



Access of abandoned children and orphans with HIV/AIDS to antiretroviral therapy — a legal impasse

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In 2002, 13% of children aged between 2 and 14 years in South Africa had lost a mother, a father or both parents.¹ The Centre for Actuarial Research at the University of the Western Cape estimated that by July 2002 more than 885 000 children under the age of 18 had lost their mothers, with 38% of those deaths attributed to AIDS.² Seen in the context of South Africa's high rate of mother-to-child HIV transmission, a great number of orphaned children are likely to be living with HIV, having contracted it through birth. Although there is no research examining the impact of HIV on the number of children who have been abandoned, anecdotal evidence suggests that children's homes are seeing steep increases in the number of children requiring care, many of whom are infected.

Children and ART

Both UNAIDS and the World Health Organisation (WHO) recommend antiretroviral therapy (ART) for children with HIV/AIDS, where clinically indicated. The Southern African HIV Clinicians Society gives the following rationale for the administration of paediatric ART: '(i) restoration or preservation of immunological function ...; (ii) improvement of clinical symptoms; (iii) reduction of morbidity and mortality; and (iv) maximal and durable suppression of viral load.

The overall objective of therapy is to enhance the quality and quantity of life and to promote physical, social and intellectual development of the child in the context of a functional family. A practical goal is to avoid hospitalisation by minimising the impact of intercurrent disease ...'³

Where previously very few children were able to access ART in South Africa and would not benefit from it as outlined above, it is anticipated that with the roll-out of ART in the public sector,⁴ substantially more children with HIV/AIDS might be in a position to do so. Yet it is important to note that legal barriers exist preventing certain categories of vulnerable children from accessing ART. One such group is children without parents or legal guardians.

The legal position

South African common law requires that before medical treatment, including HIV testing, can be administered to a

child, consent must be obtained from a parent or legal guardian. The Child Care Act of 1983 regulates a number of issues pertaining to children, and also requires the consent of a parent or guardian to 'any medical treatment' administered to a child under the age of 14 and 'the performance of any operation' on a child under the age of 18.⁵ (It should be noted that the Choice of Termination of Pregnancy Act of 1996 provides that young women of any age may seek and obtain termination of pregnancy without the consent of their parents. The Act makes provision for counselling and includes a recommendation that parental consent be sought, but this is not mandatory.) HIV testing, the provision of ART and post-exposure prophylaxis (PEP) for child survivors of rape are considered to be 'medical treatment' and therefore necessitate the consent of a parent or guardian for children under the age of 14. In the absence of parental consent, the Minister of Social Development may be approached to give consent and in urgent cases the medical superintendent of a hospital may give consent for medical treatment for children aged under 14 years. The High Court is the upper guardian of all children and may also be approached for consent.

Increase in informal caregivers

The increase of AIDS mortality rates, the impact of HIV on families and the rise in the number of orphans in South Africa has created a situation in which a growing number of children are cared for informally by grandparents, aunts, uncles, siblings or sympathetic members of the community. Many caregivers are unaware of the need to formalise the care relationship and those who do attempt to foster or adopt children in their care face a lengthy process administered by an increasingly overstretched system.

Caregivers who have not formalised their relationship with the children they care for are not recognised in law as the legal guardians of orphaned or abandoned children, and therefore cannot give the consent needed for the medical treatment of these children.

In the context of ART this would give rise to the unfortunate state of affairs in which health workers, in keeping with the provisions of the Act and common law, would have to apply to the Minister of Social Development or the High Court for special permission to administer this treatment. With an increasing number of children being orphaned and abandoned by parents with HIV/AIDS, and in time requiring ART if they have contracted the virus, it is clear that the current legal arrangement creates an intolerable situation.



AIDS Law Project cases

The experience of the AIDS Law Project (ALP) might be informative in this regard. The ALP provides legal advice and assistance to the University of the Witwatersrand (Wits) Paediatric HIV Working Group, a group of paediatricians and other health workers who provide treatment and care to children and their families in the public sector.

In May 2003, the Harriet Shezi Clinic, which forms part of the Wits Paediatric HIV Working Group, secured private funding to provide ART to 10 children with HIV/AIDS attending the clinic. In 2003, ART was not available in the public health system and provision of this therapy was designed as part of a research study intended to: (i) evaluate the administration of ART to children attending urban public hospitals; (ii) build capacity in state hospitals for the administration of antiretroviral medicines to children and their families by developing a model treatment clinic where public sector staff can be trained in effective management of paediatric HIV; and (iii) assess the feasibility of, and identify what the obstacles are in administering antiretroviral medicines in a resource-poor setting.⁶

Four of the children who were selected to receive the treatment had no parents or guardians and were being looked after by relatives or friends. The ALP brought an urgent application on behalf of the four children in the Johannesburg High Court, requesting the court to grant permission for the children to commence treatment. The order granted by the court authorised Dr Meyers of the Wits Paediatric HIV Working Group to provide the children with treatment in accordance with the protocol laid out in 'Antiretroviral Therapy in Children, Southern African HIV Clinicians Society Guidelines'³ and the WHO's *Scaling Up Anti-retroviral Therapy in Resource-limited Settings: Guidelines for a Public Health Approach*.⁷ The High Court granted this order on 10 June 2003 and the children started ART immediately. A similar order was granted for another child on 19 August 2003.⁸

Although both court applications were successful, it was clear that it would not be feasible to approach the court on behalf of each child requiring HIV testing or treatment who was without a legal guardian. The announcement on 8 August 2003 that the Cabinet approved the roll-out of ARVs in the public sector created an urgent need for effective and efficient mechanisms to be put in place to ensure that these children would be able to access treatment when it became available.

