

## Case report

# Health insurance coverage for vulnerable children: two HIV orphans with Burkitt lymphoma and their quest for health insurance coverage in Kenya

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## SUMMARY

The United Nations and WHO have summoned governments from low-income and middle-income countries to institute universal health coverage and thereby improve their population's healthcare access and outcomes. Until now, few countries responded favourably to this international plea. The HIV/AIDS epidemic, a major global public health challenge, resulted in over 11 million orphans in sub-Saharan Africa. Extended families have taken responsibility for more than 90% of these children. HIV orphans are likely to be poorer and less healthy. Burkitt lymphoma is the most common childhood cancer in sub-Saharan Africa. If orphans need lifesaving chemotherapy, appointing legal guardians becomes necessary to access health insurance. However, rules and regulations involved may be unclear and costly. This hinders its access for poor families who need it most. Uninsured children risk hospital detention over unpaid medical bills and have lower survival. Our case report depicts the quest for health insurance coverage of two HIV orphans with Burkitt lymphoma in Kenya.

## BACKGROUND

Despite an international plea for universal health coverage (UHC) by the United Nations (UN), WHO, and over 500 health and development organisations, only a few governments of low-income and middle-income countries have implemented UHC to improve access to the medical care of their populations.<sup>1,2</sup>

HIV/AIDS is one of the world's major public health challenges, particularly in low-income and middle-income countries. Worldwide 36.9 million people live with HIV.<sup>3–7</sup> A serious consequence of the HIV/AIDS epidemic is the increased number of orphans.<sup>8</sup> Over 11 million children have lost one or both parents to HIV/AIDS in sub-Saharan Africa.<sup>9</sup> The vast majority of these HIV orphans are looked after by resource-limited and fragile relatives.<sup>9</sup>

Burkitt lymphoma is the most common childhood malignancy in sub-Saharan Africa, an area where malaria is holoendemic. Its incidence is high in immunosuppressed HIV patients.<sup>10</sup> If an HIV orphan with Burkitt lymphoma needs lifesaving chemotherapy, appointing a legal guardian becomes necessary to obtain health insurance.<sup>11–13</sup> The rules and regulations for acquiring legal guardianship may be ill-defined, long-winded and expensive. This particularly hinders access by poor families

to not only legal guardianship, but also to health insurance.<sup>11–14</sup>

We report a case of two HIV orphans with Burkitt lymphoma and their quest for health insurance coverage in Kenya.

## CASE PRESENTATION

### Case 1

A Kenyan boy born in 2014 to HIV-positive parents was first diagnosed with HIV at 6 months. His mother abandoned him at his grandmother's home when he was 2 years, without informing the grandmother about their HIV status. "My husband and I had warned her against getting together with the boy's father since we knew about his HIV status, but she did not listen. I suspect she was afraid to face us when she got infected," the grandmother explained. The grandparents already took care of three other grandchildren. Their household did not have a regular income, and they lived below the poverty line. The grandfather depended on manual jobs in the village while the grandmother sold farm produce. The grandmother first found out about her grandson's HIV status when she was called by a nurse from a local clinic following up on the boy who had been lost to follow-up for a year. "I felt ashamed when I found out that my daughter and grandson were infected," the grandmother said. Subsequently, the boy was put back on treatment. Treatment and consultation fee was free of charge except for 1€ for blood investigations done every 3 months. The mother of the boy died due to HIV-related complications in 2016, and the father, who did not live with the family, committed suicide (table 1).

