How children access antiretroviral treatment at Kgapane District Hospital, Limpopo, South Africa

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Abstract

Background: At Kgapane Hospital, Limpopo Province, only 20% of eligible children initiated antiretroviral treatment (ART) in 2007. The aim of this study was to improve the ART programme by assessing how children were accessing ART, and to explore the factors that facilitate or obstruct this access.

Method: Mixed methods were used in a descriptive study of human immunodeficiency virus (HIV)-infected children admitted to the hospital over a seven-month period and their caregivers. Children's subsequent attendance for ART was tracked and caregivers were interviewed about factors influencing access and attendance.

Results: Of 132 children initially admitted, 14 (10.6%) subsequently died and 13 (9.8%) relocated. Sixty of the remaining 105 (57.1%) returned within one month to the antiretroviral clinic, three (2.9%) attended later and 42 (40.0%) did not return at all. Quantitative data associated with poor attendance were younger age, higher CD4 count, maternal caregiver, no income and participation in the prevention of mother-to-child transmission program. Qualitative factors included a lack of money for transport, poor social support, and mothers who struggled to accept their diagnosis, had poor understanding of HIV and strong traditional beliefs. Primary care providers delayed HIV testing and referral, displayed poor attitudes, and were insufficient in number. Quantitative factors significantly associated with good attendance were prior knowledge of the child/mother's HIV status, mother's ART treatment and referral to the dietician.

Conclusion: There are serious deficiencies in the prevention, diagnosis and treatment of HIV in children. Factors were identified to improve health services and these highlight the need for broader strategies aimed at addressing poverty, stigma and education.

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Introduction

South Africa has the highest number of people living with human immunodeficiency virus (HIV) in the world.[1] Although the Millennium Development Goals[2] aim to reduce the under-five mortality rate by two-thirds, the rate in South Africa increased from 60 to 69 deaths per 1000 children between 1990 and 2006. One of the major causes is the high burden of disease from HIV and acquired immunodeficiency syndrome (AIDS). Without any intervention about a third of HIV-infected infants die from an HIV-related cause before their first birthday and half before their second birthday.[3] In South Africa the mortality rate of HIV-infected children is twelve times that of uninfected children.[3] Most children die from pneumonia or diarrhoea, and malnutrition is a frequent underlying problem. HIV and AIDS alone accounts for at least 35% of deaths among all South African children.[4,5]

Preventing and treating HIV more effectively in children is therefore a national priority. South Africa will need to address the prevention of mother-to-child transmission (PMTCT), HIV treatment for pregnant women and treatment of children with HIV.[6] Although HIV testing is being accessed by an increasing number of pregnant women this does not always translate into completion of the PMTCT programme. Mothers often fail to return at six weeks to determine their babies' HIV status. Factors that impede follow-up include poverty, poor paternal support, a different caregiver postpartum, and misconceptions about HIV risk and testing.[7-9] In Southern Africa only 9% of HIV-exposed infants are currently started on co-trimoxazole prophylaxis, which also demonstrates the poor follow-up of babies born to HIV-positive mothers.[10]

South African primary health care has adopted the Integrated Management of Childhood Illness approach, which includes the assessment of HIV risk in all children. Despite this, nurses are not routinely testing for HIV. Nurses may be embarrassed to raise the topic, assume that it is unnecessary or that mothers will find it unacceptable. They may also be concerned that they do not have adequate knowledge and skill to deal with HIV in children.[11]

For those diagnosed with HIV the most important predictors of mortality in resource-limited settings are the following: World Health Organization (WHO) clinical stage, CD4 count, and weight-for-age.[12] Prior to April 2010 the South African guidelines for initiating antiretroviral treatment (ART) in children relied on the WHO clinical stage and CD4 count.[13] This required regular and competent follow-up in order to identify the children who needed ART.

