ensured by providing a thick description of the research results, supported with quotations from the participants (Babbie & Mouton, 2009; Polit & Beck, 2012). Dependability refers to the stability of data over time, therefore a dependability audit was established when the process, as well as the results, were fully described by the researchers (Streubert & Carpenter, 2011; Babbie & Mouton, 2009). Confirmability was established by the researchers illustrating as clearly as possible the evidence and thought processes that led to the conclusions reached regarding caregiver's experiences of accessing ART for their HIV-positive children at PHC clinics in NMB (Streubert & Carpenter, 2011).

## 3. Ethical considerations

Ethical approval was obtained from the Nelson Mandela Metropolitan University's Research Ethics Committee (Human) prior to conducting the research. The reference number H10HEANUR003 was allocated. The researcher was aware of the vulnerability of the participants and the need for protection against further harm. Therefore the study was conducted in such a way as to uphold the ethical principles of no harm, confidentiality, privacy and anonymity (Streubert & Carpenter, 2011).

All of the information about the aims of the study, including procedures of the study and possible advantages, were disclosed to the participants. They were informed about the reason for their inclusion in the study, the duration of the study and how the results would be published. The participants were offered the opportunity to consent, whereby an informed consent form was signed, or to decline to take part in the study. They were also informed of their freedom to withdraw from the study at any time.

## 4. Results

This study sought to establish the experiences of caregivers accessing ART at PHC clinics for their HIV-positive children. The following themes, pertinent to this article, in that they related to accessing ART for children at PHC clinics, are presented below:

### 4.1. Shock and disbelief when receiving the diagnosis

The participants attested to various emotions after receiving the diagnosis of HIV, firstly in relation to themselves and then to their child. Their reactions of shock and disbelief were particularly associated with fear of the future as HIV is considered a life-threatening disease. The caregivers described their feelings:

*'But it wasn't, ja, for me to find out I was HIV-positive was a shock, but it wasn't, um, as a lot of hurt as when I found out that he (child) got HIV from me' [P 32]*

*'In the beginning, I felt very bad, I felt really sick, but after about per month I felt better and I got used to the fact that he (child) had HIV' [P19]*

The participants indicated that they struggled to comprehend the news at first. It often took time for the shock to wear off, and for the person to comprehend the gravity of the news:

*'I couldn't believe I had HIV and I could not understand what they were saying to me, it was difficult to accept that I was HIV-positive, it was a big shock' [P 26]*

The results of this shock and disbelief could result in caregivers avoiding going to the clinic to access ART for the children, because shock and disbelief are linked to denial. A caregiver describes having to care for, and access ART for her granddaughter, because the parent refuses to attend the PHC clinic:

*'And now there was no one [the mother] that's wanting, coming to, want to coming come here to get the tablets, now I'm, I am volunteer myself to come and fetch for my granddaughter' [P 20]*

#### 4.2. Stigma and discrimination

The issues of stigma and discrimination have been highlighted since HIV/AIDS was first discovered, owing to the fears of those infected and those who were trying to avoid infection. A caregiver related what happened to her child in pre-school:

*'And he told me the thing, the reason he cried, is because he hear people saying you had AIDS and now [then] you died' [P 23]*

The research findings indicated that participants experienced the painful effects of stigma and discrimination:

*'Then my other children were scared of both of us and they said that he and I should not stay in this house, because he is HIV, I was so unhappy I cried and cried' [P19]*

*'It doesn't help to tell other people about my child because they will laugh at him and will make jokes of that so I prefer to keep it to myself' [P24]*

Participants reflected on the advice given by counsellors related to avoiding stigma and discrimination, namely, the practice of hiding ART, and thus HIV status, from family:

*'The counselling here told me that that if I'm give him the drugs I must not to be in front of the people, I must give him where other people cannot see it, because people can talk wrong' [P21]*

A caregiver voiced her anguish following the discrimination she received due to her child requiring ART at the clinic, which can lead to people avoiding accessing ART:

*'If I'm at work the teacher comes to the clinic to fetch the tablets; so one mother saw the teacher at the clinic and she ask what is she doing with this child in THAT room (ART), so she find out that my child was positive and took her child out of the crèche; I still want to cry now even' [P31]*

And a participant speaks about stigma preventing people from attending clinics to access ART:

*'So now if you go that side [to access ART] then the people they will talk and that's why some people that are HIV-positive, they come to the clinic, get tested and afterwards they don't come to the clinic because they are afraid of the people (judging them)' [P25]*