In 2017, the 3-year-old boy was hit by a motor-bike and rushed to the nearest health facility where the doctor noticed a swelling on his groin. He was referred to Moi Teaching and Referral Hospital (MTRH), an academic hospital in Eldoret, for further check-up. The boy was admitted into the paediatric ward with inguinal swelling for 2 weeks, loss of appetite, weight loss, cough and discharge from the ear. The diagnosis of Burkitt lymphoma, a very aggressive type of B-cell non-Hodgkin's lymphoma, was confirmed by a fine needle aspirate and lymph node biopsy. Burkitt lymphoma, the fastest growing human tumour, is the most common childhood cancer in sub-Saharan Africa. This increased incidence of Burkitt lymphoma compared



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**Table 1** Socio-demographic and clinical characteristics of patients

	Case 1	Case 2
Vulnerability child	HIV orphan	HIV orphan
HIV-status child	HIV infected	–
Child taken in by	Grandparents	Grandparents, aunt
Caretakers have legal guardianship	No	No
Income household	Below poverty line	Above poverty line
Cancer diagnosis	Burkitt lymphoma	Burkitt lymphoma
Health insurance status caretakers	No health insurance	Health insurance
Informed by medical team of need for health insurance	Yes	Yes
Applied for health insurance	Yes	–
Caretakers aware that health insurance only covers child's medical bills in case of legal guardianship	No	No
Informed by medical team of need for legal guardianship	No	Yes
Applied for legal guardianship	No	Yes
Child detained in hospital over inability to pay medical bill	Yes	Yes
Condition child during hospital detention	Deceased	Alive
Obtained hospital waiver	Yes	Yes
Obtained legal guardianship	No	Yes
Obtained health insurance cover for child	No	Yes
Cancer treatment outcome	Death	Survival

with the rest of the world is related to endemic malaria in many parts of the region. The development of Burkitt lymphoma is not only associated with chronic malaria but also with Epstein-Barr virus and HIV infection.<sup>10 15–17</sup> The boy was started on an intensive multiagent chemotherapy regimen with central nervous system prophylaxis.<sup>18</sup> The 6-month regimen consists of a prephase and eight cycles. During admission, hospital staff advised the grandmother to get health insurance, as it would cover the inpatient and outpatient treatment costs of her nuclear family, including the grandson. The grandmother subsequently applied for the health insurance coverage. However, no one mentioned to her that health insurance would only cover her grandson's treatment if she had legal guardianship, which she did not have. During Burkitt lymphoma treatment, the family income decreased significantly. "Since I had to stay with my grandson in the hospital during his admission, I was not able to sell farm produce which was my source of income," reported the grandmother. They depended on family and friends to send money for daily use while in the hospital. After the boy had received prephase and the first course of chemotherapy, his health deteriorated. He developed diarrhoea and vomiting episodes and died at the age of 3 years.

The body of the boy was not released to the family for burial but detained in the morgue since they had an outstanding hospital bill which needed to be cleared first. The grandmother learnt that her health insurance could not cover her grandson's outstanding hospital bills because she did not have legal guardianship. "I was very afraid that my grandson's body would not be released to us for burial," the grandmother said. She talked to social workers at MTRH about her financial issues and was given an appointment with the hospital waiver committee. The first time she appeared before this committee was 2 days after the death of her grandson. She presented her case and was asked to go back home and raise the money. "At that time I felt desperate as I knew we were unable to collect the required sum of money to release my grandson's body," the grandmother explained.

She sought help from the district commissioner who instructed the division officer to write a letter to the hospital explaining the financial situation of the family, which the grandmother and her neighbour presented to the committee 4 days after her grandson's death. "I felt powerless because there were no clear rules, criteria or regulations for hospital bill waiver," she said. The neighbour had to arbitrarily promise to pay the monthly health insurance contribution fee for the family in the future. After deliberations, the committee agreed to waive the whole hospital bill, and the family was asked to go home and wait for communication on when they could collect the body. Six days after her grandson's death, the family was called to collect the body for burial. However, on arriving at the morgue, the family was told that they were still not allowed to take the boys' body home for burial. Apparently, the hospital bill had been waived but not the mortuary fee. His corpse would, therefore, remain in detention at the morgue until the mortuary fee was paid in full. This fee included 52€ for the first week of detention, plus an additional 8€ for subsequent extra days the corpse was detained. The grandmother said, "The practice is very unfair and cruel. I felt guilty towards my grandson, who was denied a decent funeral because of our poverty." Fundraising was held by the extended family to try raise money for the mortuary fee. After payment, the grandson's body was released for burial 10 days after his death.

