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# Preventable but neglected: rickets in an informal settlement, Nairobi, Kenya

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**Setting:** The primary care clinics of Médecins Sans Frontières within the informal settlement of Kibera, Nairobi, Kenya.

**Objective:** To describe the demographic and clinical characteristics of children clinically diagnosed with rickets from September 2012 to October 2013.

**Design:** Descriptive retrospective case review of diagnosis and treatment course with vitamin D and calcium using routine programme data.

**Results:** Of the 82 children who met the clinical diagnosis of rickets, 57% were male, with a median age of 12 months and 14 months for females. Children with rickets were found to have ⩽3 hours/week sunlight exposure for 71% of the children and malnutrition in 39%. Clinical findings on presentation revealed gross motor developmental delays in 44%. The loss to follow-up rate during treatment was 40%.

**Conclusions:** This study found that rickets is a common clinical presentation among children living in the informal settlement of Kibera and that there are likely multiple factors within that environment contributing to this condition. As rickets is a simply and inexpensively preventable non-communicable disease, we suggest that routine vitamin D supplementation be formally recommended by the World Health Organization for well-child care in Africa, especially in the contexts of informal settlements.

Nutritional rickets is a disease whose aetiology is related to a lack of vitamin D, calcium and sunlight exposure. Globally, it is one of the most common non-communicable diseases afflicting children, particularly in certain populations in developing countries.[1,2] Left untreated, rickets can have chronic sequelae, including developmental delays, skeletal abnormalities and painful pathological fractures.[3] Despite this burden and previous recommendations from many industrialised countries, there are no public health initiatives to address rickets prevention in resource-limited countries.[4,5]

Known risk factors for rickets include prolonged breastfeeding, early supplemental feeding with low vitamin D and calcium-rich foods, reduced sunlight exposure, overcrowded living situations, sex, dark skin pigmentation and air pollution.[6] However, a review of rickets literature reveals a paucity of reports from sub-Saharan Africa; existing reports have mainly focused on cases seen in tertiary care settings.[7–11] While populations in informal settlements in Africa are at increased risk of rickets, we are not aware of any publications from a primary care setting within an informal settlement in Africa.

Médecins Sans Frontières (MSF) operates the only large-scale primary care programme for the informal settlement of Kibera in Nairobi, Kenya, which has an estimated population of 200 000.[12] In 2011–2012, the programme noted an increasing number of cases of rickets among children. While recommended for all high-risk children, and usually routine practice in industrialised countries, vitamin D supplementation was not provided by MSF or the Kenyan Ministry of Health.[13]

The purpose of this study was to describe 1) the demographic, social and clinical characteristics of children presenting with rickets at the MSF clinic, 2) treatment outcomes, and 3) challenges with loss to follow-up in Kibera, Nairobi, Kenya.

## METHODS

### Design

This is a descriptive, retrospective case review using routinely collected programme data.

### Setting

The informal settlement of Kibera, in Nairobi, Kenya, lies 5 km from the centre of Nairobi and is considered one of the largest slums in Africa. Kibera occupies approximately 2.6 km$^2$ and consists of a heterogeneous cluster of 12 adjoining villages, with highly mobile and diverse ethnic groups.

MSF operates two primary care clinics, Kibera South Health Centre (KSHC) and Silanga Clinic. The two clinics are in distinctly different parts of Kibera; KSHC is the larger of the two and sees on average approximately 1330 children aged <5 years per month, while Silanga Clinic cares for 930 children per month.

Health care is provided by a multidisciplinary team consisting of clinical officers, nurses, mental health counsellors, nutritionists and social work staff, as described elsewhere.[14] Supervising clinical physicians provide training, oversight and direct patient consultations as needed on a daily basis. In September 2012, clinical staff and nutritionists underwent formal training on the causes of rickets and its clinical diagnosis based on physical examination findings, and developed a specific MSF treatment protocol.

