



HIV/AIDS AND EDUCATION IN JAMAICA:

IS THE HIV EPIDEMIC AFFECTING THE SUPPLY OF EDUCATORS AND THE DEMAND FOR EDUCATION IN JAMAICA?

BARRIERS TO INTEGRATION OF HIV/AIDS INFECTED/AFFECTED CHILDREN INTO THE JAMAICAN SCHOOL SYSTEM

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HIV/AIDS AND EDUCATION IN JAMAICA

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EXECUTIVE SUMMARY

Reason for the study

The study team was asked to review current evidence on the effect of the HIV/AIDS epidemic on the education sector in Jamaica, given reports of its impact in sub-Saharan Africa.

Methodology

I: Secondary data were reviewed to identify factors associated with the supply of educators (evidence of excess mortality among teachers due to HIV/AIDS) and demand for education (changing fertility patterns, pediatric mortality trends) to identify evidence of any reduction of the school age cohort.

II: Finally, as programmes aimed at primary and secondary prevention of HIV/AIDS will increase the population of persons living with HIV/AIDS, the team thought it necessary to collect information, through focus group discussions with teachers, community members and parents, on the readiness of the education sector to accept children affected by the epidemic – those who were either infected with the virus as well as the healthy offspring of HIV positive parents.

Supply of educators

The limited data we had available did not provide any evidence of excess mortality among teachers due to HIV/AIDS. The main causes of premature death (<60 years) were chronic diseases (hypertension, heart disease, cancer) and accidents and violence, consistent with the epidemiology of the age group.

Demand for education

The cohort of school age children is declining, mainly due to decreased fertility, especially in the two youngest reproductive cohorts, women 15-19 and 20-24 years. The 2002 Reproductive Health Survey report increased abstinence (more persons not in sexual unions), increased condom use and an increase in the proportion of pregnancies reported as planned. Demographic statistics also show an increase in the prevalence of births within legal marriage. Morbidity and mortality trends show more women being infected and therefore dying (leading cause of death in reproductive age women), further reducing the reproductive age cohort. Reductions in HIV mortality however suggest that more persons are surviving with the disease than in the past. In spite of increasing mother to child transmission, the overall mortality among children is not sufficient to impact the population of children seeking an education.

Access to education for AIDS affected children

Parents and guardians of HIV affected children expressed reluctance to disclose their status (if the parent was HIV positive) or that of the child (if the child was infected) for fear of stigma, even to close relatives, as ignorance regarding the disease was still the order of the day. This was supported by the views expressed by some teachers that ‘they should be quarantined.’

In communities exposed to persons living with HIV/AIDS, both school personnel and community members were more supportive and positive toward having the HIV affected child in the classroom. Where this experience was lacking however, there were very negative attitudes and an unwillingness to share the same space.

Parents reported that non-infected offspring were denied an education when teachers knew of the parents’ status, necessitating the move of children to other schools. Financial constraints were also significant as the cost of medication and special diets conflicted with the needs of other family members for simple things such as bus fare and lunch money. The mental health of these children was also compromised as they knew something was wrong, but often they were not told what the problem was, and parents felt that this affected their academic performance. Parents also felt that the disease affected the academic performance of infected children.

Support for HIV positive teachers

School personnel were less negative toward working with HIV positive colleagues, but expressed reservations nonetheless.

Conclusion and Recommendations

There is evidence in Jamaica of a declining school age cohort, which may be a secondary effect of more deliberate reproductive behavior, as fertility has declined significantly among women under 25 years of age. Discriminatory attitudes and practices in schools were evident in the report of parents of affected children and confirmed by the attitudes of some school personnel. The one positive feature was that when persons have been exposed in a one on one situation with HIV positive persons, attitudes improve as fears are allayed. And fear is what drives the negative behavior.

In order to improve access to education for the HIV affected school age population, intensive efforts are needed to educate school personnel, through where possible, one on one contact with affected individuals, to personalize the epidemic for the general population and allay concerns about the personal risk from contact with infected persons.

Support services will be necessary for adults working in education to ensure access to health care so they can continue to be productive adults as long as is possible.

IS THE HIV EPIDEMIC AFFECTING THE SUPPLY OF EDUCATORS AND THE DEMAND FOR EDUCATION IN JAMAICA?

Wilma Bailey^a and Affette McCaw-Binns^b

INTRODUCTION

At the end of 2003, the Caribbean had an estimated prevalence of HIV/AIDS of 2.3% (1.4-4.1), second only to Sub-Saharan Africa (7.5%; 6.9-8.3). Prevalence rates in the Caribbean antenatal population, a proxy for the general population, range from 0.1% in Cuba to 1.2% in Jamaica to 5.6% in Haiti (UNAIDS, 2004). While the pace of growth of the AIDS pandemic seems to be slowing in sub-Saharan Africa, antenatal population rates there range from 5% in Uganda to 17% in Malawi to 38% in Botswana (Asamoah-Odei, et al, 2004).

