

Home-based care for orphaned children infected with HIV/AIDS in Uganda

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Abstract

The primary aim of this paper is to describe an outreach programme from a main state hospital in sub-Saharan Africa, which has been running for three years. This programme is based in Mulago Hospital, Kampala, Uganda and cares for up to 200 children infected with HIV/AIDS in their home. We describe the clinic and how we meet the families and enrol them, the infrastructure of the programme and the personnel involved. Children and their families receive physical, psychological and social care and we describe each aspect of this. The knowledge base about older children with AIDS in Africa is scarce and the secondary aim of this paper is to publish observations that were made while providing care. This includes demographics and the health problems encountered among children living with HIV/AIDS in a resource-poor setting who do not receive antiretroviral medication. Finally, we discuss the strengths and weaknesses of this model of care and the prerequisites to setting up a similar model.

Introduction

The AIDS pandemic continues unabated in poorly resourced countries—there are 40 million people currently living with HIV or AIDS, mainly in Sub-Saharan Africa (UNAIDS, 2002). Despite the efficacy of reducing perinatal HIV transmission in this population (Guay et al., 1999), the infrastructure does not exist, even though Nevirapine and HIV rapid testing have been made free to eligible countries (Boegringer & Abbott Laboratories, 2003). As a consequence, 2.4 million children aged < 15 years are living with HIV/AIDS in sub-Saharan Africa. Each day 1,600 children die from AIDS in Africa as opposed to 500 per year in either the USA or Europe (UNAIDS, 2002). Between 25–39% of infected African women transmit HIV to their offspring (Dabis, 1992), but infected children have a very high mortality in early infancy.

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The population of Uganda is almost 25 million, with 50% aged less than 15 years. HIV prevalence has gone down to 5% in the adult population (UNICEF, 2004), mainly due to the government actively promoting a national response to HIV/AIDS (UNAIDS, 2002). At the end of 2001, there were 110,000 children infected with HIV in Uganda and the need to support HIV-positive children living in Kampala, by providing care in their homes and thus supporting their families, was identified by an assessment carried out by local paediatricians.

Methods

The clinic where we make initial contact

This programme was instigated by a British charity, Child Advocacy International, at the beginning of 2001. The charity has been working with the department of paediatrics at Mulago Teaching Hospital for many years, mainly in acute paediatrics. Local paediatricians expressed the need for care for HIV-positive children, in their own homes. This need was identified when they noted that after the initial diagnosis was made, children were often not brought to clinic for ongoing care. They believed this was due to stretched resources in vulnerable families.

Families bring a child they suspect may have HIV along to the immuno-suppression outpatient clinic in the hospital. This clinic has an open door policy and accepts all comers without charge for attending. Each parent/carer receives pre-test counselling and, if the carer gives permission, the child is tested for HIV-1 antibodies. This is done by a commercial enzyme-linked immunosorbent assay, confirmed by a commercial Western Blot technique if positive. The carer receives the result during post-test counselling. The HIV-positive child then receives care at the clinic whenever the family is able to bring them along. Despite the expertise of the doctors, antibiotics and antifungals are often unavailable and the family may queue for many hours only to find that there is no medication left in the pharmacy. This often contributes to a family's decision not to use precious resources and not to travel back to clinic.

The home-based programme

The outreach team attends one clinic each week. Families who may benefit from the programme are identified by clinic health care staff, including nurses, doctors and counsellors.

Before offering enrolment onto the programme, a member of the outreach team confirms that the child's serology is positive. The criteria set by our donors mean that we only enrol children who are orphans. We take this as a child who has lost one or both parents, or a child whose mother or father has left the family home.

Polymerase chain reaction (PCR) is unavailable due to its cost, so children under 18 months of age suspected of having HIV are excluded from the programme as there is no means to confirm their diagnosis. There were some children younger than 18 months referred directly, having been tested by PCR as part of a research study on site at the hospital. There is no clinical condition, for example severity of illness, which results in the child being excluded. Children are often enrolled and supported while critically ill inpatients and while terminally ill.