### Study population

The study participants were all children seen at the MSF clinics between September 2012 and October

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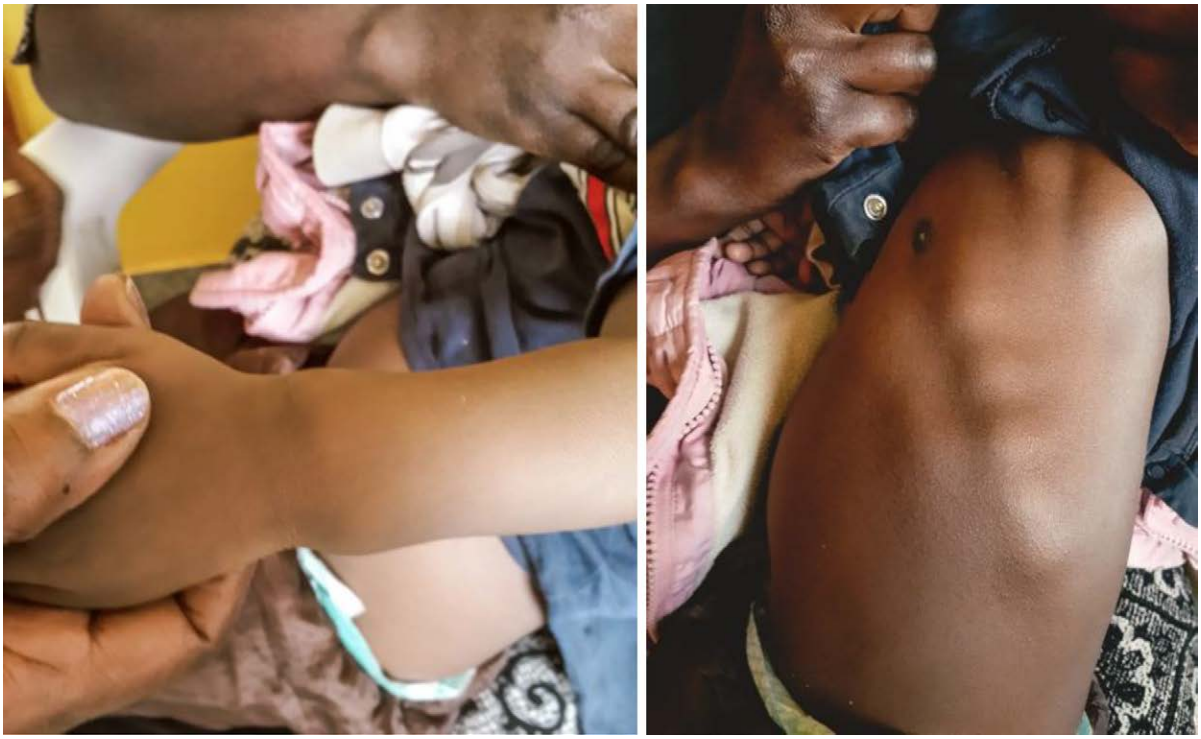

**FIGURE 1** Photographs of typical clinical features of rickets from the Médecins Sans Frontières clinic in Kibera. Rachitic rosary of the ribs are enlargements of ribs that appears as 'beading'. The junctions thicken because of disorganisation of the chondrocytes at the growth plate due to vitamin D and calcium deficiency. A similar process occurs at the wrists and knees. (images used with parental permission).

2013 who received a clinical diagnosis of rickets. Diagnostic criteria were based on a previous study that developed five clinical criteria with good sensitivity and specificity.[15] These included: age <5 years, widened wrists, rachitic rosary of the ribs, pain on walking and height-for-age <2 standard deviations (SD) below the mean (Figure 1). Because the majority of our patients were aged <18 months, we did not use the latter two diagnostic criteria, which have not been validated in this age group in Kenya. To receive a clinical diagnosis of rickets, a patient had to be aged <5 years and have either widening of the wrists or rachitic rosary of the ribs; use of these criteria yielded a predicted sensitivity of 89% and specificity of 59%.[15]

### *Data collection and variables*

Data were collected at diagnosis and throughout treatment for each child diagnosed with rickets in either clinic. Variables included age, sex, date of diagnosis, treating clinic, village of residence, day-care attendance, reported sunlight exposure, breastfeeding duration, anthropometric measurements, presenting symptoms and clinical findings. Religion and social customs were not recorded. Outcome measures included clinic attendance, nutritional consultation, supplementation and loss to follow-up. Clinical improvement was also reported by treating clinicians, and included reduction in presenting symptoms of rickets or physical examination findings, but was not specifically quantified.