## Case 2

A Kenyan boy was born in 2013 to HIV-positive parents. His mother refused treatment despite encouragement from family because she thought she had been bewitched. She instead sought the help of a traditional healer and died in 2014. The father, on the other hand, had accepted his HIV status and was on treatment. The father was cared for by his sister, the boy's aunt, while he was sick. "I did not feel ashamed or fear how people would respond to my brother's and sister in law's HIV status. But there are many people who are afraid to take an HIV test and disclose their status because they fear people's reactions and discrimination," the aunt stated. Unfortunately, the father died in 2016 in a motorcycle accident. After the boy became an orphan at 3 years old, he was initially put under the care of his elderly and frail grandmother for 1 year, after which his aunt took over his care. The aunt was already taking care of three of her late brothers' children in addition to her own children. She ran a business with which she earned 100€ per month. Neither the grandmother nor the aunt were aware of or had legal guardianship over the boy.

In 2017, a week after moving in with the aunt, the 4-year-old boy started complaining of stomach pains and developed abdominal distension, sunken eyes, loss of appetite and was having night sweats. The patient was taken to a county hospital where a CT scan showed a mass in the abdomen, which the doctor suspected to be malignant. He was referred to MTRH where an ultrasound-guided biopsy was done, and flow cytometry confirmed Burkitt lymphoma. The patient was subsequently transferred to the paediatric ward to start chemotherapy. A social worker inquired about the aunt's health insurance status at first admission. The aunt was already registered with health insurance and was advised to seek legal guardianship of the patient so as to add him as a dependent in her health insurance cover. The aunt asked one of her daughters to inquire from the children's court in their home town about legal guardianship. The family was told that the aunt and her husband together with grandparents from the patient's maternal and paternal side, were required to appear before the court. In addition, a home visit

by the court had to be planned. The family gave up since they found this to be tedious. “Our family income decreased because I had to close my shop to accompany my nephew to hospital for admission,” the aunt said. After receiving the first course of treatment, the patient was clinically discharged. Because the aunt could not pay the hospital bill, the boy was detained at the hospital. During his detention, the boy was being taken care of by his sister as the aunt looked for money to clear the bill. “I felt desperate, powerless, ashamed and afraid since we were not allowed to go home. My nephew also felt sad, guilty and ashamed that he was detained in hospital,” the aunt explained. The aunt described hospital detention practices as unfair and dehumanising. “I went to the hospital mortuary to cry since nobody there knew me and no one would ask me why I was crying,” stated the aunt. After 1 week in detention, the aunt had managed to put together the required amount of money through donations from extended family, friends and well-wishers, and the boy was released. Subsequently, the aunt inquired from a children’s court in Eldoret about legal guardianship. She was this time told that she needed death certificates of the boy’s parents, and a letter from the ward administrator confirming the current status of the boy. Additionally, she had to hire a lawyer who would present these documents in a court of law. Once she had gathered all documents, the aunt hired a lawyer for 58€ to represent them in court. The aunt got the guardianship certificate and presented it to the health insurer, and the patient was added as a dependent to her insurance coverage. The patient finished his treatment successfully and is currently on follow-up at the outpatient oncology clinic.

It is important to note that the case reports and quotes were checked and endorsed by the families concerned.