Perceptions regarding the pandemic have begun to shift from that of a health crisis to a broader perspective of its impact on social and economic development. In the education sector, it has the potential to affect both providers of education, the teachers, as well as those seeking education, the students. In southern and eastern Africa, many countries are losing teachers to AIDS or facing HIV associated teacher absenteeism (Grassly et al, 2003). Demand for education is also affected, since many children are facing HIV related illness themselves or the death of parents or siblings, compromising their access to family resources needed to attend school. In Zambia deaths among primary school teachers exceeded 4 per day by 1998; an annual loss of 4% of primary school teachers or two thirds of the annual output of newly trained teachers (Kelly, 2000).

In order to estimate the effect on the Caribbean education sector, Schenker, using 2002 prevalence data, developed the information in Table 1. Assuming that risk of infection among teachers is similar to the general population, he estimated that some 2400 Caribbean teachers are now HIV positive and by 2010, this will increase to over 3300.

Given the situation in sub-Saharan Africa, and the projections for the Caribbean, the aim of the investigation is to examine the available evidence to document how the epidemic is affecting the education sector in Jamaica. The problem has been approached from the twin perspectives of supply and demand. On the supply side, the hypothesis was that since HIV is the leading cause of premature death in the reproductive age group, and because education employs many persons in this age group, the sector could be losing teachers to the epidemic. On the demand side two converging forces, namely lifestyle changes such as increased condom use, could reduce fertility, while growing mother to child transmission would increase child mortality, and together reduce the number of children seeking an education.

The objectives of the study were to examine available secondary data to:

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- a. Determine whether there is any evidence that HIV deaths generally, and specifically among teachers were under-reported
- b. Determine the contribution of HIV disease to premature mortality (deaths under 60 years of age) among teachers
- c. Determine whether there has been a decline in fertility, possible due to changes in lifestyle secondary to HIV education or for other reasons
- d. Document the incidence of pediatric HIV (mother to child transmission) and its impact on infant and young child mortality
- e. Determine the effect of this incidence on demand for primary education.

A companion paper (Bailey and McCaw-Binns, 2004) will report on primary data collected to determine the readiness of the education sector to:

- a. Accept HIV positive children in the learning environment and
- b. Support the medical and social needs of HIV positive teachers

This paper presents information on the analysis of available secondary data.

The study was approved by the ethical review committee of the Faculty of Medical Sciences, University of the West Indies.

MATERIALS AND METHODS

Supply

Three data sources were examined to determine the epidemic's impact on teachers:

- a. Mortality database, UWI: Deaths for 1998
- b. Ministry of Health: HIV surveillance database, case notifications and deaths
- c. Ministry of Education: Deaths among teachers under 60 years of age.

Previous research undertaken by the Department of Community Health and Psychiatry provided access to a database of registered and unregistered deaths for 1998 (UWI mortality database). This database was constructed using a multi-source methodology to identify all deaths for 1998 and included events notified to the Registrar General's Department, events occurring in all public hospitals, and cases reported to the police and the Coroner's Court. The four sources of data were merged to provide the most complete information possible on each death. Demographic information on decedents included their age, gender and occupation. All deaths identified as being due to HIV disease were compared with the proportion of those which were registered. The cause of death, by occupation, was examined to determine the incidence of deaths among teaching professionals attributed to HIV disease.

We sought information from the Ministry of Education on reported deaths among teachers under 60 years. The UWI mortality database was reviewed for deaths among reported members of the teaching profession to identify the listed causes of death. Cases common to the Ministry of Education and UWI mortality database were compared.

Demand

To examine demand, we looked for evidence of changes in fertility. Trend data from the Reproductive Health Surveys (1975-2002; National Family Planning Board) were used to examine changes in total fertility and age specific fertility rates. Reported condom use was examined to determine whether public education regarding safe sex practices were having any noticeable impact on reproductive behaviour, yielding a secondary benefit, namely decreased fertility.

Among children, we examined the incidence of paediatric HIV infection and the contribution of HIV to deaths in children, using both the Ministry of Health and UWI mortality database.

Data were analysed using SPSS for Windows, version 11.5. Chi-squared tests were used to test for differences among categorical variables.

RESULTS

Mortality and registration of deaths among HIV positive persons

A total of 646 deaths were identified as having occurred to HIV positive persons for 1998. Of the deaths identified, 10% of all deaths but only 4% of HIV deaths had not been registered, suggesting no problems with the timely registration of HIV deaths. The cause specific mortality rate for HIV/AIDS in 1998 was 30.5/100 000. HIV was ranked as the seventh leading cause of death in 1998 but was the leading cause of death among reproductive age women and the second leading cause of death among reproductive age men, behind accidents and violence.