Some of the participants felt that the reason for discriminatory behaviour was related to ignorance:

*'I think it's just that people haven't got enough knowledge about the HIV virus, need more information to enable them to know that there is nothing wrong; just like the other sicknesses around' [P31]*

#### 4.3. Ineffective patient flow at PHC clinics

While there has been considerable research about barriers to rolling out antiretroviral packages in South Africa, much less has been written about the relationship between patients and the health system, and their reasons for opting out of treatment programmes. Women's (caregivers) experiences with the public health system could affect their consequent health-related behaviour, such as missing appointments, which will impact on the health of the HIV-positive child (Sprague, Chersich & Black, 2011). The participants in this study highlighted their disapproval of the long waiting times when they attend the clinic in NMB:

*'I have to bring her (granddaughter) to get the medication but it takes long. I have taken a day off work to come here, just to fetch tablets' [P20]*

*'Yoh! I've come at 6.30 am then I see the nurse at 8 am and then I have to wait until 3 pm [for medication], it is all day till 3 pm' [P31]*

The problem with the long waiting times appeared to be multifaceted:

*'I think today is a long wait because there is only one sister who is working, and if I can tell you the truth, is only one sister here who works well on this side (paediatrics) when she's here, even if she is alone she's doing her job quick, quick, quick, yah, she's not here today' [P34]*

*'They [the staff] go to lunch from 1 to 2pm, so we must wait for them to come back, you stay here for the whole day' [P34]*

Participants had some advice for the staff at the clinics regarding how to improve patient flow:



*'Yoh! It's, I think they must put the medicines in the room for the kids; I think they know they give us the dates so they know on this date we're going to see 30 kids' [P31]*

*'Just maybe the medicine for the children it must be the side where the children are treated and all that.' [P34]*

#### 4.4. Lack of compassion by staff towards patients and caregivers at PHC clinics

Participants recounted experiencing a lack of care and compassion from the nurses in the PHC clinics, which they indicated was unacceptable, and could lead to them avoiding attending the clinic to access ART:

*'I feel that can make me feel better is just that, um, I will want the sister that is in charge to support us' [P25]*

Due to the much publicised staff shortages in PHC clinics cursory exchanges at best were experienced between participants and staff:

*'I'm going to say that there must be someone here that is always willing to help [the patients], not someone who is always busy doing other stuff' [P34]*

A participant shared a negative experience with a staff member which she remembered vividly and which made her wary of interacting with staff at the clinic, possibly she might even prefer not to attend:

*'Yes they are not nice, they are very rude, they are very rude, Yoh! I was so angry there, I was so angry I didn't know what to do, so must keep quiet' [P30]*

A participant indicated her need for more compassionate care and understanding from staff regarding her efforts to adequately care for her child, and her related frustrations:

*'so I just wanted to ask can't they organise if if the mother and the child they are both positive and they come for treatment can't they maybe going one room like now I'm here my file is that side, I had to ask and beg for my dates to be the same [as my child]' [P31]*

The assertion of a lack of care was cited as a barrier to care by the participants who contended that staff were not approachable, and could be rude. Most participants attested to the need for more time with the staff so that they could obtain essential information, failing which the following could occur, where the caregiver was not adequately taught about the medication:

*'Tablets? It's take two at, are in, at at the at the time, or one, two in the morning one in the night, and the medicine like a one, I don't know these spoons [participant stop speaking, looks confused and angry]' [P20]*

#### 4.5. Challenges related to financially caring for HIV-positive children

Most of the caregivers interviewed by the researchers were unemployed and struggling to survive, with few economic or educational assets to assist them. Therefore, even the R320 per month child care grant was considerable money for them, but it might not be enough to assist them to travel to the clinic to access ART for their children. Besides even securing the grant appeared to be a challenge:

*'It will help me if I get the grant but at the moment I am struggling with, I am struggling to get the grant, I'm struggling' [P25]*

*'I came with a letter to the doctor, then tomorrow I must go to the police station for an affidavit that I'm not working and I don't get paid, then I will go and take it to the social worker' [P24]*

Highlighting the challenges of high transport costs as a significant reason why caregivers did not visit the clinic for follow-up and to fetch medication for the HIV-positive child:

*'I have to have taxi fare to get to clinic if she has fever or a rash, and then I don't have taxi fare' [P18]*