## GLOBAL HEALTH PROBLEM LIST

- ▶ The UN, WHO and more than 500 health and development organisations worldwide have summoned governments from low-income and middle-income countries to implement UHC and thereby improve admittance to medical services and treatment outcomes of their citizens.<sup>1</sup> Until now, few countries responded favourably to this international plea.
- ▶ UHC forestalls populations from being pushed into long-term poverty while paying medical therapies out of their pockets. UHC plays a central role in reducing socioeconomic disparities in healthcare access and outcomes.<sup>2</sup>
- ▶ Since its emergence in the 1980s HIV/AIDS is one of the world’s major public health challenges, particularly in low-income and middle-income countries, with 36.9 million people globally living with HIV.<sup>3–5</sup>
- ▶ Stigma among people living with HIV/AIDS has been associated with poor adherence to therapy and is a crucial impediment to the acceptance of HIV services.<sup>6,7</sup>
- ▶ A clear impact of the HIV/AIDS epidemic in low-income and middle-income countries is the increased number of orphans and vulnerable children.<sup>8</sup> Over 11 million children under the age of 15 years living in sub-Saharan Africa have lost one or both parents to HIV/AIDS.<sup>9</sup>
- ▶ Children who lose parents to HIV/AIDS might also be infected with HIV and often find themselves battling the very disease that leads to the demise of their parents.<sup>19</sup>
- ▶ In nearly every sub-Saharan country, extended families have taken responsibility for over 90% of orphaned children.<sup>9</sup>
- ▶ Burkitt lymphoma is the most common childhood cancer in sub-Saharan Africa, an area where malaria is holoendemic. Its incidence is high in immunosuppressed HIV patients.<sup>10</sup>

- ▶ HIV orphans are likely to be poorer and less healthy than non-orphans.<sup>9</sup> If an HIV orphan needs medical treatment, such as lifesaving chemotherapy for Burkitt lymphoma, appointing a legal guardian becomes necessary to access health insurance.<sup>11–13</sup>
- ▶ The rules and regulations involved in obtaining legal guardianship may be unclear, tedious and costly. This hinders its access by poor families who need it the most.<sup>11–13</sup>
- ▶ Uninsured patients risk being detained in hospitals. Hospital detention practices can be defined as a refusal to release living patients and bodies of deceased patients if patients and their families are unable to pay their hospital bills.<sup>20</sup>
- ▶ Hospital waivers are described as a right given to individuals to access health services at no charge or at a reduced fee.<sup>21</sup> Although in theory, these waivers appear beneficial, in reality, no clear rules or selection criteria exist in assigning waivers. As a result, waivers can be exploited creating more social injustice and unequal access to healthcare.<sup>22–25</sup>
- ▶ There is a need for increased social services support and guidance in navigating the social and legal processes for families caring for orphaned and vulnerable children with HIV.

## GLOBAL HEALTH PROBLEM ANALYSIS

### Universal health coverage

The UN, WHO and more than 500 health and development organisations worldwide have summoned governments from low-income and middle-income countries to implement UHC and thereby increase admittance to medical services and treatment outcomes of their citizens. Until now, few countries responded favourably to this international plea.<sup>1</sup>

The concept of UHC is grounded on the UN Universal Declaration of Human Rights. It explicitly states that healthcare is a fundamental human right of all people around the globe regardless of, for example, their income level, sex, age or nation of descent. The goal of UHC is to ensure that all people can get medical services they need without suffering economic hardships when paying for these services.<sup>1,26</sup>

UHC directly impacts the health of a country. Citizens who are able to access medical services are healthy, and this enhances productivity and stimulates economic growth. UHC permits citizens to afford and provide better schooling for their children. UHC forestalls citizens to be pushed into long-term poverty while paying medical therapies out of their pockets. UHC thus significantly leads to durable development and plays a central role in reducing socioeconomic disparities. UHC shows that a government is earnestly dedicated to improving the well-being of all its citizens and is not solely favouring the elite.<sup>26–28</sup>

Despite ongoing investments by the Kenyan government whose overall goal is to make health services more effective, accessible and affordable, access to basic health services remains a significant challenge.<sup>29,30</sup> In 1966, the Kenyan government established health insurance through the National Hospital Insurance Fund (NHIF). Every Kenyan citizen over 18 years is allowed to uptake NHIF. Contribution for self-employed or unemployed Kenyans is around 5€ per month. Contribution for Kenyans working in the formal sector is based on their income. Despite its affordability and obvious benefits, less than 10% of the Kenyan population has health insurance. NHIF covers inpatient and outpatient healthcare of the contributor and nuclear family members in public hospitals.<sup>31–33</sup> As our two cases clearly demonstrate NHIF will only cover the medical expenses of orphans if their caretakers have obtained legal guardianship.