Mortality among teachers

A total of 74 teachers were identified in the mortality database, two thirds (66%) of whom were women. Table 2 shows that among men, circulatory disorders and external causes were the main causes of death, while among women, it was cancer followed by circulatory disorders. Among younger teachers (less than 60 years of age), cancer and external causes accounted for most premature deaths while among older persons (60+ years), circulatory diseases such as hypertension and heart attacks and other chronic diseases such as diabetes mellitus were among the main causes of death. The category "all other" includes 3/10 cases of diabetes mellitus among younger persons and 4/11 in the older age group. Only two deaths were attributable to communicable diseases, both due to pneumonia. No HIV deaths were identified although it is possible that deaths among HIV positive persons might be reported as pneumonia.

The Ministry of Education reported 137 deaths among teachers 29-60 years of age between 1993 and 2001; 21% among men and 79% among women – a higher female prevalence than the mortality data base. Of nine cases common to this and the mortality database, the three males had their occupations listed on the death certificates as teachers, while two of the six women were listed as housewives. This may account for why we identified fewer female

teachers in the mortality database. Of nine (9) HIV deaths among professionals, none were teachers.

Demand for education: Changes in fertility behaviour

Over the past decade, the general fertility rate, a measure comparing total births to the number of reproductive age women, declined by 18% from 106 per 1000 population in 1991 to 87/1000 in 2000. When age specific fertility rates over time are examined, most of the recent improvements occurred among the two youngest age cohorts, women 15-19 years and those 20-24 years, shown in solid lines in Figure 1. In those two age groups, between 1997 and 2002, age specific fertility decreased by 29% and 24% respectively, with little or no change observed in the older age groups. Women were now averaging 2.5 children and having them later than 15 years ago when the HIV epidemic started. Between 1997 and 2001, registered births decreased by 12.3%, from 54 787 to 48 065.

Further evidence of more deliberate reproductive behavior is the growing tendency over successive reproductive health surveys for women to report that their last pregnancy was intentional or planned. Since 1989, the reported prevalence of planned pregnancies have increased from 25.4% (1989) to 29.1% (1993) to 34.4% (1997) over the duration of the epidemic. While still quite low at one third of all births – it suggests that a growing number of women are using methods which are effectively controlling their fertility. Contraceptive prevalence increased from 55% in 1989 to 66% in 1997 to 69% in 2002.

Use of condoms as a contraceptive method has grown from 8.6% in 1989 to 23.5% in 2002. Among young adults (15-24 years), ever use of condoms increased from 75.8% in 1997 to 89.8% in 2002, with the prevalence among teenagers increasing from 73.9% to 91.1% and among young adults from 77.1% to 89.0%.

Figure 2 shows that the HIV epidemic has grown steadily since the first reported case in 1986. Mortality however is slowing, suggesting that some persons may be gaining access to antiretroviral drugs. When new cases, plotted on a logarithmic scale and smoothed, are examined over time, the gap has been closing between men and women, especially those under 50 years, indicating that this is now a generalized, heterosexual epidemic. Among children and youth (persons under 20 years) no gender differences are seen, with their incidence practically overlapping the older females (50+ years). See Figure 3.

HIV in children

Among children, new cases seem to be slowing. In 1998 paediatric AIDS claimed 61 children under 15 years and a total of 66 under 20 years (see Table 3). The majority of deaths were among young children under five years of age (79%). All infant deaths occurred outside of the perinatal period (>28 days of age).

Even if the rate has tripled since 1998, and without anti-retroviral therapy, its impact on the educational sector in terms of reducing the school age population is limited at this time. What can be expected is that until the momentum of the epidemic slows, and with programmes to

identify HIV positive mothers being expanded, birth of HIV positive children who may be identified early will probably increase. With access to antiretroviral drugs however, mortality should decrease and the population of HIV positive children surviving to school age will grow. The system will therefore have to ready itself to integrate these children into the classroom.

DISCUSSION

Occupation

There is no evidence from our database of significant numbers of HIV deaths among Jamaica teachers – the leading causes of premature mortality being cancer, cardiovascular disease, diabetes mellitus and accidents and violence. There is anecdotal evidence from consultants providing care to the HIV infected population that deaths have occurred among teachers. We present data for only one year, which may not represent an adequate enough sample to speak definitively. Data from the Ministry of Education proved unhelpful as very few cases had information on the actual cause of death.

