

## OPINION / OPINIE

the mundane and the daily struggle and to gain, however fleetingly, a sense of pleasure, comfort, intimacy and belonging.

The present levels of urban violence, crime, unrest and uncertainty in South Africa promote a fatalism and despondency which are extremely detrimental to any AIDS prevention effort. Expecting an individual to take initiatives to prevent an infection today which will remain silent and only cause ill-health in 7-10 years' time is possibly expecting too much. The day-to-day struggle, together with the prevalence of violence and crime, militates against such initiatives.

### AIDS causes poverty

Some of the main factors linking poverty to AIDS have been highlighted: AIDS in turn also promotes poverty. Job and income loss, rejection, discrimination and stigmatisation, and finally ill-health and death all contribute to an individual's and a family's misfortune, and to the overall cycle of poverty.

The many links between poverty and AIDS combined with the biological features of the epidemic such

as the long latent yet infectious period in HIV infection, the paralysis of the body's immune system and the prevention of any natural or herd immunity, the vertical perinatal transmission and the association of HIV infection with other STDs, highlights the extreme complexity and malignant nature of the epidemic.

It is not surprising therefore, that preventive efforts are having no discernible impact and inevitably we face an epidemic with devastating and tragic consequences. South Africa has been one of the last countries in Africa to be affected by HIV/AIDS. However, the legacy of apartheid and its devastating impact on the normal cultural, traditional and family life of black South Africans and its ultimate contribution to the cycle of poverty, together with an industrial economic system that promotes migrancy, mobility and exploitation, ensure that South Africa will be no exception and will face a massive and devastating AIDS epidemic.

#### CLIVE EVIAN

Community AIDS Information  
and Support Centre  
Johannesburg

## Paediatric HIV/AIDS in schools

Children all over South Africa who are infected with HIV or even have full-blown AIDS will presently reach school-going age without the schools, the community — and worse, the medical professionals in the community — being ready to meet the challenge. Public hysteria about the epidemic, the widespread lack of sound information about the disease and its spread, and the insulation of many rural communities from what many erroneously perceive as an 'urban disease' will make victimisation of the child and his/her family almost inevitable, unless educational and health authorities in the community prepare themselves adequately.

In South Africa, the pattern of spread has changed from one of risk behaviour associated with male homosexual contact to one dominated by heterosexual contact.<sup>1</sup> This change has led to the discovery of an increasing number of children with HIV whose mothers were often unaware that they had been infected by a sexual partner. The epidemic has spread to all segments of society and even to rural areas.

At present, only 2% of all reported AIDS patients in the USA are children younger than 13 years.<sup>2</sup> By contrast, 20% of AIDS cases in South Africa are paediatric.<sup>1</sup> To complicate matters, the epidemiology of AIDS the world over is changing. The number of women infected with HIV, especially those in their childbearing years, is rising and an increase in the number of children with vertically transmitted AIDS is to be expected. The impact of the epidemic on children can already be seen in the USA. In New York State,<sup>2</sup> AIDS is the leading cause of death among Hispanic children aged 1 - 4 years and the second leading cause of death among black children in the same age group. An exhaustive source book on paediatric AIDS in the USA<sup>2</sup> noted that in 1992 an estimated 10% of all paediatric beds were occupied by children with AIDS.

The emotional and social stigmatisation that accompany a diagnosis of HIV infection and the fear that the

presence of an infected child engenders among teachers, other children and parents alike, were the root causes of the draconian measures first suggested by the educational authorities as guidelines for schools in South Africa. These guidelines seem more concerned with protecting the authorities against litigation than promoting the interests of either the suffering child or the rest of the school. These policies were not formally published and copies were difficult to obtain, even by the medical profession. However, a measure of good sense seems to have returned with a newspaper report of more compassionate, comprehensive guidelines (for the Cape Province at least),<sup>3</sup> although no paediatrician from this medical school has officially been informed of these guidelines, or given the opportunity to comment on them. It is heartening, however, to learn that the Independent Schools Council of South Africa, which represents most independent schools in the country, is in the final stages of drawing up guidelines in consultation with medical experts, educationists and parents. It is important to keep in mind, as this council did, that all guidelines must ultimately be acceptable to parents of school-going children. Without their co-operation, no guidelines will achieve their aim.

There is a great need for information on admission policies and safety procedures in schools in respect of HIV-positive children, as well as appropriate, age-related education for these children. In many smaller centres and remote areas, the local doctor is one of the few trained resource persons with information on health hazards who can advise the school management in cases of children or staff members who are HIV-positive. It is a source of disquiet to us that the general level of knowledge of many health care professionals as to the risks of transmission and the nature of the disease itself is so inadequate that such professionals are not able to give competent guidance when called upon to do so by the communities they serve. They will therefore not be able to allay any unreasonable fears.