### HIV/AIDS and stigma

HIV/AIDS has disseminated at a disturbing degree globally from its first appearance in the early 1980s with the number of new infections rising per annum.<sup>8,9</sup> It is one of the world's key public health challenges, especially in low-income and middle-income countries. Worldwide, 36.9 million people are living with HIV, of which 1.8 million are children between 0 and 14 years.<sup>5</sup> In Kenya, 1.5 million people are reported to be living with HIV, with over 100 000 being children.<sup>34</sup>

HIV stands for 'human immunodeficiency virus', which is the virus that causes HIV infection. The abbreviation 'HIV' can refer to both virus and HIV infection. AIDS stands for 'acquired immunodeficiency syndrome'. AIDS is the most advanced stage of HIV infection. HIV attacks and destroys the infection-fighting CD4 cells of the immune system. Loss of these CD4 cells hinders the body's ability to battle infections and certain cancers. Without therapy, HIV can slowly ruin the immune system and progress to AIDS. HIV is disseminated through contact with blood, semen, pre-seminal fluid, rectal fluids, vaginal fluids or breast milk of a person with HIV. Antiretroviral therapy is used to treat HIV infection. Patients need a daily combination of HIV medicines, often called antiretrovirals.<sup>35</sup> A recent study revealed that 59% of all people living with HIV have access to antiretroviral therapy.<sup>34</sup>

Stigma among people living with HIV/AIDS has been associated with poor adherence to therapy and is a crucial impediment to the acceptance of HIV services. Stigma can be lived through in three different ways: enacted, anticipated and internalised stigma. Enacted stigma relates to actual discrimination of patients with HIV. Anticipated stigma refers to patients' awareness and future expectations of adverse HIV perspectives, prejudices and discrimination in society. Internalised stigma directs to the incorporation of negative perspectives and sentiments of patients themselves regarding their HIV-positive status. Stigma originates from various misapprehensions about HIV transmission and condemnations of socially marginalised populations that are incommensurately infected with HIV, such as same-sex couples and drug users.<sup>6,7</sup>

The accounts of both the aunt and grandmother in our cases indeed underline the emotional toll of the various types of stigma regarding HIV/AIDS. The mother of the first case did not dare inform her parents about their HIV status, and when the grandmother later found out, she felt ashamed. The aunt of the second case confirmed the societal prejudices and discrimination reported by previous studies.<sup>6,7</sup> Neighbours may not only gossip, but also expel affected families out of communities due to fear of infection. At school, pupils may bully the children and teachers can disregard the family circumstances and send children home when the struggling guardians cannot afford school supplies.<sup>36</sup>

### Orphans and vulnerable children

Over 153 million children globally have been orphaned, of whom 145 million live in low-income and middle-income countries. In these countries, the number of orphans and vulnerable children has amplified greatly due to the HIV/AIDS epidemic and AIDS-related death.<sup>37,38</sup> In sub-Saharan Africa over 11 million children are orphaned, and in Kenya an estimated 2.6 million children, in fact, 12% of all Kenyan children, are orphaned and vulnerable.<sup>9,39</sup>

Children orphaned by HIV/AIDS face many destructive disadvantages. During the period that their parents had suffered from AIDS, their households were exposed to major financial stress. Their sick parents had to cover medical bills while at the same time, they were less able to earn money through farming or working. Consequently, the families lacked the income to buy sufficient nutrition. After the parents had passed away funeral expenses needed to be paid and

unprotected orphans often lost their parents' land, houses and other properties as well.<sup>36</sup> Apart from the traumatic experience of seeing their parents fall sick and die, these children are now forced to live in even greater poverty.<sup>9</sup> Lack of basic needs such as food makes these children more underweight or malnourished.<sup>39</sup> Orphans may also be infected with HIV themselves and commonly lack access to routine immunisations or preventive care. Consequently, they are more prone to illness.<sup>36</sup> In addition, orphans have less access to proper education, school supplies, clothes or shoes and may therefore either be sent away or drop-out from school.<sup>39</sup> Orphanhood harms their physical, cognitive and emotional development. Survival strategies, like eating less and vending possessions, further enhance the orphans' vulnerability.<sup>9</sup>