Interactions between health care professionals and patients is another crucial factor in determining whether patients test for HIV and return for follow-up. Poor communication about the diagnosis and treatment, negative attitudes, blaming patients for their health problems and not maintaining confidentiality were all issues raised by patients.[14-16] Poor patient experience makes it more likely that patients will seek help from traditional medicine and delay starting ART.[17]

Stigma has also been associated with reduced utilisation of health services.[18] Even in settings with a high testing rate there is still much fear of the consequences of a HIV-positive result, such as the reactions of the partner and the community, as well as the implications for sickness and death.[19]

ART is known to be effective in children,[20] but there are many associated requirements: health facilities should function well, and have an adequate supply of drugs, an effective laboratory service and an adequate supply of skilled health workers. In the public sector in South Africa there is currently a severe shortage of professional staff, which heavily impacts on the ability of health facilities and services to offer adequate HIV care and treatment.[21]

This study was conducted at a typical rural district hospital in the Limpopo Province of South Africa. In Limpopo, about 20% of pregnant women test positive for HIV, and, in 2001, out of 27 000 children estimated to have HIV only 2 500 were receiving ART. At Kgapane Hospital in the Mopane District, by the end of 2007 only 98 children were receiving ART, although it was estimated that more than 470 should be eligible.

The main aim of the study was to investigate how children were accessing ART at the hospital and to explore the factors that were preventing or facilitating this.

Method

Study design

Mixed methods were used to identify the factors that impact on children's access to ART. Quantitative data were extracted from the children's medical records to evaluate attendance at the ART clinic and to record information on demographic, clinical and contextual variables that might be associated with attendance. Qualitative data that explored issues related to access and attendance were obtained from interviews with the children's caregivers.

Setting

The Kgapane District Hospital serves the Greater Letaba subdistrict in the Limpopo Province of South Africa, which has a rural population of 380 000 people. There are 20 primary care clinics that refer patients to Kgapane Hospital. At the time of the study only one clinic was accredited to provide ART, while all the others referred HIV-infected patients to the hospital for ART. The hospital had received accreditation to initiate ART in August 2005. HIV-infected patients not yet eligible for ART were usually followed up at the local clinics.

Selection of study population

All known HIV-infected children not yet on ART between the ages of 28 days and 12 years, who were admitted to Kgapane Hospital between 1 June and 31 December 2008 and then referred to the ART clinic, were included. Purposeful sampling was undertaken of caregivers of children between the ages of 28 days and 12 years, who were admitted to the paediatric ward at Kgapane Hospital between May and July 2009 and whose children were eligible to start ART. Caregivers were then selected depending on who was available at the time scheduled for the interview each week.

Data collection

Baseline data were collected from the medical records of all the included children during their hospital admission and again three months later to evaluate attendance at the ART clinic.

Ten in-depth interviews were conducted by the researcher with the caregivers who gave consent. A female lay counsellor, who could speak Sepedi and Xisonga, assisted with translation. The interview guide addressed the following issues: the experience of health care at the local clinic and hospital, factors that made accessing treatment easier or more difficult, and how caregivers felt about their child's HIV and ART.

Data analysis

Quantitative data were analysed by the Centre for Statistical Consultation at Stellenbosch University. The analysis looked for associations between the baseline variables and poor attendance. Poor attendance was defined as failure to attend or late attendance. Categorical data were analysed using two-way summary tables and the chi-square test. Ordinal and continuous data were analysed using analysis of variance (ANOVA).

The interviews were audiotaped, translated and transcribed verbatim. A research assistant checked the translation and transcription. Concurrent data analysis was conducted in order to identify themes and categories that needed further exploration. The Framework method was used for qualitative data analysis.[22]

Ethical approval for the study was granted by the Health Research Ethics Committee at Stellenbosch University and the management of Kgapane Hospital.

