

Lessons from the field

Optimizing paediatric HIV care in Kenya: challenges in early infant diagnosis

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Problem In 2003, the goal of the Kenyan Ministry of Health was to avail antiretroviral treatment (ART) to 50% of the estimated 250 000 eligible individuals by the end of 2005. By July 2005, 45 000 adults and more than 2000 children were on treatment. A study was conducted to determine the barriers to identification of HIV-infected children.

Approach Existing government policies were reviewed and the ART register of the Kenya National AIDS Control Programme was used to identify facilities providing ART. This paper reports the findings around diagnosis and staging of HIV infection in children.

Local setting At the time of the study, 58 health facilities were providing ART to children. Only one institution had achieved universal HIV testing in the antenatal clinics. Six facilities systematically followed up HIV-exposed children. HIV antibody testing was not readily available to the children. Although four research centres were capable of carrying out diagnostic HIV polymerase chain reaction (PCR), the services were restricted to research purposes. Other constraints were inadequate physical infrastructure, inadequate systems for quality control in the laboratories and shortage of staff.

Lessons learnt The policy framework to support identification of HIV-infected children had been established, albeit with narrow focus on sick children. The assessment identified the weaknesses in the structures for systematic diagnosis of HIV through laboratory or clinical-based algorithms. The researchers concluded that health staff training and implementation of a systematic standard approach to identification of HIV-infected children is urgently required.

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Une traduction en français de ce résumé figure à la fin de l'article. Al final del artículo se facilita una traducción al español. الترجمة العربية لهذه الخلاصة في نهاية النص الكامل لهذه المقالة.

Background

Kenya's population of 30 million people has nearly 1.2 million people living with HIV/AIDS with at least 250 000 in need of immediate antiretroviral therapy (ART). In 2003, the Kenyan Ministry of Health started a programme to rapidly scale up ART with the goal of progressively delivering effective ART, according to standardized regimes, to HIV-infected people in need of treatment, reaching 50% by the end of 2005 and 80% by the end of 2008.¹ As a medium-term goal, the Kenyan government adopted WHO's "3 by 5" initiative, which aimed at providing 95 000 people with ART by end of 2005, of whom 10% were to be children. By July 2005, 45 000 adults and more than 2000 chil-

dren were on treatment, most of them older children. The obvious inequitable access to HIV treatment is of major concern considering that 90% of the HIV infections are due to mother-to-child transmission of HIV and without treatment, half of the infected children do not live to celebrate their second birthday and therefore need to be identified as early as possible to benefit from the newly availed antiretroviral (ARV) therapies.²

There was therefore a need to conduct a survey to identify the gaps existing within the current delivery of paediatric HIV care. This paper specifically reports systems and structural barriers to early identification and staging of children exposed to, or infected with, HIV.

Methods

The existing Kenyan Ministry of Health policies on HIV diagnosis in children were reviewed. Institutions providing ARV were identified using the national ART register in seven of the eight provinces, and a convenient sample of 58 government and mission facilities/non-governmental organizations providing ART to children was chosen, where a rapid assessment was conducted in the months of August and September 2005. A standard tool of structured questions and checklists was used to obtain information. In addition, qualitative information was obtained through face-to-face and/or telephone interviews. The key respondents were medical superintendents and matrons in charge

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of the facilities; physician(s) and heads of pharmacy, laboratory, mother and child health clinics, as well as ART clinic personnel. All possible entry points for paediatric HIV care were assessed and included maternal and child health clinics, paediatric inpatient wards and outpatient services as well as the comprehensive HIV clinics. Voluntary counselling and testing centres located within the 58 facilities were also surveyed.

The African Network for the Care of Children Affected by AIDS (ANECCA) 10-point package for comprehensive paediatric HIV care was used as the benchmark for monitoring and evaluating sites providing ART to children.³ We also used the integrated management of childhood illnesses (IMCI) chart to assess the facilities' capacity to screen and stage HIV-infected children. However, this paper focuses only on barriers to the early confirmation of HIV status and staging of HIV-infected children.

Results

Policy environment

In 2003, the National AIDS/STD Control Programme (NAS COP) developed a five-year strategic plan to guide the scaling-up of ART. A review of this strategic document showed that identification of HIV-infected/exposed children was not specifically provided for and the models of care adopted by the document precluded maternal and child health services as entry points for care for HIV-infected children. In 2004, NAS COP developed guidelines for HIV testing in clinical settings.⁴ These guidelines provided for universal HIV testing in all paediatric wards and for children infected with, or suspected to have, tuberculosis.