All these orphaned children need practical placement strategies.<sup>8,19,40</sup> In almost every sub-Saharan country extended families, like the aunt and grandparents in our cases, have taken responsibility for more than 90% of orphans. This is based on a strong cultural tradition of extended family networks and informal fostering.<sup>9,36</sup> But as the HIV/AIDS epidemic advances, the guardians may fall sick themselves or become overwhelmed with dependent orphans. Their poverty worsens with every extra orphan under their care. Orphans are often looked after by fragile resource-limited guardians and elderly grandparents or by nobody at all. Numerous studies illustrate that the increasing amount of street children and households led by siblings indicates that extended family networks and informal fostering have reached their capacity limits and that their resources have been exhausted.<sup>36</sup> Subsequently, these orphans are subjected to worsening medical and psychological hardships. Not only their nutrition, growth, development, access to healthcare, but also their education and a place for shelter are at risk.<sup>41</sup> An investigation showed that only 8.6% of the 11 million orphaned children in 17 sub-Saharan nations received one basic service like medical care, psychosocial support or protection.<sup>38</sup>

### Burkitt lymphoma

Burkitt Lymphoma, a very aggressive subtype of non-Hodgkin's lymphoma, is the most commonly diagnosed childhood cancer in sub-Saharan Africa. This increased incidence of Burkitt Lymphoma, compared with the rest of the world, is related to endemic malaria in many parts of this region. Burkitt Lymphoma is classified into three types based on geographical distribution: (1) endemic or African Burkitt lymphoma, which is common in young children in sub-Saharan Africa who also have malaria and Epstein-Barr infection; (2) sporadic or non-African Burkitt lymphoma, which is rare and seen outside Africa; and (3) immunodeficiency-associated Burkitt lymphoma, which is most common in immunosuppressed patients with HIV infection.<sup>10,15-17</sup>

Survival rates for non-Hodgkin's lymphoma are higher than 80% in high-income countries. Yet survival rates in low-income and middle-income countries vary considerably and are disproportionately low in Africa.<sup>42-50</sup> A previous retrospective medical records study at MTRH showed that only 29% of the Kenyan children with Burkitt lymphoma had event-free survival.<sup>42</sup> The large disparity in the survival of Burkitt lymphoma between high-income versus low-income and middle-income countries is associated with the higher prevalence of malnutrition and low socioeconomic status in the latter countries.<sup>42-50</sup> The access of poor households to the costly conventional cancer care in specialised cancer clinics is often restricted. Health insurance could importantly help these families to get potentially life-saving treatment for their children. The medical records study at MTRH explored the impact of health insurance status at diagnosis on treatment outcomes. It was found that 73% of patients had no health insurance at diagnosis. Treatment outcomes and



survival between insured and uninsured children varied significantly: 53% of insured versus only 20% of uninsured patients survived.<sup>42</sup> Based on these findings, a dedicated healthcare provider at MTRH actively helps families with registering for NHIF. Of the 150 children who are annually diagnosed with a malignancy at MTRH, 5%–10% are orphans without legal guardianship arrangements. For these vulnerable children timely entering NHIF proves a very big challenge, as clearly illustrated by our cases, which threatens their chances of survival.

### Legal guardianship

Almost all governments worldwide, including the Kenyan government, acknowledges that every child has a right to health and medical care. The provision of which is the responsibility of both the parents and the national governments concerned.<sup>51</sup> When a parent or both parents die, for instance, due to the HIV/AIDS epidemic in sub-Saharan Africa, access to this fundamental human right is jeopardised.