Results

Quantitative data

Initially, 132 children were enrolled in the project. Their demographic profile is shown in Table I. The mean age was 4.2 years [standard deviation (SD) 3.62] and 66 (50.0%) were female. The biological mother was the main caregiver in 93 (70.5%) cases. Twenty-nine (21.9%) of the children were maternal orphans. The majority of the children's families, 74 (56.0%), had no income. Sixty-two (46.9%) children lived within 20 km of the hospital.

Table I: Demographic data on study population (n = 132)

Variable		n (%)
Sex, % female		66 (50.0)
Main caregiver	Mother	93 (70.5)
	Grandparent	26 (19.7)
	Aunt	10 (7.6)
	Sibling	2 (1.5)
	Father	1 (0.7)
Mother	Alive	101 (76.5)
	Dead	29 (22.0)
	Unknown	2 (1.5)
Income source	None	74 (56.1)
	Salary	44 (33.3)
	Old age pension	12 (9.1)
	Foster care grant	16 (12.1)
	Child support grant	106 (80.3)
	Other	2 (1.5)
Distance from hospital (km)	0–10	29 (21.9)
	11–20	33 (25.0)
	21–30	20 (15.1)
	31–40	29 (22.0)
	41–50	14 (10.6)
	51–60	2 (1.5)
	71–80	2 (1.5)
	> 80	3 (2.2)

The children's clinical profile is shown in Table II. Seventy-five (56.8%) of the children had previously been diagnosed with HIV but only 32 (24.2%) were referred with a CD4 count result. Only 23 (17.4%) of the children were known to have received vitamin A within the last six months and only 48 (36.6%) were receiving co-trimoxazole prophylaxis. Only 35 (26.5%) of the children and their mothers had received antiretroviral (ARV) prophylaxis as part of the PMTCT programme. Forty (30.3%) of the children showed signs of severe malnutrition. Forty-two (32.6%) were WHO stage 4 and 61 (46.2%) were stage 3. The three most common diagnoses were pneumonia, gastroenteritis and pulmonary tuberculosis. The median CD4 per cent was 13.7% [mean 14.7, SD 9.1%, 95% confidence interval (CI): 12.9–16.5%].

Table II: Clinical profile of study sample (n = 132)

Variable		n (%)
Referral source	Primary care	107 (81.1)
	Private general practice	5 (3.8)
	Other	20 (15.1)
HIV status known on admission		75 (56.8)
Received PMTCT (enlarge *)		35 (26.5)
WHO stage at referral	1	5 (3.8)
	2	23 (17.4)
	3	61 (46.2)
	4	42 (32.6)
Presence of severe malnutrition†		40 (30.3)
Vitamin A up to date at referral‡	Yes	23 (17.4)
	No	27 (20.5)
	Unknown	82 (62.1)
Receiving co-trimoxazole at referral§	Yes	48 (36.6)
	No	83 (62.9)
	Unknown	1 (0.5)

*Received PMTCT indicates whether the mother and/or the child had received any nevirapine or azidothymidine

†Defined as less than 70% expected weight for height, and also by visible severe wasting or by the presence of nutritional oedema

‡Up to date according to the national guidelines on vitamin A prophylaxis. Non-breastfed infants 0–5 months: 50 000 IU single dose; all infants 6–11 months: 100 000 IU single dose; All infants 1–5 years: 200 000 IU every 6 months

§All HIV-exposed infants are to be started on co-trimoxazole prophylaxis at four to six weeks of age, and once they are diagnosed with HIV to continue co-trimoxazole indefinitely if they are not on ART. It should only be stopped when on ART and clinical and immunological indicators confirm that the immune system is restored

The mothers' clinical profile is shown in Table III. Of the 101 mothers who were still alive, 77 (76.2%) were diagnosed with HIV before their children were referred: 82 (81.2%) were WHO stage 1 and 16 (15.8%) were receiving ART.