Health facility survey

A total of 58 facilities were identified to be providing paediatric HIV services. These facilities were broadly classified as government, faith-based and nongovernmental organizations, and included two national referral hospitals, 11 district hospitals, six health centres sponsored by the government, 12 mission hospitals, 18 mission health centres and four children orphanages. In the 42 (72%) that provided information on number of children in care, 6639 children were being followed up in the

paediatric HIV clinics and 1988 (30%) were on ART. There were only seven sites having more than 100 children on ART on follow-up.

Identification of HIV-infected/exposed children

Follow-up of mother–infant pairs in the maternal and child health clinics

Only six facilities had well established systems of referral and follow-up of HIV-exposed infants identified in the prevention of mother-to-child transmission of HIV (PMCT) programme. None of the facilities had a mother–child hand-held clinical record that clearly identified HIV-exposed or infected children. The existing mother's cards had a slot for antenatal HIV status of mother but this information was rarely transferred to the child's immunization/growth monitoring card. In most facilities, no attempt was made to ask the mother her HIV status or to check the antenatal clinic card that might indicate the child's HIV status.

Testing of children

We did not find any copies of the national guidelines for HIV testing in clinical settings in these facilities and none of the facilities had in-house policy guidelines on HIV counselling and testing for children. Most health caregivers were not clear on testing guidelines for children. However, many recognized the inadequacy of the voluntary counselling and testing guidelines in addressing HIV testing in children.⁵

In almost all the facilities assessed, children attending child welfare clinics were not routinely assessed using the IMCI criteria, and HIV testing was only offered on rare request by the clinicians.

A large number (31%) of the 58 health facilities did not provide on-site HIV testing to children. Children were not routinely tested in the voluntary counselling and testing centres located within the facilities, in keeping with the existing policy that the individual who is being tested must be legally competent to give informed consent. Children brought by parents or guardians were referred to the other clinics for diagnostic testing where testing was done at a cost denying many access to this service. In all the facilities, contrary to the 2004 policy, there was no routine testing of children whose parents or siblings were

identified as HIV infected or those in high-risk clinics, for example in tuberculosis clinics.

Only four facilities were capable of performing a diagnostic deoxyribonucleic acid (DNA) polymerase chain reaction (PCR) on children under 18 months, and even then only as research or pilot studies. None carried out routine processing of HIV DNA samples for routine clinical care of HIV-infected children. We did not find any facility that had staff trained in dry blood spot techniques of specimen collection. All other facilities had antibody-based tests for HIV diagnosis in children. None of the facilities assessed had an algorithm for early infant diagnosis.

Staging of HIV-infected children

None of the facilities had job aids to guide health-care workers on appropriate clinical staging for HIV-infected children. The facilities surveyed were able to stage HIV disease in children in areas where appropriately trained personnel were deployed; however, this was not done routinely. Clinical staging was best done at the paediatric wards. Five facilities did not have the capacity to perform basic tests required pre-ARV initiation, such as haemogram, renal and liver function tests. There were 26 facilities with various types of CD4 machines reflecting the different sources of support but reagents for the CD4 machines were either lacking or their supplies were erratic, therefore universal capacity for clinical and immunological staging of children was lacking.

Laboratory human resource and infrastructure

Human resource capacity

Except for four high level facilities that had university-trained laboratory personnel, all other laboratories visited were under the supervision of a diploma-level laboratory technologist. All laboratory staff were capable of performing at least one form of HIV testing.

All laboratories reported a lack of adequate personnel to cope with the HIV workload in addition to carrying out other routine laboratory assays.

Laboratory infrastructure

Most of the facilities had adequate laboratory space as well as HIV diagnosis and treatment-monitoring capacity. The most common HIV tests available were the

Rapid Tests. Determine® and SD Bioline HIV-1/2 were the commonly used tests for HIV testing in children, while Uni-gold™ was used as the tiebreaker.