### *Treatment*

After initial evaluation, all patients were started on an age-based dosage of vitamin D, where children aged <12 months received 1000 IU daily and those aged >12 months 2000 IU daily. All patients were prescribed calcium (children <10 kg received 500 mg daily, those >10 kg 1000 mg daily). All children received vitamin D and calcium for a total of 6 weeks as part of the MSF rickets treatment protocol. Children diagnosed with malnutrition received nutritional supplements. After 6 weeks of treatment, the children were given a preventive dose of vitamin D for another 12 weeks or were seen by the supervising medical officer if there was no improvement.

### *Analysis*

For each child, data were recorded on a standardised sheet by clinical officers and then single-entered into an Epi-Info 7 database. Statistical analyses were performed using the Epi-Info 7 Analysis software package (Centers for Disease Control, Atlanta, GA, USA). Comparisons between males and females were performed because of previously reported sex differences in rickets.[16] Analysis was completed using Fisher's exact test, with a 5% level of significance. For continuous data comparisons, a Wilcoxon rank sum test was used with a 5% level of significance.

### *Ethics review*

For this study, data had been collected previously for use in routine MSF programme management. Consequently, informed consent from patients or their fami-

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Conflict of interest: none declared.

**TABLE 1** Demographic and environmental characteristics of children with clinical rickets in Kibera, Nairobi, Kenya, September 2012–October 2013

| Characteristics | Male *n* (%) | Female *n* (%) | *P* value |
|---|---|---|---|
| Frequency of rickets | 47 (57) | 35 (43) | |
| Age, months, median [IQR] | 12 [10–15] | 14 [11–17] | 0.11 |
| Treatment clinic | | | |
| Kibera South Clinic | 11 (23) | 6 (17) | |
| Silanga Clinic | 36 (76) | 29 (83) | 0.6 |
| Day-care attendance* | 11 (24) | 10 (30) | 1.0 |
| Sunlight exposure† | | | |
| ⩽3 h/week | 27 (82) | 9 (50) | |
| >3 h/week | 6 (18) | 9 (50) | 0.03 |

*Of total reported: males = 46, females = 33.
†Of total reported: males = 33, females = 18.
IQR = interquartile range.

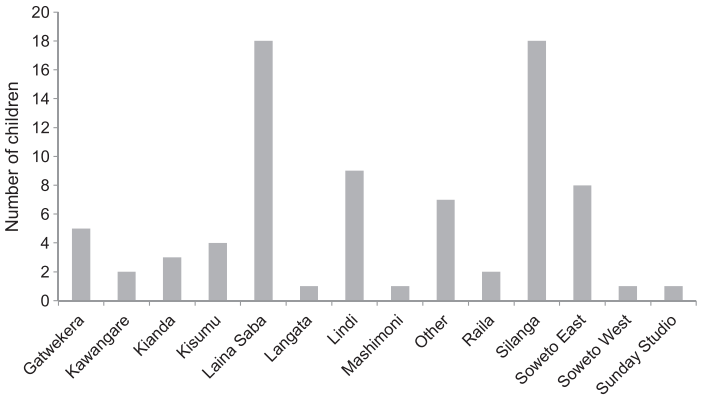


**FIGURE 2** Frequency of rickets cases by village in Kibera, Nairobi, Kenya, September 2012–October 2013.

lies was not obtained by the treating clinicians. For images, parental consent was obtained.

This study was approved by the Ethics Review Committee at the Kenyatta National Hospital/University of Nairobi. It met the Médecins Sans Frontières' (Geneva, Switzerland) Ethics Review Board-approved criteria for analysis of routinely collected programme data. It also satisfied the requirements of the Ethics Advisory Group of the International Union Against Tuberculosis and Lung Disease, Paris, France.

## RESULTS

Between September 2012 and October 2013, a total of 125 children with suspected rickets were seen, of whom 82 met the inclusion criteria for the clinical diagnosis of rickets. Table 1 compares the demographic and environmental characteristics of male and female patients. There was a trend towards a predominance of male children within the study group (57%); the median age of presentation was 2 months younger for males.