After a full explanation in the local language, the caretaker is offered the opportunity to allow the child to be enrolled in the programme. The carer is told that a monthly visit by

staff to their home in a vehicle with only the charity emblem on it would occur. The offer of enrolment was rarely declined due to the fear of stigmatization. If a family do ask to be enrolled without home visits this is arranged with the same level of support as other families. At this stage families are also informed about help that we are unable to give. In particular, we do not assist with school fees and do not provide antiretroviral medication. They are informed that we keep a record of the child's health but encourage them to continue to keep a patient-held record in the event of the child receiving health care from professionals unfamiliar with their past medical history.

The personnel

Staff visiting the home of a child are a nurse with qualifications in HIV counselling, who has been trained in the management of opportunistic infections in children with HIV, and a driver. A paediatrician provides medical advice, either at the weekly clinical review of children visited or by mobile telephone in an emergency. Other personnel available to the programme include a social worker and a nutritionist with expertise in HIV/AIDS. Families are visited on the same day of the same week each month and this is circled on a calendar. It is rare not to find families at home.

Physical support

Vitamin A is given every six months and mebendazole every three months to all children in the family. The family are supplied with oral rehydration solution (ORS) and anti-pyretic medication and educated in their use. Each visit is an opportunity to give nutritional advice, with particular emphasis on the value of using local produce. The World Food Programme provides food security for all families enrolled and they attend a nutrition clinic to collect food and receive education about its optimal use.

At each home visit, the infected child is provided with one month's supply of prophylactic co-trimoxazole and multivitamins. Opportunistic infections are diagnosed and treated according to guidelines designed for this programme and based on the *Manual of International Child Healthcare 2002* (Southall, 2002). The guidelines are algorithm based and easily followed by a nurse in the field. The treatments suggested are available in the medication trunk carried in the vehicle. It is clearly indicated on these algorithms when the child would need to receive more expert care and admission to hospital should be offered. Families are reminded about the importance of prophylactic co-trimoxazole and early attendance with opportunistic infections. When children are hospitalized all medication is provided and sufficient food is also provided for the child and carer. Without this level of support most carers could not afford to stay in hospital care and may take their sick child home to die. The hospital clinic is also open two days a week to 'all comers'. If children on the programme become sick between home visits, they can attend this clinic.

The African American AIDS Initiative based at Mulago has recently provided 25 of the children enrolled in this programme with antiretrovirals and monitor them at clinic. Families often attended the programme office, open six days per week, for both physical and psychological support at any time.

Psychological support

Psychological support comes by virtue of a team, well known to the family, who visit them regularly in their homes and whom they see at the clinics. Support is also available when the

child is admitted to hospital or when the child dies. Quite simply 'knowing that someone cares' has been the most frequently quoted benefit of this support programme.

Each month there is a meeting to which all carers are invited and assisted with travel expenditure. This meeting is well attended by more than 100 carers each month. The meeting is led by elected chairpersons and facilitated by the programme's counsellor and social worker. At the beginning of each meeting those attending are asked which issues they would like to discuss. Basic health education, education about HIV and its prevention and nutritional advice are covered. Frequent questions include how to avoid getting infected when caring for a child with HIV and how to provide nutritional support for a child when they have an intercurrent infection. Psychological issues such as how to deal with losing the child or how to deal with one's own serostatus are discussed. Carers who have lost children frequently continue to attend after the child's death for ongoing support and to provide support to others. Invited speakers include child psychologists, nutritional experts and paediatricians.

The main benefit for people who attend this support group is empowerment of the carers through education and openness. Self-confidence visibly improves as they become increasingly aware and realize they are not alone. Individuals become more confident and express opinions. People share practical tips about the management of common ailments and carers often make notes at these meetings in order to share the information gleaned with their neighbours and friends. These meetings provide a forum for discussion among carers and result in the formation of support networks.