One assumption of the information in Table 1 worthy of challenge is whether the risk of HIV infection to Caribbean teachers is the same as in the general population. Unlike the profile of the African teacher, who Kelly suggested were more ‘prone’ to engage in higher risk sex behaviour because of their social status, better income, mobility and spousal separation. In the Caribbean however teachers may be a relatively lower risk group as unlike some of their African counterparts, they are not very mobile, that is they do not live far from where they work, a factor associated with increased likelihood of transactional sexual activity. Many are married. Thus, in spite of being in the high risk reproductive age group, with significantly more teachers being female than male, the profession’s overall rates of infection may be lower than the population average. Even in sub-Saharan Africa, Bennell reports that in South Africa the incidence in teachers is one-third of what it is in the general population (teachers, 12%; antenatal population, 35%). In Malawi mortality among secondary school teachers is lower (0.8%) than among primary school teachers (1.01%) and the general reproductive age population 20-49 years (1.37%). In all instances, projected teacher mortality, based on the experience in the general population, was significantly lower than expected.

The data now suggest that the epidemic’s impact on the education sector is not yet being felt in the Caribbean, and as in sub-Saharan Africa, with changing sexual behaviour, and increased access to antiretroviral drugs, especially among the educated and employed, HIV mortality will stabilize and probably decline. The situation however needs to be monitored. One variable of value would be absenteeism and sick leave, especially among single and male younger members of the profession.

Fertility/Reproductive behaviour

The 2002 Reproductive Health Survey documents a significant decline in fertility and an increase in safe sex practices in the two youngest age cohorts, 15-19 and 20-24 years, to

whom most of the HIV/AIDS education messages have been directed. Ever use of condoms increased among young adults however little difference in consistency of use was noted, although more teenagers reported using a condom at every intercourse (up to 22% from 16%). More young adults were reporting the absence of a steady partner (from 39% to 51%), there were more births in wedlock (moving from 13% in 1997 to 18% in 2001), with increasing reproduction in older age groups. All suggest that marriage and delayed reproduction are options being exercised by more reproductive age adults.

Decreased births, a combination of the cohort effect of fertility declines of the 1980s reducing the reproductive age cohort (TFR declined from 4.5 in 1975 to 2.5 in 2002), and positive behavior change is reducing the school age cohort. These provide the education sector with an opportunity to reduce class size and improve education quality, without any appreciable loss of educators due to the epidemic.

Even though more infants are being delivered to HIV positive women, a growing voluntary counselling and testing programme in antenatal clinics may reduce mother to child transmission. In spite of this, the society will have to contend with HIV positive children as access to anti-retroviral drugs means more children will survive to join the school age population and will want to attend school like other children their age. The schools need to be prepared for this eventuality.

CONCLUSIONS AND RECOMMENDATIONS

The current data do not support the thesis that at this time we are losing significant numbers of educators to the HIV epidemic in Jamaica. While we can't demand that teachers disclose their HIV status, monitoring teacher attendance, need for sick leave, especially prolonged leave necessitating substitute teachers, will give some indication of whether schools have to cope with more ill teachers than before. The education and other sectors also need to ensure that health insurance providers support routine surveillance and testing, provision of anti-retroviral treatment and social support for teachers who do contract this disease.

The data however suggest that health care programmes for teachers need to include greater attention to other lifestyle chronic diseases such as hypertension, diabetes mellitus, heart disease as well as screening for the more common neoplastic diseases.

All schools need to develop training programmes to ensure that the school environment is HIV friendly and teachers and ancillary staff have the skills to care for HIV positive children as well as protect themselves from unnecessary exposure.

Table 1: Estimated number of HIV positive teachers in the Caribbean and projections to 2010

Country	HIV prevalence (15-49 yrs)	Total teachers 2001	Estimated infected teachers 2002	Projected total teachers 2010	Estimated infected teachers 2010
Total Caribbean	2.3	106 144	2 441	145 419	3 345
Belize	2.0	3 055	61	4 186	92
Dominican Republic	<i>1.7-2.5^c</i>	57 035	1 426	78 138	2 049
Guyana	<i>2.5-2.7</i>	9 264	250	12 692	377
Jamaica	1.2	22 931	275	31 416	384
Trinidad and Tobago	<i>2.5-3.2</i>	13 859	347	18 987	514

Source: UNAIDS *epidemiological fact sheets on HIV/AIDS and sexually transmitted infections: 2004 update* (prevalence); *Joint Program Identification Study, April-June 2003* (personal communication, i_schenker@hotmail.com (teacher statistics))

^c Difference in prevalence between 2002 and 2004. Data in italics used for the estimates

Table 2: Cause of death among teachers, by gender and age, 1998: Jamaica

Disease group	Males	Females	<60 years	60 or more years
Communicable diseases	4.0% (1)	2.0% (1)	2.6% (1)	2.8% (1)
Neoplasms	8.0% (2)	32.7% (16)	28.9% (11)	19.4% (7)
Circulatory disorders	32.0% (8)	22.4% (11)	13.2% (5)	38.9% (14)
External causes	24.0% (6)	10.2% (5)	26.3% (10)	2.8% (1)
All other	28.0% (7)	28.6 (14)	26.3% (10)	30.6% (11)
Ill defined causes	4.0% (1)	4.1% (2)	2.6% (1)	5.6% (2)
Total	100% (25)	100% (49)	100% (38)	100% (36)