HIV orphans are likely to be poorer, tend to come from lower-educated families, and are less healthy than non-orphans. If an HIV orphan needs expensive lifesaving treatment, like the children in our cases who required chemotherapy for Burkitt lymphoma, appointing a legal guardian becomes a prerequisite to access health insurance.<sup>9</sup> Legal guardianship is a judicial process whereby a person is appointed by will or deed by either a parent of the child or by order of the court to take care of the child.<sup>11 12</sup> In both our cases, neither the grandmother nor the aunt were aware of legal guardianship.

Applying for legal guardianship may be complicated and costly, especially for the often poor and less educated families who need it. For instance, the application for guardianship in Kenya requires the following documents and procedures: (1) copy of child's birth certificate; (2) applicant's identification; (3) deceased parent(s) death certificate(s); (4) proof of ability to take care of the child including proof of earnings; (5) consent from surviving parent; (6) child's school reports; and (7) any other documents demonstrating applicant's fitness as guardian. These documents are subsequently filed in court after which the court directs a children's officer to do a home visit and write a report which is presented in court during a hearing.<sup>12 13</sup> Some families may live in very remote areas, where access to the required documents and institutes is limited. Other families, like the aunt in our case report, may find the whole process tedious and give up before even starting.

A study carried out in the USA determined the rates and predictors of guardianship planning of HIV-infected adults. It revealed that only half the mothers had disclosed their HIV diagnosis to at least one of their children, and only 57% had made formal plans for the children's care.<sup>52</sup> A Kenyan study on the provision of foster care to orphaned children in Kibera, the second largest African slum showed that 56% of 82 respondents interviewed were forced by circumstances similar to the aunt and grandmother in our cases. The greatest problems faced while providing care to the orphaned children included the provision of education, food and health.<sup>7 12 14</sup>

### Hospital detention practices and hospital waivers

Hospital detention practices refer to the refusal of releasing clinically discharged patients when their relatives are incapable of paying the patients' hospital bills.<sup>20</sup> Our case report clearly shows that both living and deceased patients can be detained. Accounts of hospital detention stem from Africa, Asia, Latin-America and Europe.<sup>53</sup> Patients of all ages can be imprisoned as is shown by the two young children in our cases. Detention concerns both acute and chronic diseases.<sup>20 23 54–65</sup> Incarcerating patients violates international human rights, such as the rights not to be imprisoned as debtors and to enter medical care.<sup>66 67</sup>

Previous reports emphasised the psychological stress provoked by hospital detention. Also, our case report confirmed that not only the young orphan with Burkitt Lymphoma, but also the guardians were suffering.<sup>64 66 68</sup> A previous study conducted at MTRH found that half of all uninsured childhood cancer patients were detained inside the hospital.<sup>23</sup>

Public hospitals in low-income and middle-income countries occasionally provide waivers to help the most disadvantaged households benefit from their health services.<sup>23 24 69 70</sup> Although these waivers theoretically appear to be beneficent the reality may be quite different. Waivers can be abused, thereby creating new chances for corruption.<sup>23–25</sup> Clear procedures, rules and selection criteria are often absent. The guardians of both orphans in our case report also complained about the lack of transparency and feelings of abuse of power by the waiver committee. Waivers might not be granted to households in need but to wealthy and mighty persons who offer bribes.<sup>69 70</sup> Unfortunately, waivers thereby can lead to more social injustice and unequal access to healthcare services.<sup>23–25</sup>

### Recommendations

#### Universal health coverage

International financial institutions, health organisations, and donor countries should demand that governments in low-income and middle-income countries use aid to implement UHC.<sup>20 22</sup> Governments in low-income and middle-income countries should prioritise UHC achievement. The Kenyan government should ensure that all its citizens are registered with the already available and affordable national health insurance scheme by making registration mandatory.