Table III: Clinical profile of the mothers in the study population (n = 101)

Variable		n (%)
HIV status known on admission	Yes	77 (76.2)
	No	24 (23.8)
On ART	Yes	16 (15.8)
	No	85 (84.2)
WHO stage at referral	1	82 (81.2)
	2	7 (6.9)
	3	11 (10.9)
	4	1 (1.0)

Of the 132 children enrolled in the study, 14 (10.6%) died during their admission and 13 (9.8%) were transferred elsewhere, leaving 105 to be followed up locally. Sixty (57.1%) returned within one month for follow-up, three (2.9%) attended late and 42 (40.0%) did not return at all.

The association of baseline variables with attendance is shown in Tables IV and V. Younger children and those with a

Table IV: Association between age, CD4 per cent and attendance

Continuous variables	Attendance				P value
	Poor (n = 45)		Good (n = 60)		
	Mean	95% CI	Mean	95% CI	
Age	3.34	2.39–4.29	5.93	5.03–6.84	< 0.01
CD4%	17.40	13.86–20.93	12.78	10.54–15.03	0.03

Table V: Association between categorical variables and attendance

Categorical variables	Attendance		P value
	Poor (n = 45) n (%)	Good (n = 60) n (%)	
Child's HIV status known before admission	14 (31.1)	49 (81.6)	< 0.01
Main caregiver is the mother	38 (84.4)	34 (56.7)	< 0.01
Mother alive	39 (86.6)	38 (63.3)	0.01
Mother's HIV status known before admission	25 (55.5)	38 (63.3)	< 0.01
Mother on ART	2 (4.4)	13 (21.6)	< 0.01
Mother received PMTCT	19 (42.2)	7 (11.6)	< 0.01
Referral to dietician	27 (60.0)	57 (95.0)	< 0.01
Child support grant	40 (88.8)	42 (70.0)	0.02
Income type:			0.03
None	32 (71.1)	27 (45.0)	
Salary	11 (24.5)	23 (38.3)	
Old age pension	2 (4.4)	10 (16.7)	

higher CD4% had poorer attendance. Factors significantly associated with poor attendance were having a maternal caregiver, no income, and if the mother or child had received PMTCT. Factors significantly associated with good attendance were prior knowledge of the child's or mother's HIV status before admission, the mother already receiving ART and referral of the child to the dietician at the hospital.

Qualitative data

Accepting HIV diagnosis

Four women, all of whom had prior knowledge of HIV and ART from various sources, clearly accepted the diagnosis of HIV for their children:

"First of all I hear the signs and symptoms from the radio and some of them that she was having at that time. Then when I come here they told me that this child after taking blood that she has been tested positive then I don't have fear because I have already prepared by the radio."

One woman explained how acceptance of the diagnosis made a difference:

"Because when I see at our community those that are coming at the hospital. The others take treatment and drink they live. But others they don't take treatment and say the hospital is lying they say I am having HIV, they are dying."

Those women who had no access to the media, did not gain knowledge from the clinics or did not have experience of HIV were the ones who found it most difficult to accept the HIV diagnosis of their children.

Antiretroviral treatment is welcomed

All the women welcomed ART for their children but only four of the women were aware that treatment was available prior to coming to the hospital.

"I am feeling happy because now when she is starting to take this treatment it will be a relief for me because what I was seeing from the beginning was tough."

Traditional beliefs or understanding of the illness

Three of the women took their children to a traditional healer, and sometimes also to church, before they went to the clinic or hospital.

"I was telling myself there is some spirits, because there are many child when they are still young they are getting ill, then it will go."

"They were taking the child to the church, even using traditional medication, then I see that there is no progress so I decided to take the child here."

HIV testing is delayed

Seven of the children did not have timely HIV tests done before referral. In one case the biological mother refused to allow the grandmother to request a test and another mother was too afraid:

"Because the people were saying if you take blood for HIV and you find out you are HIV positive you are going to die. That thing makes me to be afraid to take blood so I said if I take the blood then it comes being positive it means I am going to die."

The other five cases were not offered HIV testing by health care workers, despite them having visited the clinic numerous times.