Children on ART have to eat before they take the medication, and initially they also experience increased hunger due to the effects of the treatment. However, the challenge for caregivers is being able to afford to buy food for their child:

*'It is always necessary to have something for her to eat because each time she takes the medication she must eat well; ooohhhhh! I am sick sick sick.' [P18]*

The poverty levels experienced by the participants were overwhelming:

*'Sometimes I don't have money to buy food for the child; sometimes we do have food, sometimes we don't have nothing to make food' [P24]*

Financial woes were discussed by all the participants. Women with no work and reliant on childcare grants paying R320 per month had to feed, clothe and transport their children – an impossibility. Lack of food is a precursor to non-adherence in the 'no food no medication' genre:

*'I am trying by all means to get it [food] but like even if I haven't got something in my house I will go to my sister and ask something for him to eat before, he must eat to take his pills, I can't getting the grant' [P21]*

#### 4.6. Improvement in HIV-positive children's health due to ART

The caregivers reflected favourably on the effects of ART on the children in their care, with most declaring that the child's

health improved dramatically following initiation of treatment. For this reason caregivers need to be encouraged to attend the clinic to access ART:

*'Yes yah it is much better because she was nearly dead, it's very good for me to see that she is so much better, she's got no problems with the treatment' [P26]*

*'I brought him to the clinic he was only four years old, and he is now 11 years old and he's not been sick since then' [P19]*

ART can significantly reduce the morbidity and mortality of HIV-positive children. It is therefore essential that access to effective ART is increased, maintained and improved, from as early an age as possible. The following quotations from the participants highlight the benefits of accessing ART expeditiously:

*'Whoooo! I was crying, I think hey! What if the baby is dying? I think oh I was crying a lot but now I see the baby she's fine, and if you see her now you don't say she is positive' [P28]*

*'Yah she is well, she doesn't get sick, she's just fine, she's like any other baby' [P34]*

There is no doubt as to the success of the antiretroviral drugs in most of the HIV-positive children whose caregivers were interviewed, thus emphasizing the need to assist caregivers to access ART for the HIV-positive children in their care.

## 5. Discussion of research results

South Africa has committed to the Millennium Development Goals (MDG's) which include MDG 4, to reduce by two thirds the mortality of children under five and reversing the spread of HIV/AIDS by 2015. And yet, every year 20,000 babies are stillborn and another 22,000 die within the first month of their lives. In total, at least 75,000 children die before their fifth birthday (Health Systems Trust, 2016). There is no doubt that the HIV epidemic has added an enormous burden to the healthcare services in South Africa, particularly where services for children are involved (Health Systems Trust, 2016).

Reactions to learning that one's child has a chronic illness would be varied, but they are always powerful. Emotions may range from shock to relief, with denial, anger and grief over the loss of health equally common emotions. Learning about a diagnosis of being HIV positive is considerably more difficult than for most chronic illnesses however, because HIV is a complex disease that affects all aspects of life, economic, social, educational, medical and psychosocial (National Institute of Health, Patient Education Center, 2001).

While numerous studies attest to the psychological sequelae regarding a diagnosis of HIV-positive, for both mother and child, there is a dearth of literature on how these feelings could affect accessing ART at PHC clinics (Agrawal, Srivastava, Goyal, & Chaudhury, 2012). In a study by Hackl, Somlai, Kelly, and Kalichman (1997) re-emphasised in Sanders (2008), HIV-positive women stated that they struggled with extreme emotional distress (shock) and disbelief after

receiving the diagnosis. To adequately assist caregivers to cope with this disease, and offer comprehensive treatment, care and support, it is essential to explore the importance of all stakeholders being aware of the psychological effects of HIV. For instance shock and disbelief, which is linked to denial, in connection to hearing about their child's HIV-positive status is significant, because these emotions can affect the caregiver's ability to fully process the diagnosis and even to comprehend the gravity of the news. This could result in failure to take the diagnosis seriously and to access treatment for the child (Cichocki, 2009).

The HIV/AIDS epidemic has been accompanied by an epidemic of fear, ignorance, and denial, leading to stigmatisation of, and discrimination against, people with HIV (Adelekan & Edoni, 2012). The participants in this study all experienced forms of stigma and discrimination, often in the form of lack of support from family, friends and community. It was postulated that with the availability of ART a change in perception of HIV would occur. This has not happened in South Africa, where stigma and discrimination continue unabated (Peltzer & Ramlagan, 2011). These authors indicate that individuals experiencing high levels of stigma would also have poor physical and mental health (Peltzer & Ramlagan, 2011), which was seen in many caregivers interviewed for this study.