Referral system for specimens and return of results

Only one laboratory visited had systems in place for referring patients or transporting samples from one site to the other. For tests that were not performed within a specific site, patients were given laboratory request forms and sent to have the tests done elsewhere. Such patients were frequently referred to private hospitals where the cost of most of the tests was likely to be higher than in the public hospitals, therefore inaccessible to many children. Even where such tests were done there was no system for delivery or return of test results, and patients had to wait until their next appointment to have their test result reviewed. All specimens from patients had identification tags on tubes, which included patient name and inpatient/outpatient number and hence there was the potential for involuntary HIV disclosure as patients moved to different laboratories seeking services. Although all laboratory requests are supposed to be on a standard form, in most of the facilities this was being done on ordinary paper and/or improvised forms. Virtually each facility had their own mechanism of recording laboratory results. None of the laboratories was involved in an organized network of well equipped facilities that provided routine support for lower-level facilities.

Good laboratory practice

Some of the hospitals had made efforts to develop standard operating procedures (SOPs) for some of the laboratory investigations done. However, none of the hospital visited had any SOPs for preventive maintenance of the existing equipments.

Quality control procedures

Except for internal quality assurance (QA), which was being followed where necessary, there were no other quality control (QC) methods in place, except for two major referral hospitals. Even where internal QC was followed, there was no documentation seen during this survey. Where tests were carried out at different service provision points and

by different cadre of staff, the main laboratory was given every 10th sample to retest without disclosure of initial results and both the results were later compared. One provincial hospital had an elaborate research laboratory that also provided essential QC for the service provision laboratory.

Data management

Only 80% of these facilities had records indicating the number of children tested for HIV. However, there was a wide discrepancy in facilities' ability to report certain indicators. One district hospital's database was only able to record completed years and therefore children under 18 months were generally categorized as being under two years. Therefore, any indicator capturing HIV testing at 18 months was meaningless.

The majority (72%) of the facilities used the recommended Ministry of Health registers to capture data, but the original registers were missing in most facilities forcing the health-care providers to improvise using hardcover black books or photocopied registers. Some registers were modified to accommodate the indicators required by partners supporting the sites. In summary, there was no uniform reporting system and the structures to support reporting, for example registers and computers, were insufficient.

Discussion

There are several key observations from this study. The policy framework to support identification of HIV-infected children that had been established narrowly focused on sick children and did not address identification of HIV-infected children in PMCT settings. PMCT is a major entry point to care for HIV-exposed and infected children. Children of women who had accessed PMCT services were not able to benefit from co-trimoxazole prophylaxis, early HIV diagnosis and regular follow-up beyond the prescribed "well child" visits for immunization and growth monitoring. The existing tools were not supportive of a systematic follow-up of the children and policies were not adequately disseminated.

Both HIV antibody and DNA PCR testing capability were available in-country, even though the latter was

not available for routine clinical care settings. The assessment identified the weaknesses in the structures and systems available and the lack of systematic diagnosis of HIV through laboratory or clinical-based algorithms. Existing policies excluded children from the free HIV-testing services offered through voluntary counselling and testing, and therefore HIV-antibody testing which was widely available could only be accessed at a cost for the children. There were serious lapses in management of the laboratories. The laboratories lacked systems for referring samples and instead referred patients but not necessarily to specific facilities. Preventive maintenance of the equipment and good laboratory practice were not in place in the majority of the laboratories.