The amount of sunlight exposure was reported by the families of 51 patients. Seventy-one per cent of these children had ⩽3 hours of sunlight per week. There was a seasonal difference in the diagnosis of rickets, with a peak (29% of all cases) during the rainy season of 2013 (March–April), which was independent of monthly total clinic patient volumes (data not shown). Figure 2 shows that two of the 12 main villages within Kibera accounted for 44% of the cases of rickets diagnosed during the study period.

The children's nutritional characteristics are shown in Table 2. The majority of children were still breastfeeding. Overall, moderate or severe malnutrition was found in 29% of children, with a *Z*-score (weight for height) of ⩽2 SD. Using mid-upper arm circumference (MUAC) scores, 39% were found to be malnourished, with scores of <125 mm.

The clinical characteristics of the children are shown in Table 3. Most (67%) presented with typical rickets symptoms of weak-

**TABLE 2** Nutritional characteristics of children with rickets in Kibera, Nairobi, Kenya, September 2012–October 2013

| Characteristics | Male *n* (%) | Female *n* (%) | *P* value |
|---|---|---|---|
| Currently breastfeeding* | 36 (77) | 19 (54) | 0.06 |
| Age initiated supplemental feeding, months, median [IQR] † | 6 [4–6] | 6 [6–6] | 0.5 |
| Weight on intake, kg, median [IQR]‡ | 8 [7–9] | 8 [7–8] | 0.6 |
| Height on intake, cm, median [IQR]§ | 71 [66–75] | 71 [66–75] | 1 |
| *Z*-score (wt for ht)¶ | | | |
| ⩽3 SD | 5 (11) | 4 (12) | |
| >3 and ⩽–2 SD | 6 (14) | 7 (21) | 0.8 |
| >2 and ⩽ –1 SD | 12 (27) | 10 (30) | |
| ⩾1 SD | 21 (47) | 12 (36) | |
| Average MUAC measurement, cm, median [IQR]¶ | 128 [120–138] | 126 [122–136] | |
| MUAC¶ | | | |
| ⩾125 cm | 27 (61) | 20 (61) | |
| 115–124 cm | 8 (18) | 7 (21) | |
| <115 cm | 9 (21) | 6 (18) | |

*Of total reported: males = 47, females = 35.
†Of total reported: males = 25, females = 17.
‡Of total reported: males = 44, females = 32.
§Of total reported: males = 41, females = 31.
¶Of total reported: males = 44, females = 33.
IQR = interquartile range; SD = standard deviation; MUAC = mid-upper arm circumference.

**TABLE 3** Clinical characteristics of children with rickets in Kibera, Nairobi, Kenya, September 2012–October 2013

| Characteristics | Cases ($n$ = 82) $n$ (%) | Age at enrolment months, median [IQR] |
|---|---|---|
| Presenting symptoms | | |
| Generalised weakness | 18 (22) | 13 [11–14] |
| Enlarged head | 23 (28) | 12 [10–15] |
| Swelling of wrists | 25 (31) | 12 [11–16] |
| Clinical examination findings | | |
| Motor weakness | 23 (28) | 12 [10–15] |
| Swelling at wrists | 72 (89) | 13 [11–16] |
| Frontal bossing | 55 (67) | 13 [10–16] |
| Rachitic rosary of chest | 44 (54) | 13 [10–16] |
| Enlarged anterior fontanel | 30 (37) | 13 [10–14] |
| Unable to sit at 7 months | 9 (11) | 10 [9–12] |
| Unable to stand at 12 months | 21 (26) | 14 [13–17] |
| Unable to walk at 14 months | 19 (23) | 16 [14–18] |

IQR = interquartile range.

ness, wrist swelling and/or an enlarged head. The rest had physical signs of rickets with no specific rickets-related presenting complaint. Collectively, 44% children were found to have some degree of gross motor developmental delay.

Forty-nine (60%) patients completed the full 6-week course of treatment. Complete treatment meant a total of four clinical visits, and loss to follow-up varied by visit. There was no standardised quantitative documentation of clinical improvement, but staff recorded their clinical impression of improvement in 65% of those who were not lost to follow-up. This usually meant reduced joint pain or weakness and improvement in developmental delays.