Patient flow can be defined as the movement of patients through the various set locations in a PHC (Sprague et al., 2011), which the participants pointed out as being problematic in the PHC clinics sampled for this study. Implementing a formalised patient flow in clinics, in order to limit the time spent per patient per day in PHC facilities, could dramatically improve the experience of accessing ART for caregivers of HIV-positive children.

In order to improve service delivery related to the provision of ART in PHC clinics the reasons for low access, initiation and adherence to ART by caregivers of HIV-positive children need to be recognised and acknowledged (Richter, Rochat, Hsiao, & Zuma, 2012). Thus far, research related to patients and ART has focused on adherence, or individually on patient values and healthcare provider values, but not on improving the clinical experiences of patients and their families, an area vital to supporting the on-going response to HIV and ART, particularly for children where the access depends on the experiences of the caregiver of the HIV-positive child (Campbell, Scott, Madanhire, Nyamukapa, & Gregson, 2011). Therefore improving interactions between mothers and healthcare providers, through training and supervision of staff, should be promoted to allay fears of negative staff reactions (Gourlay, Birdthistle, Mburu, Iopenda, & Wringe, 2013).

All of the participants in this study were living in poverty and caring for their child was a major financial challenge. Although South Africa is deemed a middle-income country, it has one of the greatest levels of income inequality in the world (Majumdar & Mazaleni, 2010). Added to this, rural and African residents bear the largest burden of HIV illness. Combined with the concurrent high levels of unemployment, far too many people are left in extreme poverty (Province of the Eastern Cape, 2013). Most of the caregivers in this study were unemployed and struggling to survive on the R320/month child care grant, a paltry amount of money but for many in South Africa the only source of income, provided they

were able to access the grant. It is evident from the anecdotes shared by participants in this study that they feel unsupported financially, and are fighting to survive.

Participants reflected favourably on the effects of ART on their HIV-positive children's health, most emphasising dramatic improvements in health following initiation of treatment. This in itself is the perfect reason to improve access to ART for HIV-positive children, and to ensure adequate support for the caregivers of HIV-positive children in the form of suitable health education in line with each family's need. Studies have shown that HIV-positive women with adequate social-support networks are less prone to mental distress and have a better quality of life; therefore healthcare professionals should focus on minimising and relieving psychological distress in caregivers by emphasising the promotion of mental health, and fostering resilience to stress and adversity (Chipimo, Tuba, & Fylkesnes, 2011).

## 6. Recommendations

It is suggested that standardised programmes be developed and implemented in the PHC clinics to assist the interdisciplinary teams to successfully optimise ART, care and support for caregivers who bring their HIV-positive children to PHC clinics. Strategies to ensure that ART is provided in such a way that resources are maximised and a continuum of services or care are ensured, is essential, particularly when working with children and their caregivers.

## 7. Limitations of the study

A paucity of accurate statistical data regarding the number of children infected with HIV in general, and in need of ART in particular, country-wide, and especially at district level, was experienced. Equally, it was found that there was a lack of statistics relating to HIV-positive children who were lost to follow up visits (defaulted on treatment) at PHC level.

## 8. Conclusion

The main focus of this study was to explore the experiences of caregivers of HIV-positive children who were accessing ART at PHC clinics. This qualitative study has exposed numerous challenges experienced by the participants as they negotiated the South African public health system, namely the PHC clinics, particularly in NMB, in order to obtain essential ART for the HIV-positive children in their care. The study has also highlighted positive experiences in the form of the efficacy of ART and the resultant improvement in health of many of the HIV-positive children attending the PHC clinics where the study was conducted. However, clinical practice is far from ideal at PHC level with several shortcomings identified. Long-standing health-systems issues (such as staffing and service accessibility) and community level factors such as stigma, fear of disclosure and even the denial (linked to shock and disbelief) mentioned in this article, have not changed over time and continue to plague ART programmes (Gourlay et al., 2013).

Strengthening PHC clinics by ensuring adequate resources and improving interactions between caregivers and health-providers should be promoted to expedite trust in staff and the healthcare system, all of which could improve ART provision and care for HIV-positive children (Gourlay et al., 2013). Optimising access to ART, care and support is a prerequisite to enhance caregiver's experiences while accessing ART for their HIV-positive children at PHC clinics to encourage adherence to life-saving therapy.

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