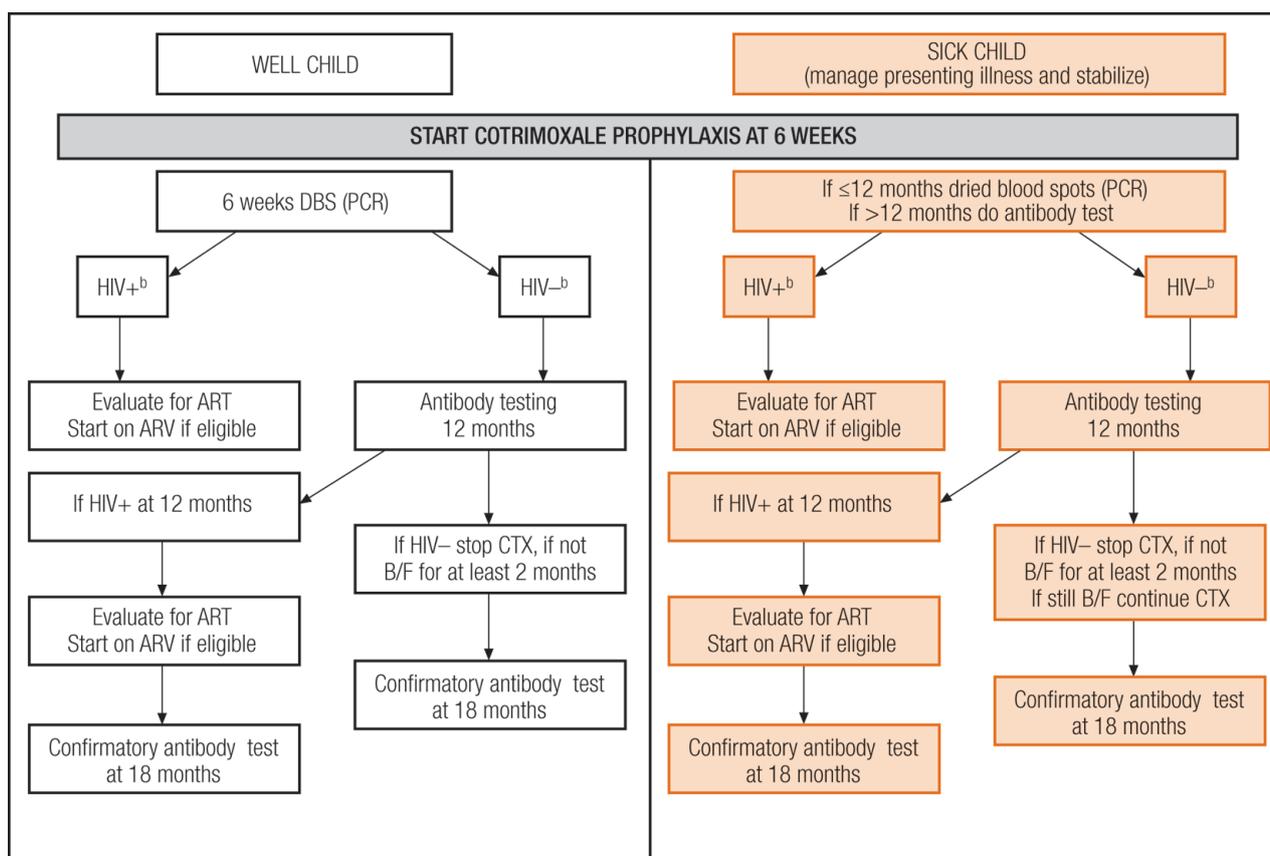
IMCI guidelines and WHO HIV-staging clinical tools that required minimal laboratory testing were also available. However, these algorithms were rarely used and staff lacked basic job aids to support their use.

Recommendations

Several recommendations can be made from this study. The first is the need to revise the existing national HIV-testing policies to embrace testing in the early infancy as a pillar of early infant diagnosis. These policies need to be widely disseminated to ensure health providers are aware of the content. Second, there is a need to develop a clear standard system of follow-up of children identified as HIV-exposed through PMCT services. Issuing the mother-child welfare card during the initial antenatal visit or at first contact for those delivered at home, with a clear indication of HIV-exposure status, should facilitate this referral.

Health-care personnel should be trained to routinely use a standard tool like IMCI to identify children suspected to be HIV infected, stage them, test and link them to care. Subsequently, national tools for paediatric HIV care should be developed and supplied to all facilities offering care. All health facilities and community organizations should have directories that will assist in referring children to appropriate care, psychosocial support and primary health care services, including immunization. All children who are enrolled in HIV

Fig. 1. Algorithm for early infant diagnosis, 2006^a



B/F, breastfeeding; CTX, cotrimoxazole; PCR, polymerase chain reaction.

^a Exposure status should be determined for all infants of unknown status at the six week visit or on first contact.

^b Counsel on infant feeding as per national guidelines.

programmes should be staged using clinical criteria where CD4 machines are not available. Consequently, simple staging tools should be developed and availed to frontline health-care workers.

Early identification and diagnosis is vital for survival of HIV-infected children. There is an urgent need to develop a system to avail diagnostic facilities such as PCR testing and P24-antigen testing for infants in partnership with the existing facilities. We propose that a referral laboratory is established at provincial level and is mandated to provide training and supervision of lower-level facilities.

There should be a national consensus on the indicators necessary to monitor identification and treatment of HIV-infected children. We suggest the indicators be reported at the following levels: health facility, district, province and national. At the same time, national tools for paediatric HIV care should be developed and supplied to all facilities offering care.