A similar forum for HIV-positive children has been developed and is called the children's club; it is attended by 60 children on a regular basis. These children only attend with their carers' permission and only after their diagnosis has been disclosed to them by their carers. An older child leads this children's group, with close supervision by an experienced social worker and counsellor.

Carers often discuss concerns with the team nurse in the privacy of their home. It is usually in this setting that a carer will seek support and advice about the gradual disclosure of a child's diagnosis to him/her. This will usually be prompted by questions from the child. If the mother is unwell, and at her direction, discussion around the ongoing care of her children after her death is introduced, again in the home.

Social support

The programme supports income-generating projects by giving small loans to the carers. This allows carers to invest in projects, for example setting up a stall to sell cooked food, and thus to support their families in a sustainable manner. Fifty of the carers have so far taken part in this scheme. The interest has been recycled from this scheme and used to buy a plot of land just outside Kampala. The families in the programme are using this to grow food.

Results

Providing home-based care has allowed regular ongoing contact with children infected with HIV and their families. Meticulous records of each interaction with the child and family are made in order to provide optimal care. A retrospective review of these records has allowed us to make observations about children living with HIV in Uganda with regard to their medical condition and with regard to the demographics of the families in which they live. We describe observations made in the first ten months after the programme was introduced, before any children were on antiretroviral medication.

Home visits began in March 2001 and by mid-January 2002 children had been seen on 850 occasions and data collected on 645 occasions. Approximately ten children were seen each week at the bi-weekly clinic, accounting for another 480 reviews. A full assessment of past medical history was obtained for 135 children.

Demographics

Median age of participants was 87 months (7¼ years), with a range from 11 months to 12 years. In 48% of cases the mother was the carer, the grandmothers in 28%, aunts in 18% and fathers alone in just 5%. The families generally lived in one- to two-room houses, with an average occupancy of seven people, five of them children. In 52% of the homes there were no HIV-positive adults, usually those lead by a grandmother or aunt. In 42% of homes there was one HIV-positive adult, usually the mother, and in 7% there were two HIV-positive adults. The majority of children, 88%, were the only HIV-positive child in that household, but in 8% of cases there was one other HIV-positive child, in 1.5% there were two others, in 2.3% there were three others and in 0.7% there were four other HIV-positive children.

Sixty per cent of all children in the families attended school. For HIV-affected children, only 47% of those old enough to attend school did so, either because of ill health or due to lack of school fees. This compares with a primary school enrolment rate of 87% in Uganda.

Hospitalization and vaccination

HIV-positive children were frequently admitted to hospital. Sixty-four per cent had been admitted on at least one occasion, many several times and a few up to ten times. Only 65% were appropriately immunised, compared to a country average of 75%.

Centres for Disease Control (CDC) classification

Following history and examination, children were classified according to the 1994 Centre of Disease Control (CDC) system for HIV infection (CDC, 1994); see Table I.

A full assessment of past medical history was obtained for 135 children and Table II reflects common past medical problems discovered at initial assessment and at follow-up visits.

Tuberculosis (TB)

Approximately 35% of children have been diagnosed and/or treated for TB (Table III). The diagnosis of TB was made at a regional TB clinic after a chest X-ray, sputum for acid-fast

Table I. Clinical categories according to the 1994 CDC revised classification system for HIV infection in children.

Clinical category	Number of cases N = 135	% of cases
No clinical signs category N	3	2
Category A	8	6
Category B	71	53
Category C	53	39
Total number classified	135	100

Table II. Past medical history at time of enrolment and at follow-up.

Symptom, clinical sign or illness	Percentage affected at enrolment	Percentage affected at follow-up
Chronic cough	77	67
Dermatitis	70	60
Recurrent or prolonged fevers	65	32
Lymphadenopathy	59	20
Recurrent diarrhoea	57	19
Oral candidiasis	54	10
Pneumonia	54	20
Parotitis	52	14
Otitis media	50	12
Probable candidial oesophagitis	36	5
HSV stomatitis	34	1.5
Herpes zoster	25	1.7
Finger clubbing	17	14
Bacterial meningitis	0	5.2
Cryptococcal meningitis	1.5	RIP
Tuberculous meningitis	1.5	RIP

bacilli if the child was old enough, and a Mantoux test, although they were frequently anergic.