## DISCUSSION

This is the first study of clinically diagnosed rickets from a primary care setting in a slum context in sub-Saharan Africa. Importantly, it highlights a number of social and environmental factors that contribute to rickets in this setting that need better recognition. In addition, given the potential long-term sequelae of rickets and its relatively simple and low-cost treatment, this study prompts consideration of a public health policy for rickets prevention in the African setting. Rickets prevention strategies for children are widely available in industrialised countries, and have been recommended previously for developing countries.[13]

This study suggests that multiple environmental and social factors have contributed to the development of rickets in this population. Incongruous as it seems, many of these children suffered from lack of exposure to sunlight. Sunlight is the primary source of vitamin D for more than 90% of total daily requirements.[17] Sunlight exposure was recorded at ⩽3 h per week in 71% of patients' families, and is comparable to findings by others.[18] More males reported a greater lack of sunlight exposure. This may be related to the overall lower age of boys within the study group, cultural reasons or both.

The lack of adequate sunlight exposure is most likely related to multiple issues linked to slum conditions, where there is a very high population density with living structures in close proximity to each other. This leads to restricted sunlight exposure and less space for children to gain access to sunlight.[19] In addition, construction techniques rarely provide for window space, resulting in little or no sunlight exposure within the homes, day-care centres or schools. Furthermore, in Kibera there may be specific cultural practices of protecting young children from illness, security risks or the 'evil eye' by keeping them inside.[20]

Our study suggests possible seasonal variability related to the rainy season, which has been shown to contribute to the lack of sunlight exposure.[21] Clothing also has a significant impact on sun exposure.[22] Anecdotally, in Kibera it is typical for infants and young children to be swaddled or overdressed when outside the home, which can lead to less sun exposure. Dark skin pigmentation also leads to significantly less vitamin D production.[23] Despite multiple studies, there is no consensus on the amount of ultraviolet exposure time necessary to achieve adequate vitamin D levels for those with increased skin pigmentation.[24]

A higher frequency of rickets cases (44%) was found among the two villages closest to Silanga Clinic. Although the clinical staff may have been more eager to diagnose rickets cases at the Silanga Clinic, it is suspected that there are environmental, social, cultural and behavioural differences among those living in specific villages that place children at higher risk of developing rickets.

There was a large proportion of malnutrition in the children with rickets, which suggests that the lack of vitamin D, calcium and other micronutrients in the diet also contributed to the problem. It was not standard practice to screen for other specific micronutrient deficiencies in our context. In this study, 39% of children with MUAC measurements were found to be moderately or severely malnourished, with an MUAC of <125 mm. This can be compared to the prevalence of malnutrition of <10% in all children aged <5 years by MUAC screening in our programme (data not presented). An association between malnutrition and the development of rickets has been reported by others.[7,25]

Clinical findings of children with rickets were consistent with previous reports.[26] What was striking, however, was the frequency of associated gross motor developmental delay observed in this cohort (44%). It could be argued that our criteria for establishing developmental delay—being able to sit, stand or walk—were too inclusive, and there was no comparison control group. However, similar delays in these age groups have been found previously in association with rickets, but not at this high a frequency.[25]

We also noted a high loss to follow-up rate, of 40% overall. This rate is similar to that reported from a recent study of chronic disease patients in Kibera.[14] These findings suggest that the population is highly mobile between primary homes elsewhere in Kenya and Kibera, a point that should be considered in any future prevention and treatment strategies.

Strengths of this study include the fact that it was completed in primary care clinics in the context of an urban informal settlement, which, to our knowledge, has never been done before. In addition, because of its operational nature, it more likely reflects 'real world' results than those of a prospective study in a referral-based tertiary care facility. Data handling was carefully supervised by a data manager and a project epidemiologist, and the study report followed STROBE guidelines.[27]

Limitations of this study are directly related to its operational methodology. For example, there was no routine biochemical or radiographic confirmation for the diagnosis of rickets. The clinical diagnostic criteria were adapted from those previously validated in an African setting with children aged ⩾18 months.[15] However, this is usually an easily recognisable clinical diagnosis, particularly within the context of malnutrition, developmental

delay and younger age. In addition, there were no formalised outcome criteria for clinical improvement, merely clinical assessments. Adequate assessment of improvement would require laboratory confirmation, which was beyond the scope of this resource-constrained primary care setting.