In conclusion, policies, guidelines and clinical and laboratory structures are required to accelerate diagnosis of HIV-infected and exposed children. Health-care workers need to be trained, supervised and provided with tools to ensure that HIV-exposed or infected children are identified and enrolled into care.

Limitations of the study

This assessment had several limitations, including the fact that we only focused on sites already offering ART. We did not gain access to some sites and for logistical reasons we did not visit far-flung health facilities. It would also have been desirable to understand community barriers (e.g. costs) to access to HIV testing for children. However, we believe that the information we collected from the 58 sites generally reflects national challenges in paediatric HIV and the findings would be broadly applicable to most health-care settings.

Impact of the study on paediatric HIV care in Kenya

The findings of this survey were disseminated to the National Paediatric HIV Steering Committee in March 2006. A national network for collection and referral of blood samples for DNA PCR has been established with close to 10 000 specimens being processed between January 2006 and March 2007. All the four laboratories identified as capable of performing DNA PCR and three others that were not part of this survey have either joined the national network for early infant diagnosis or are in process of joining. In addition, a national algorithm for the early infant diagnosis has been developed (Fig. 1) and has been disseminated widely and is included in all trainings on paediatric HIV care and PMCT. The policies on paediatric HIV testing have been updated to include routine offer of HIV testing to all children accessing the health-care system and routine offer of

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early infant diagnosis for all six-week-old infants on their first immunization clinic visit.⁶ A combined mother-child card has also been finalized and will be piloted soon. ■

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Competing interests: None declared.

Résumé

Optimisation des soins pédiatriques en rapport avec le VIH/sida au Kenya : difficultés d'un diagnostic précoce chez l'enfant

Problématique En 2003, Le Ministère de la santé kenyan s'était donné pour objectif de faire bénéficier d'ici fin 2005 d'un traitement antirétroviral (ART) 50 % des 250 000 personnes qui pourraient y prétendre d'après les estimations. En juillet 2005, 45 000 adultes et plus de 2000 enfants étaient sous traitement. Une étude a été menée pour déterminer les obstacles s'opposant à l'identification des enfants infectés par le VIH.

Démarche Les politiques gouvernementales existantes ont été examinées et le registre de délivrance du traitement ART du programme kenyan anti-VIH/sida a été utilisé pour identifier les établissements distribuant ce traitement. Le présent article rapporte les résultats en rapport avec le diagnostic et le stadage de l'infection à VIH chez l'enfant.

Contexte local Lors de la réalisation de l'étude, 58 établissements de santé dispensaient le traitement ART à des enfants. Un seul de ces établissements appliquait un dépistage systématique du VIH dans son service anténatal. Six établissements pratiquaient un

suivi systématique des enfants exposés au VIH. On ne disposait pas facilement d'un test de recherche des anticorps applicable aux enfants. Si quatre centres de recherche étaient en mesure de diagnostiquer le VIH/sida par une technique de type PCR, ils n'exerçaient ces capacités qu'à des fins de recherche. L'étude a révélé d'autres contraintes : infrastructure matérielle inadéquate, insuffisance des systèmes de contrôle de la qualité des laboratoires et pénurie de personnel.

Enseignements tirés Un cadre politique pour l'identification des enfants infectés par le VIH a été établi, même s'il est trop étroitement axé sur les enfants malades. L'évaluation a mis en évidence les faiblesses des structures de diagnostic systématique du VIH par des examens en laboratoire ou par des algorithmes partant de données cliniques. Les chercheurs ont conclu qu'une formation du personnel de santé et que l'application de la démarche standard d'identification systématique des enfants infectés par le VIH s'imposaient d'urgence.

Resumen

Optimización de la atención pediátrica para el VIH en Kenya: problemas del diagnóstico precoz en la infancia

Problema En 2003 la meta del Ministerio de Salud de Kenya para fines de 2005 era proporcionar tratamiento antirretroviral (TAR) a un 50% de las 250 000 personas que se estimaba que debían recibirlo. En julio de 2005, 45 000 adultos y más de 2000 niños estaban recibiendo tratamiento. Se realizó un estudio para determinar los obstáculos que dificultaban la identificación de los niños infectados por el VIH.