Table 5: Contribution of HIV/AIDS to mortality among infants and children, 1998: Jamaica

Age group	Number of HIV/AIDS deaths	Rate/100 000 population in age group	Rank of HIV/AIDS among age specific causes	Total deaths in age group	Total age specific mortality rate /100 000
Infants (<1 year)	24	42.2	6	1134	1991.7
1-4 years	28	12.0	1	222	95.0
5-9 years	6	2.3	4	114	43.5
10-19 years	8	1.6	10	330	65.7

Figure 1: Age specific fertility rates, Jamaica: 1975-2001

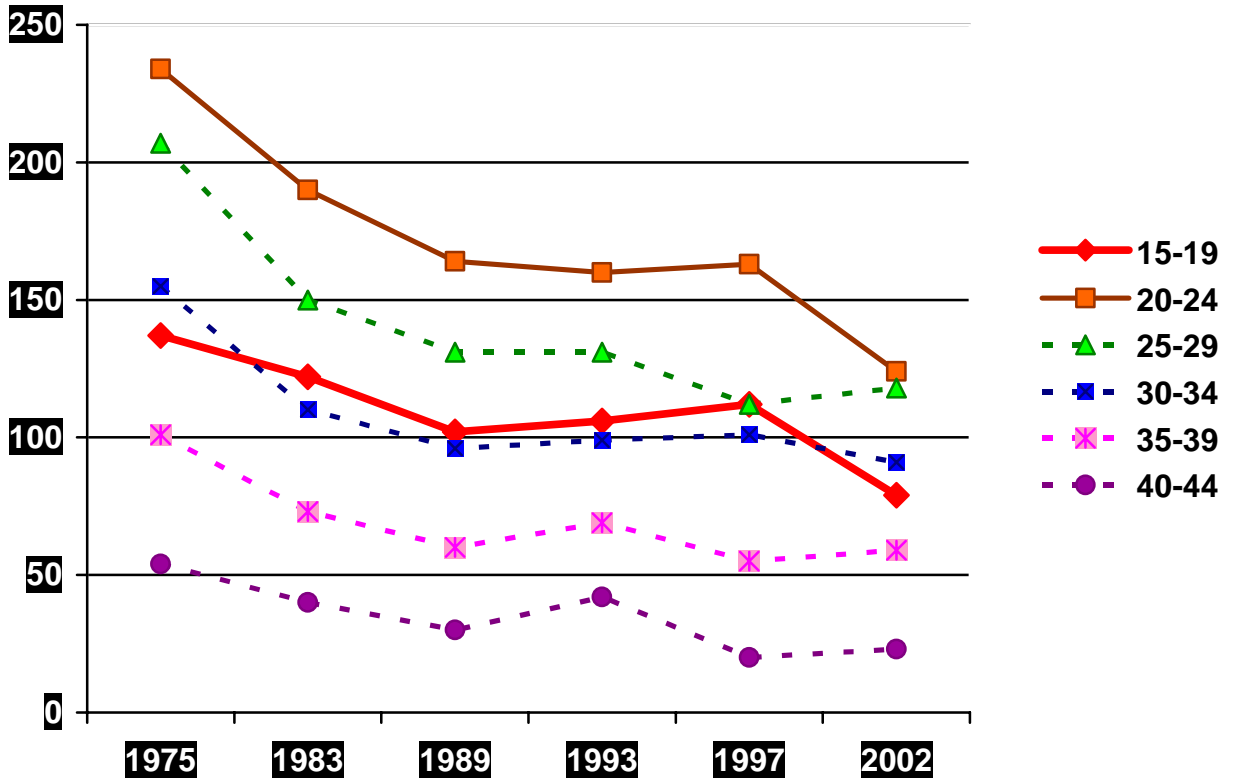


Figure 2: Incidence of HIV disease and deaths, Jamaica: 1986-2002

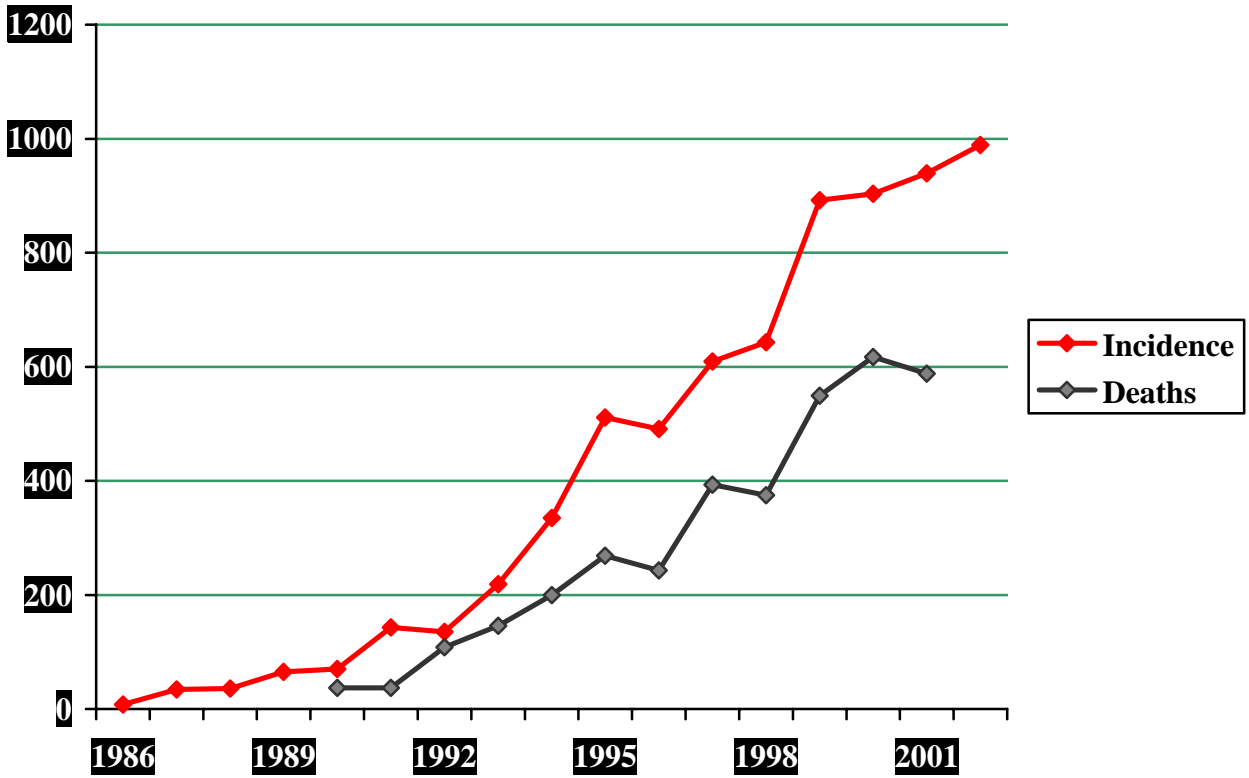
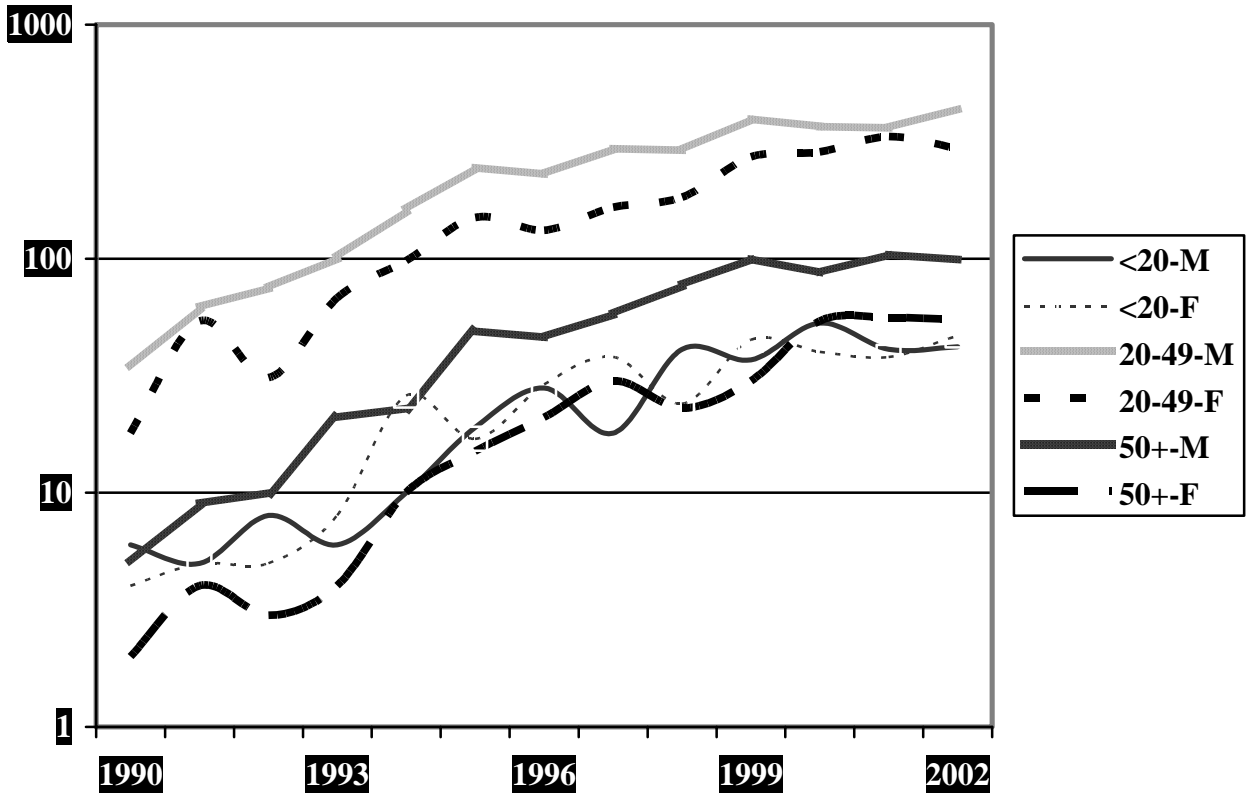