#### HIV orphans

Government agencies in low-income and middle-income countries should implement programmes that strengthen family capacity to support orphans by facilitating their access to healthcare and education. Timely interventions, when the parents become ill and not after they have deceased, are required. Yet, the top priority of government programmes should be to keep the children's parents alive by: (a) enabling access to medical treatment and (b) primary prevention. Public health advertising and awareness campaigns must educate citizens about HIV/AIDS hazards and simple applicable preventative measures, such as condom use.<sup>36</sup>

#### Legal guardianship

Public awareness campaigns by the government and civil society to raise awareness about legal guardianship and its benefits should be conducted among: (a) the community and (b) healthcare providers. Governments should proactively provide legal aid and pro-bono legal services to assist HIV/AIDS affected parents and HIV orphans to write wills or deeds and appoint guardians.<sup>12 52</sup>

#### Childhood cancer

The large difference in childhood cancer survival between high-income versus low-income and middle-income countries can be addressed by ensuring health insurance cover of all costs associated with childhood cancer treatment, including anticancer agents and supportive care.

#### Hospital detention practices

The UN should investigate hospital detention practices and advise governments about how to stop it.<sup>20</sup> Governments should end hospital detention practices and make it punishable by law as it violates international human rights treaties. Implementing UHC, which prevents hospital detention, is required.<sup>20 22</sup>

## Hospital waivers

Governments should make information on hospital waiver system, procedures, rules and selection criteria available to the general public to ensure disadvantaged households benefit.

**Contributors** SL: conceptualised and designed the data collection instrument, analysed and interpreted the data, drafted the initial manuscript and approved the final manuscript as submitted. FN: conceptualised and designed the study, analysed and interpreted the data, critically reviewed and revised the manuscript and approved the final manuscript as submitted. GK: conceptualised and designed the study, analysed and interpreted the data, critically reviewed and revised the manuscript and approved the final manuscript as submitted. SM: conceptualised and designed the study and data collection instrument, analysed and interpreted the data, critically reviewed and revised the manuscript and approved the final manuscript as submitted.

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## Learning points

- ▶ Only a few low-income and middle-income countries have responded favourably to the international plea for universal health coverage (UHC) to improve their population's admittance to medical services and treatment outcomes.<sup>1,2</sup> International financial institutions, health organisations, and donor countries should demand that governments in low-income and middle-income countries use aid to implement UHC.<sup>20,22</sup>
- ▶ The HIV/AIDS epidemic is a major public health challenge, especially in low-income and middle-income countries, giving rise to an enhanced number of orphans. In sub-Saharan Africa over 11 million children have lost one or both parents to HIV/AIDS.<sup>3–5,8,9</sup> Extended families have taken responsibility for most of these orphans.<sup>9</sup> Government agencies should implement programmes that strengthen family capacity to support orphans by facilitating their access to healthcare and education. Yet, the top priority of government programmes should be to keep the children's parents alive by enabling treatment access and by prevention. Public awareness campaigns must educate citizens about HIV/AIDS hazards and simple applicable preventative measures, such as condom use.<sup>36</sup>
- ▶ HIV orphans are likely to be poorer and less healthy than non-orphans.<sup>9</sup> If an HIV orphan needs medical treatment, such as lifesaving chemotherapy for the most common sub-Saharan childhood malignancy Burkitt lymphoma, appointing a legal guardian becomes necessary to access health-insurance.<sup>10–13</sup> Communities and medical teams are often not aware about this requirement. The rules and regulations involved may be unclear, tedious and costly. This hinders its access for poor families who need it most.<sup>11–13</sup> Public awareness campaigns by the government and civil society to raise awareness about legal guardianship and its benefits should be conducted among both the community and among healthcare providers. Governments should proactively provide legal aid and pro bono legal services to assist HIV/AIDS affected parents and HIV orphans plan for guardianship and write wills or deeds.<sup>12,52</sup>
- ▶ Uninsured patients risk being detained inside hospitals over the inability to pay hospital bills.<sup>20,58,70</sup> Governments should end hospital detention practices and make it punishable by law as it violates international human rights treaties.

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