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Despite the significant impact of the AIDS epidemic, Yogeve and Connor<sup>2</sup> mentioned a recent survey among medical residents (presumably in the USA), where two-thirds of those surveyed did not plan to treat people with AIDS and three-quarters were not prepared to give life-saving treatment to HIV-positive patients. Reasons for this reluctance were: (i) increased risk of infection; (ii) difficulties in caring for these patients; (iii) financial disincentives; and (iv) lack of expertise in the management of the disease. The MASA recently published guidelines for the management of AIDS cases,<sup>4</sup> and subsequent correspondence in the columns of the *SAMJ* reflected many of the same sentiments as those expressed by the Americans surveyed. These are valid concerns, even if they are exaggerated. The risk of transmission after a single episode of percutaneous exposure to HIV is reportedly as low as 0.42%,<sup>5</sup> but is perceived to be much higher (and therefore frightening) by many health care workers. It is also especially difficult to learn new skills, such as managing AIDS patients, without exposure to such patients and many doctors feel unsure of their clinical competence in this field. Since the risk of acquiring HIV infection from casual contact is for all practical purposes zero, there is no reason why HIV-positive children should be denied access to schools.

Where children have full-blown AIDS, their condition (neurological, as well as general health) should dictate whether they stay at school, are transferred to specialised institutions or are cared for at home. Their needs in this respect are no different from those of other children with long-standing infective conditions. Ideally, care of children infected with HIV or with full-blown AIDS should be community-based, comprehensive and multidisciplinary. This is going to be very difficult to achieve in the face of the reluctance of some members of the health care team to become involved.

Formal age-appropriate information on sex and other related health matters is not given to primary school children at present. This is a major problem, since undoubtedly some older primary school children are already sexually active, or at least experiment with sex. Health care professionals should familiarise themselves with the necessary age-appropriate information on sex education, should they be called upon by patients or the community they serve to give advice.

The child infected with HIV frequently represents disease in the family unit, because 80% of HIV-positive children have acquired the disease from their mothers<sup>2</sup> who, most often, have had sexual relations with an infected partner. Even those children who acquired the disease from infected blood products or as a result of being molested represent families in desperate need of care and support.

HIV-positive children and their families have a right to confidentiality, compassion and dignity. These children must not be denied a meaningful life, and education and the opportunity to broaden their minds by learning and socialisation are therefore essential to them. Of the children with HIV infection treated at our hospital, 3 out of 5 school-going children have had difficulty or even been unable to find a school willing to enrol them. The medical profession needs to convince educational

authorities, as well as the actual management and parent bodies of schools, that AIDS is not a mysterious disease and that its mode of transmission and the risk of infection are known. We also need to stress that common-sense safety precautions, e.g. wearing of latex gloves when exposed to body fluids, hand washing and thorough general cleaning procedures, are enough to keep the risk of casual contact transmission far below what it is for most other serious infectious diseases. At present, most safety policies advise HIV-positive children not to take part in contact sports.

In schools in the UK, apart from the predictable flurry of anxiety at the start of the epidemic, the education of HIV-positive children proceeded without hindrance.<sup>6</sup> This is credited to the common sense of teachers, backed by the government and the efforts of local education authorities and their medical advisers. Fundamental to this rational approach was the evidence that HIV is not a contagious disease in the ordinary sense, i.e. there is no practical risk of transmission in the everyday, non-sexual activities of school or work.

All schools in South Africa, together with health workers and parents in their communities, should discuss their concerns and adopt a plan of action for HIV-infected children to avoid the knee-jerk reaction of anxiety when faced with the presence of such children. In these discussions they need to be guided by national policies applicable to all schools on admission, universal protection measures, and general health and safe lifestyles (of which sex education is only a logical part). Many of the protective measures and guidelines issued by various bodies are at present confusing, inconsistent or counter-productive. The educational authorities are strongly urged to provide a set of universal guidelines based on scientific information. School authorities are also urged to carry out consultations with their communities in an open manner to help allay an 'epidemic of anxiety' and improve parent understanding.

National guidelines can only ever be a 'shell' in the light of which each HIV-infected child should be viewed as an individual and his/her special circumstances taken into account. Health care workers at local level, especially doctors, will still be consulted about the merits of individual cases. Are they all equal to the challenge?

R. P. GIE  
H. S. SCHAAF  
J. M. BARNES

Department of Paediatrics and Child Health and  
Division of Administration and Development: Research  
University of Stellenbosch

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