The primary caregiver is not a biological parent

In four cases the biological mother was not the primary caregiver. In one case each time the child got sick the mother had to be called to come and give consent for tests and treatment. In another case the mother was working on a distant farm and left her child in the care of a relative. One mother had died, leaving her child in the care of her family, without disclosing her HIV status. In the last case the child had been abandoned by her mother and there was a delay in the grandmother getting full custody. In each of these cases the end result was a delay in the child accessing care and treatment.

Lack of knowledge about HIV and antiretroviral treatment

The majority of caregivers had poor knowledge about HIV and its symptoms, about how it is transmitted, and how to protect themselves. Health talks appeared to be ineffective:

"What I know is that when I go to the clinic for my child to be seen, there is a health talk that are done at the clinic everyday for HIV. I hear everything when they talk but when I go home it is all gone."

Lack of money for transport or food

Five women struggled to find money to attend their nearest clinic and found it virtually impossible to attend the ARV clinic at the hospital regularly. Four women had to rely on relatives or use part of the child support grant to pay for transport, and one woman had to carry her child a distance of several kilometres.

Another woman struggled between earning money and leaving her children in the care of a less capable relative:

"I can't have that money (R60 return) every month to come to the hospital for treatment for my child."

A few of the caregivers also complained that they could not afford enough food to feed their children. One woman stated that the child support grant did not provide enough money to survive on. Two of the women were working to supplement the money they received from child support grants.

Lack of social support

Five women did not have the support of their partner. In a few cases this was exacerbated by parents who did not offer support because they felt that the fathers should be assisting:

"My parents say when you are having a child, the child is having a father and the father must take care of you."

Delayed referral to the hospital

Most of the caregivers complained of having visited the clinic many times for recurring and serious problems, without referral to the hospital. Some caregivers consulted local general practitioners as they were not satisfied, but they were referred back to the clinic.

Attitude of health care professionals

Some women reported that the nurses were rude, angry and unapproachable, or complained about having to assist them. One woman felt that there was a lack of confidentiality with regards to a person's HIV status. One caregiver requested a referral letter when her child was not improving, but without success:

"They said because she has more knowledge than them can she go where she is supposed to go, not here. They said they wouldn't give her the letter because she was supposed to be arrested (for giving the baby tea instead of milk). That she must go herself because she was failing to look after her baby."

Other caregivers did not feel they had the right to ask for a referral letter in order to get a second opinion.

Shortage of health care professionals

Two women complained of having had to wait for hours before seeing a doctor at the hospital or having had to return the next day:

"When I go to the clinic, they called the ambulance and the ambulance took me to the hospital. But when I reached at the hospital they said there was no doctor. I go back home and came back yesterday."

Social support from spouse, family and health care worker

Five women stated that assistance from the family or spouse, especially financial and emotional support, assisted them in attending health care facilities regularly:

"Sometimes if the child is sick maybe I don't have money then I go to my mother's sister then she gives me the money."

Health care workers are seen as supportive when they communicate effectively with caregivers:

"I am happy because every question that I ask them there they answer me the way I become satisfied."

Discussion

This study showed that early HIV testing, regular vitamin A supplementation, co-trimoxazole prophylaxis, CD4 testing and early referrals for ART were not adequately performed at primary health care clinics in Kgapane's drainage area. These findings are in keeping with the Saving Children Report.[5] The majority of the children who were referred to the hospital had advanced HIV disease and qualified to receive ART. Despite the need for ART, a large percentage of these children did not return for follow-up. The key factors that facilitated or obstructed the diagnosis, referral and initiation of ART are summarised in Figure 1.