Section 39 of the Child Care Act of 1983 makes provision for consent to be obtained from the Minister of Social Development, in the absence of parental consent. Although the provision at least theoretically provides a speedy and inexpensive mechanism to obtain consent, few organisations and individuals have been able to use it.

On 31 October 2003 the ALP wrote to the Minister of Social

Development on behalf of a number of doctors from the Wits Paediatric Working Group, requesting authorisation from the Minister to provide medical treatment (in particular access to ART) to five orphaned children with HIV/AIDS. On 3 November the Minister provided his consent, and the ALP then requested authorisation for a further 40 children in similar positions attending the Harriet Shezi Clinic, Coronation Hospital or living in children's homes. Despite repeated requests, no further response was received from the Minister. It was clear that the provisions of Section 39 would not alleviate the problems relating to consent.

Subsequently, a third urgent application was lodged at the High Court, requesting the court to:

1. Provide consent to the Wits Paediatric Working Group to test and treat eight children for HIV as they did not have parents or legal guardians to provide such consent;

2. Provide consent to the Wits Paediatric Working Group to test and treat for HIV any child under 14 who did not have a parent or guardian or whose parent or guardian could not readily be located, provided that: (i) a medical practitioner registered under the Health Professions Act 56 of 1974, certified in writing that in his or her professional judgment, the test or treatment was in the child's best interests; and (ii) if the child was in the daily care of an adult, the latter consented to the test or treatment.

On 5 December 2003 the High Court granted this order, thereby allowing the Wits Paediatric Working Group to provide ART and HIV testing to orphaned and abandoned children with HIV/AIDS in their care, without any legal impediments.⁹

Legal impasse

It should be noted that this court order only applies to the Wits Paediatric Working Group and cannot be used by other medical practitioners dealing with children in similar situations. It would seem that unless the Departments of Social Development and Health take urgent action, this legal predicament will continue until the new Children's Bill replaces the old Child Care Act. The latest draft of the Children's Bill gives caregivers or any persons who 'voluntarily care for the child either indefinitely, temporarily or partially' the right to 'consent to any medical examination or treatment of the child if such consent cannot reasonably be obtained from the parent or primary care-giver of the child'.¹⁰ The Bill also lowers the age at which children can consent to medical treatment to 12 years — provided that the child is of sufficient maturity and has satisfactory mental capacity to make sound decisions.¹¹

Although these provisions will substantially alleviate the problems in obtaining consent, it is not clear when the Bill will



be passed into law. Although the Department of Social Development indicated that it enjoys a high level of priority, there is no indication when it will become law. In the interim period, many children are left in a vulnerable and unnecessarily tenuous position.

References

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7. World Health Organisation. *Scaling Up Antiretroviral Therapy in Resource-limited Settings: Guidelines for a Public Health Approach*. WHO, April 2002.
8. *Ex Parte application of Nigel Redman N.O.* Case no. 18476/03.
9. *Ex Parte Meyers*. Case no. 29172/03.
10. Sections 32(1) and (2) of the Children's Bill (version of 12 August 2003) <http://www.pmg.org.za/docs/2003/appendices/031114childrensbill.htm> (accessed 8 Sep 2004).
11. Section 129(2)(a) of the Children's Bill (version of 12 August 2003).

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IN BRIEF

A novel and effective treatment for pruritus ani

Pruritus ani is a common proctological problem, characterised by intense itching localised in the anus and perianal skin. It may result from an underlying disorder of the epithelium in that area, or from anorectal pathology. In many cases it is not possible to determine the cause. Faecal contamination of the perineum in the absence of gross soiling, irritant chemicals in faeces, allergies to locally applied agents or components of the diet, and even psychosomatic factors have been suggested as possible causes but are not conclusively proved to be of relevance.

Capsaicin is a natural alkaloid derived from plants of the Solanaceae family, and topical capsaicin is known to be effective and safe in the treatment of pain and itching.

A double blind placebo-controlled study of capsaicin in the treatment of chronic idiopathic pruritus ani was reported recently in the journal *Gut* (2003; **52**: 1323-1326).

After an open pilot study on 5 patients, a double-blind, placebo-controlled crossover study was conducted on 44 patients. The patients were randomised to receive either capsaicin (0.006%) or a menthol placebo (1%) for 4 weeks. After a washout period of 1 week, the placebo group was given capsaicin and the capsaicin group received placebo.

Results: 31 of 44 patients experienced relief during capsaicin treatment and did not respond to menthol. During the follow-up period of a mean of 10.9 months, the 'responders' required an application of capsaicin every day to remain symptom-free.

The investigators concluded that capsaicin is a new, safe, and highly effective treatment for severe intractable pruritus ani.