Figure 3. Age specific incidence of HIV disease, Jamaica: 1990-2002



Appendix 1: Estimated number of adults and children living with HIV/AIDS, end of 2003, selected Caribbean countries

Country	Adult rate (%)	Adults and children (no.)	Adults 15-49 years	Women 15-49 years	Children 0-15 years	Deaths (2003)
Bahamas	3.0	5 600	5 200	2 500	<200	<200
Barbados	1.5	2 500	2 500	800	<200	<200
Cuba	0.1	3 300	3 300	1 100	...	<200
Dominican Republic	1.7	88 000	85 000	23 000	2 200	7 900
Guyana	2.5	11 000	11 000	61 000	600	1 100
Haiti	5.6	280 000	260 000	150 000	19 000	24 000
Jamaica	1.2	22 000	21 000	10 000	<500	900
Suriname	1.7	5 200	5 000	1 700	<200	<500
Trinidad and Tobago	3.2	29 000	28 000	14 000	700	1 900
United States of America	0.6	950 000	940 000	240 000	...	14 000

Source: UNAIDS fact sheets 2004. ... Data not reported
http://www.who.int/GlobalAtlas/PDFFactory/HIV/EFS_PDFs/EFS2004_DO.pdf.
 Accessed 7 Oct.04.

Appendix 2: Basic Demographic Indicators, end of 2003, selected Caribbean countries

Country	Population ^d	Crude birth rate	Crude death rate	Maternal mortality ratio ^e	Total fertility rate ^f	Infant mortality rate
Bahamas	317 000	18.9	8.3	60	2.3	15
Barbados	271 000	12.0	7.6	95	1.5	17
Cuba	11 328 000	11.4	7.3	33	1.6	7
Dominican Republic	8 872 000	23.0	7.2	150	2.7	31
Guyana	767 000	21.2	9.1	170	2.3	45
Haiti	8 437 000	30.0	14.3	680	4.0	92
Jamaica	2 676 000	20.1	5.7	87	2.4	13
Suriname	439 000	21.1	5.9	110	2.5	24
Trinidad and Tobago	1 307 000	13.8	7.7	110	1.6	18
United States of America	297 043 000	14.4	8.3	14	2.1	7

Source: UNAIDS factsheets 2004.
http://www.who.int/GlobalAtlas/PDFFactory/HIV/EFS_PDFs/EFS2004_DO.pdf.
 Accessed 7 Oct 04.

^d Source: UN population division

^e Source: WHO/UNICEF—World Health Report, 2004

^f Source: WHO—World Health Report, 2004

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BARRIERS TO THE INTEGRATION OF HIV/AIDS INFECTED/AFFECTED CHILDREN INTO THE JAMAICAN SCHOOL SYSTEM

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INTRODUCTION

At the end of 2003, it was estimated that there were between 410,000 and 720,000 adults living with HIV/AIDS in the Caribbean and prevalence rates ranged from just over 1 percent to almost 6 percent in the region (UNAIDS, 2004). Jamaica was estimated to have a rate of less than 2 percent. These prevalence rates made the Caribbean the second most affected region after sub-Saharan Africa. The majority of those affected were adults between the ages of 15 and 45 years but the disease is taking an increasing toll on young children. Roughly 22,000 thousand children were estimated to be infected in 2003 (UNAIDS). However, as the epidemic begins to claim more young adult women in the Caribbean and assume the pattern that now obtains in sub-Saharan Africa, it is expected that more children will become victims of the disease, with some becoming infected and others made vulnerable through orphaning and the social and economic impoverishment of AIDS affected households.