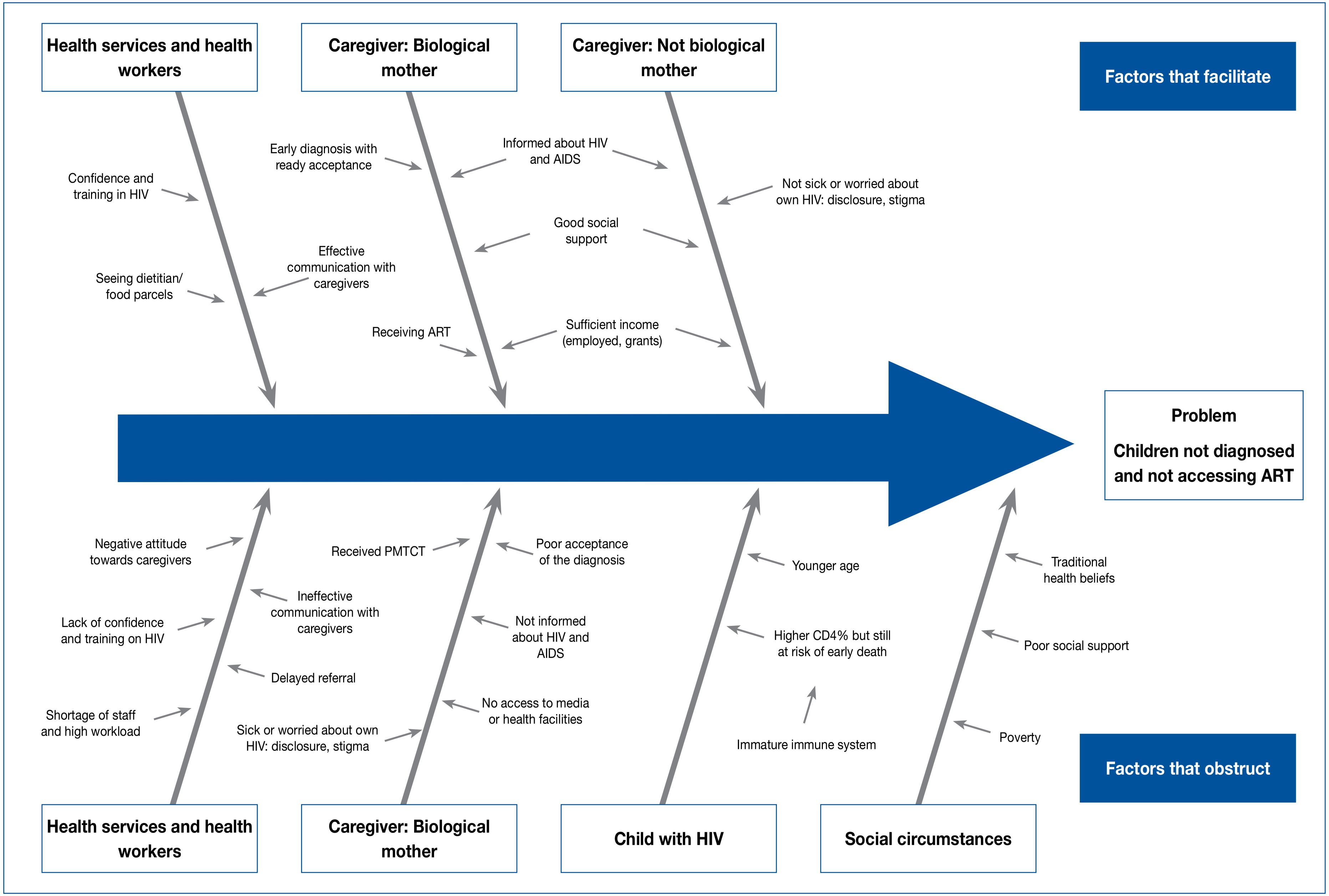

Figure 1: Conceptual framework for the factors facilitating and obstructing access to antiretroviral therapy