Enfoque Se revisaron las políticas nacionales en vigor y se utilizó el registro de TAR del Programa Nacional de Lucha contra el SIDA de Kenya para localizar los centros que ofrecían ese tratamiento. En este artículo se informa sobre los resultados relativos al diagnóstico y la estadificación de la infección por VIH en los niños.

Contexto local En el momento de realizar el estudio, 58 establecimientos de salud proporcionaban TAR a pacientes infantiles. Sólo una institución había logrado implantar de forma universal las pruebas de detección del VIH en los dispensarios prenatales. Seis establecimientos sometieron a seguimiento sistemático a los niños expuestos al VIH, pero éstos no tenían

fácil acceso a la prueba de detección de anticuerpos contra el VIH. Aunque había cuatro centros de investigación que podían llevar a cabo la prueba diagnóstica del VIH basada en la reacción en cadena de la polimerasa (PRC), esos servicios se limitaban a los trabajos de investigación. Otras restricciones eran una infraestructura física inadecuada, unos sistemas insuficientes de control de la calidad en los laboratorios y la escasez de personal.

Enseñanzas extraídas Se había establecido el marco normativo de apoyo a la identificación de los niños infectados por el VIH, si bien focalizando estrechamente esa actividad en los niños enfermos. La evaluación permitió identificar las deficiencias de que adolecían las estructuras de diagnóstico sistemático de la infección por VIH mediante algoritmos clínicos o de laboratorio. Los investigadores llegaron a la conclusión de que urge emprender actividades de capacitación del personal sanitario y aplicar un procedimiento normalizado sistemático de identificación de los niños infectados por el VIH.

ملخص

تحسين رعاية الأطفال المصابين بمرض الإيدز إلى المستوى الأفضل: تحديات تواجه التشخيص المبكر لدى الرضع

ووفرت ستة مرافق رعاية المتابعة بشكل منهجي للأطفال الذين تعرّضوا للعدوى بفيروس الإيدز. ولم يكن اختبار أصداد فيروس الإيدز متوفراً في الحال للأطفال. ورغم أنه كان بمقدور أربعة مراكز للأبحاث القيام باختبار تفاعل البوليميراز المتسلسل التشخيصي لفيروس الإيدز، فإن الخدمات كانت مقصورة فقط على الأغراض البحثية. وتمتثلت العوائق الأخرى في عدم كفاية البنية الأساسية الفعلية، وعدم ملاءمة نظم مراقبة الجودة في المختبرات، فضلاً عن نقص العاملين.

الدروس المستفادة: على الرغم من وجود السياسات الداعمة لعملية تحديد الأطفال المصابين بفيروس الإيدز، إلا أن تركيزها على الأطفال المرضى قليل. وقد حدّد هذا التقييم مواطن الضعف في الهياكل الخاصة بالتشخيص المنهجي لفيروس الإيدز من خلال المختبرات أو الخوارزميات السريرية المرتكز. وقد خلص الباحثون إلى أن الحاجة عاجلة لتدريب العاملين الصحيين، وتنفيذ أسلوب معياري منهجي لتحديد الأطفال المصابين بفيروس الإيدز.

المشكلة: كان هدف وزارة الصحة الكينية، عام 2003، هو إتاحة المعالجة بمضادات الفيروسات القهقرية لنصف الأشخاص المستحقين لها، والمقدّر عددهم بـ 250 000، وذلك بنهاية عام 2005. وبحلول تموز/يوليو 2005، كان 45 000 شخص بالغ وأكثر من 2000 طفل يتلقون هذه المعالجة. وقد أجريت دراسة للتعرف على الحواجز التي تعوق تحديد الأطفال المصابين بمرض الإيدز.

الأسلوب: روجعت السياسات الحكومية القائمة، واستخدم سجل البرنامج الوطني الكيني لمكافحة الإيدز، الخاص بمضادات الفيروسات القهقرية، من أجل التعرف على المرافق التي تقدّم مضادات الفيروسات القهقرية. وتعرض هذه الورقة البحثية الموجودات المتعلقة بالتشخيص، وتحديد مراحل العدوى بفيروس الإيدز لدى الأطفال.

المرفق المحلي: لدى إجراء الدراسة، كان هناك 58 مرفقاً صحياً يقدم مضادات الفيروسات القهقرية للأطفال، وكانت مؤسسة واحدة فقط هي التي تمكّنت من إجراء الاختبار الشامل لمرض الإيدز في عيادات الرعاية السابقة للولادة.

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