From a public health perspective, it is now clear that rickets has been overlooked in the informal settlement of Kibera. These findings probably hold true in other similar settlements in sub-Saharan Africa. These results support previous recommendations to develop a primary prevention strategy for rickets.[13]

Surprisingly, the World Health Organization (WHO) has not made any formal recommendations on the routine use of vitamin D for the prevention of rickets, especially in resource-poor contexts,[28] despite a large systematic review of the available literature in 2007 that reported there was adequate evidence to support this policy in Africa, with a favourable risk-benefit ratio.[13] Given these recommendations, and the evidence from this study, we suggest that the WHO, MSF and the Kenyan Ministry of Health consider routine vitamin D supplementation for the prevention of rickets. The choice between daily vitamin D supplementation or intermittent therapy due to the high loss to follow-up would depend on further study.

## CONCLUSION

This study found that rickets is a common clinical presentation among the children who live in the informal settlement of Kibera and that there are probably multiple contributing factors associated with that environment. As rickets is an easily and inexpensively preventable non-communicable disease, we suggest that routine vitamin D be considered for well-child care in Africa, particularly in the contexts of informal settlements.

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**Contexte :** Le dispensaire de soins de santé primaire de Médecins sans Frontières au cœur du bidonville de Kibera, Nairobi, Kenya.

**Objectif :** Décrire les caractéristiques démographiques et cliniques d'enfants ayant eu un diagnostic clinique de rachitisme de septembre 2012 à octobre 2013.

**Schéma :** Revue descriptive et rétrospective du diagnostic et du traitement par vitamine D et calcium à travers les données des programmes de routine.

**Résultats :** Sur 82 enfants répondant au diagnostic clinique de rachitisme, 57% étaient des garçons d'un âge médian de 12 mois tandis que l'âge médian des filles était de 14 mois. L'exposition au soleil déclarée par la famille était de ⩽3 heures par semaine pour 71% des enfants et 39% présentaient une malnutrition. Les constatations cliniques à l'arrivée ont mis en évidence un retard de développement moteur marqué chez 44% des enfants. Le taux de perdus de vue pendant le traitement a été de 40%.

**Conclusion :** Cette étude a constaté que le rachitisme était une affection fréquente parmi les enfants vivant dans le bidonville de Kibera et que de nombreux facteurs de l'environnement de Kibera y contribuaient vraisemblablement. Comme le rachitisme est une maladie non transmissible qui peut bénéficier d'une prévention simple et peu coûteuse, nous suggérons qu'une supplémentation en vitamine D soit formellement recommandée par l'Organisation Mondiale de la Santé dans les soins de santé aux enfants en Afrique, surtout dans le contexte de bidonvilles.

**Marco de referencia:** Los consultorios de atención primaria dirigidos por Médecins Sans Frontières en el asentamiento informal de Kibera, en Nairobi, Kenia.
**Objetivo:** Describir las características clínicas y demográficas de los niños con diagnóstico clínico de raquitismo entre septiembre del 2012 y octubre del 2013.
**Método:** Fue este un análisis descriptivo de casos, en el cual se evaluaron retrospectivamente el diagnóstico y la evolución del tratamiento con vitamina D y calcio, a partir de los datos corrientes del programa.
**Resultados:** De los 82 niños que cumplían con los criterios diagnósticos de raquitismo, el 57% era de sexo masculino, con una mediana de edad de 12 meses y la mediana de edad de las niñas fue 14 meses. En el 71% los casos de raquitismo se encontró que la exposición directa al sol era de ⩽3 horas por semana y el 39% presentaba desnutrición. El examen físico en el momento de la consulta demostró un grave retraso del desarrollo motor en el 44% de los niños. Durante el seguimiento se perdió el 40% de los casos.
**Conclusiones:** El presente estudio puso en evidencia que el raquitismo es una enfermedad frecuente en los niños que acuden a la consulta y viven en el asentamiento informal de Kibera; existen múltiples factores en el medio ambiente que contribuyen a esta situación. Dado que el raquitismo es una enfermedad no transmisible cuya prevención es sencilla y de bajo costo, se propone que la Organización Mundial de la Salud recomiende formalmente el aporte complementario sistemático de vitamina D en la consulta del niño sano en África, sobre todo en los entornos de asentamientos no estructurados.

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