The caregivers' experience of care was, in their view, negatively influenced by a shortage of health care workers and poor relationship between themselves and clinic staff. The shortage of health care workers may lead to them feeling overburdened and unable to follow the recommendations of the national HIV guidelines. Some may also feel poorly trained and lack the confidence to handle the epidemic or share in the stigma that surrounds it.[11,21,23-25] Primary care nurses work under extremely difficult conditions, with little support, often without the necessary drugs and equipment, and with a large numbers of ill patients. They may have little influence over their working conditions, which may make them feel disempowered. All these factors cause the nurses to distance themselves from their patients. This may then manifest as a negative attitude, lack of compassion or even abuse towards those they see as subordinate to themselves.[15,26-27]

Poor knowledge about HIV and ARVs has been shown to result in a delay in HIV testing of infants.[9,15] Caregivers appear to have poor knowledge, despite undergoing counselling and attending talks at their local clinics. This raises concerns about the quality of counselling and the effectiveness of communication. Poor understanding of the illness and its treatment may also result in patients seeking help elsewhere.[16]

Some of the younger children, despite high CD4 percentages, could have died before coming back for follow-up. Numerous studies have shown that HIV-infected infants have faster rates of disease progression compared to older children, even when they have a high CD4 per cent.[3,12]

Although the majority of mothers were aware of their HIV status prior to their child's admission to hospital, very few had received PMTCT or tested their children for HIV before they became symptomatic. They fear HIV testing , have a poor understanding of HIV and ART, and sometimes families choose to visit traditional healers or the church before the clinics.[9,17,19,28] If a mother tests HIV-positive her initial reactions may include anxiety, fear, disbelief and worry, and it may take her some time to accept her diagnosis.[29,30]

The association of poor attendance with the mother as the primary caregiver suggests that the mother herself could be sick from HIV or struggling to accept and disclose her own status. In many settings, including South Africa, HIV-positive mothers are often faced with multiple challenges such as poverty, poor education, HIV-related stigma, gender inequality, violence and lack of social support.[31,32] These factors can make it difficult for her to act on the recommendations made during counselling, such as disclosing her status, testing her child or returning for follow-up visits.[29,31,33,34] It is possible that uninfected caregivers may be more stable, as they are less likely to get sick or die.[35]

Poverty has been identified as a major barrier to accessing ART in other areas in South Africa.[8,16,29] Many caregivers depend on government grants and have to balance the needs of the whole family with those of the HIV-infected child. A lack of income makes it difficult to afford the cost of transport to access ART, especially if (as in this study) this is not available at the local clinic. Involving the dietician improved follow-up, possibly because the dietician gave out food supplements. However, ART can be provided by appropriately trained nurses and clinical assistants at clinics, with good clinical outcomes.[36] One South African study has shown that a broad intersectoral approach, which provided microfinance along with HIV and gender training, improved indicators for economic well-being, empowered women, reduced risk behaviour and intimate partner violence.[37]

Limitations of the study

The caregivers may not have freely discussed all their issues with the doctor. Although the interviews were translated, some nuances and meanings may have been lost or distorted. The researcher collected and interpreted the data alone, with supervision from the second author. The children who did not attend the ARV clinic were not actively traced to ascertain the reason/s for loss to follow-up.

Implications of the findings

Further research should clarify the effect of nonbiological caregivers on accessing care, explore why health workers and caregivers delay HIV testing, and review the quality of counselling and communication. Consideration should be given to actively tracing children who do not return for follow-up. Health managers should address the shortage of adequately trained health care workers, the attitudes of health care workers, the uptake of PMTCT, and consider increasing the number of primary care facilities that offer ART. Policy makers need to explore multisectoral interventions that address the stigma, poverty, and lack of knowledge about HIV and ARVs.

Conclusion

The study confirms that there are serious deficiencies in the prevention, diagnosis and treatment of children with HIV, and has identified factors that facilitate and obstruct early diagnosis and access to ART. A number of ways in which health services can be improved are suggested. The need for broader strategies aimed at addressing poverty, the HIV stigma and education is highlighted.

Declarations

The authors declared no personal or financial conflict of interest that may have inappropriately influenced them in conducting this study.

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