Growth

At each home visit, weight, height and Mid-Arm Circumference (MAC) were recorded. At enrolment, body weights were less than the fifth percentile in 62% of children and heights were below the fifth percentile in 55% of cases.

Deaths

Of 172 children enrolled over a ten-month period, 26% died, with an average age of death of seven years, nine months. Half of these children were in category C and the other half category B (CDC rating) at presentation. Seventy-five per cent of patients who died were on treatment for TB at the time of death and 75% had a history of oral candidiasis. Only 19% had been attending school in the months prior to their death.

Over a ten-month period, contact was lost with six children (3.5% of those enrolled). After the death of a parent, children often moved between the homes of different members of their extended family. Almost invariably the new carers informed the team of the whereabouts of the child to allow us to continue to visit them.

Table III. Tuberculosis.

Treatment	Number of cases	%
Currently on TB treatment	29 in total 26 pulmonary 1 extrapulmonary 2 meningitis	22
Previously treated for TB	22	16
Previously treated and currently on a new course of treatment	3	2
Total number of patients	135	100

Discussion

This programme provides physical, psychological and social support for these children and their carers. Carers feel they benefit from the programme as evidenced by the small number of children lost to follow-up and by the fact that the monthly meetings are well attended.

One particular strength of this model of care is the application of standardized clinical management protocols for the common problems encountered. Another strength is the open door policy, meaning that people in crisis have somewhere to turn when, for example, a child in their care is admitted to hospital. Probably the most important aspects of the programme are, however, the empowerment of the carers through their monthly meetings and the income-generating scheme.

The observations reported give some insight into the lives of older children with HIV infection in this setting. The average age of children in this programme was seven years. The natural history of HIV infection in vertically-infected children indicates that by three years of age the vast majority of vertically-infected children are dead and as few as 1% are asymptomatic (8–10). These studies plus the observations reported here reflect the bimodal clinical evolution of disease in children (Blanche et al., 1990) in the absence of antiretroviral medication. Most children die early in life and the small percentage that survive die at some time in the first decade. The HIV-related clinical problems experienced by this cohort of children are similar to those reported by others (Spira et al., 1999; Taha et al., 2000).

Tuberculosis is difficult to diagnose in children, particularly in a resource-poor setting (Osborne, 1995). Children with HIV may have lymphoid interstitial pneumonitis, pneumonia or bronchiectasis and this makes it an even greater challenge (Graham et al., 2001). The prevalence of TB in this group of children was 35%, which is similar to other reports (Kiwanuka et al., 2001).

Over a ten-month period, 26% of the children enrolled died at an average age of 7.8 years. This high mortality is a reflection of the fact that most of these children were clinical stage B or C on enrolment. Given that most children were enrolled soon after diagnosis, this may reflect the late stage at which the majority of children in this setting present to clinics.

This programme began in a teaching hospital and enrolled children from all over the capital city of Kampala. Networking between carers was therefore geographically difficult. A better model might have been to support families in one area or several areas close together, perhaps using community leaders to identify affected children but again using the hospital as the focal point for testing and ongoing care. This would enable the community leaders to provide support between visits and empower communities to themselves support affected families.

The prevalence of TB in this group of children makes access to a TB clinic essential, or at least facilities to undertake chest X-rays and resources to provide anti-TB medication and follow-up, as well as access to an inpatient facility to refer patients requiring admission.

This programme was relatively inexpensive, costing approximately \$10 per child per month for the medication and staff, with the cost of the food donation not included. In the absence of antiretroviral medication, this programme empowers and supports families to care for this group of children and in turn allows these children to enjoy some quality of life.

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