At the same time, although the numbers are still quite small, an increasing number of HIV positive children in Jamaica are having access to antiretroviral therapy. This means that the children are going to live longer and many will live to school age. Public schools must, therefore must be prepared for the enrolment of increasing numbers of HIV positive children as well as those living in households affected by the virus. The society must also be sensitized to those factors operating within HIV/AIDS affected households that may rob these children of the basic right to education and the means of ensuring a productive future.

Objectives

This study investigates the barriers to the integration of HIV/AIDS infected/affected children into the Jamaican school system. Specifically, it examines the problems encountered by parents and guardians in their efforts to secure places for their children in the public school system and the readiness of the education sector to accept these children into the learning environment.

Background

In a policy statement, the Committee on Pediatrics of the American Academy of Pediatrics, stated that asymptomatic children with HIV virus infection cannot be distinguished from those without and should have the same educational opportunities (Pediatrics, 2000). They should neither be excluded nor isolated within the school setting. There are no documented instances of the spread of the infection in schools and no basis for the fears of such an occurrence by school personnel. If infected children are to be integrated into the school

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system efforts must be made to allay these fears by the appropriate education and create a receptive environment. The right of all children to a primary education is upheld by the United Nations Convention on the Rights of Children and reaffirmed at the Millennium Summit in 2000. By creating opportunities and choices, education provides opportunities and this is particularly important for those children who find themselves in difficult circumstances. The education sector must be in the forefront of those offering support and services to the affected.

The Ministry of Education Youth and Culture in Jamaica has responded to the need for clear guidelines for schools to develop and institute HIV/AIDS action plans (Ministry of Education, 2004) and, in the main, the National Policy echoes the sentiments of the international community. HIV positive students are expected to attend classes as long as they are able and disclosure of status is not compulsory. Policy statements of this sort become necessary because there is a widespread perception that children known to be affected by the virus are greatly disadvantaged as a result of stigma, increasing poverty and social disruption. (Ramsay *et al.*, 2004). These factors are creating barriers to education and therefore to the development of the full potential of victims of the disease. These barriers need to be understood if HIV affected children are to be fully integrated into the education system.

Methodology

Two groups of children are affected by the HIV/AIDS epidemic. There are the relatively small numbers who are infected with the HIV virus, and there are the HIV negative children of infected parents. In both groups some are orphans, already having lost one or both parents.

Group interviews were employed to gather data from the two groups of parents and guardians. The study design envisaged the selection of purposive samples comprising nine parents/guardians of infected children and nine infected parents. However, in spite of the assistance of The Centre for HIV/AIDS Research, Education and Services (CHARES) an organization which provides care and support to the victims of the disease, and despite assurances of anonymity, the target was not met. The sample comprised four parents and guardians of infected children and eight HIV positive parents. Audio-taped interviews were conducted in the seminar room of CHARES where privacy was assured with the Moderator and Note taker in attendance. The interviews probed the socio-economic situation of the parents/guardians, support systems, coping mechanisms, experience with the school system and the attitude/behaviour of the children. Ethical approval for the interviews was obtained from the Ethics Committee of the Faculty of Medicine of the University of the West Indies.

Group discussions were also held with teachers and guidance counsellors in Basic, Primary and Secondary Schools in two parishes in the island. The purpose of these interviews was to gain an understanding of the teachers' perception and knowledge of the epidemic and their attitude to the inclusion of HIV affected children in the class rooms. An Infant/Primary school was selected in a community in the Kingston Metropolitan Area (KMA) in which previous research had revealed a pocket of infected adults and a number of deaths from the

disease. The schools served the local community and occurrences were known to members of the small community. A Primary and High School were also randomly selected from outside of the KMA for group discussions. The investigation had the full support of the Ministry of Education. In addition, in depth interviews were conducted with the directors of the two institutions that look after the infected orphans of AIDS.

RESULTS

Parents/Guardians

Of the parents/guardians of the infected children, two were males and two females. They ranged in age from 30 to 52. One of the male participants was the guardian of two infected children aged 7 and 12 who lived with him and whom he was in the process of formally adopting. The older boy had lived on the street for a while. The mother of the seven-year old was currently in the hospital dying of AIDS. The other male participant was a father who had recently taken his affected son from the child's maternal grandmother who had taken care of him following the death from AIDS of his mother. The infected child, a boy of five years, was currently living with his paternal grandmother in a household comprising six other relatives. The father reported that he had taken the child from his maternal grandmother because he was being ill treated. Both fathers were employed.

One of the female participants was the aunt of a 13 year old boy, one of twins orphaned by the death of her sister. Since the death of their mother from AIDS, they had lived with guardians, whom, the participant said, had been neglecting them. She had taken one of them to live with her and had only recently learned of his status. She was in the process of making arrangements for his twin who still lived with a guardian to be tested for the disease. The participant lived with her boyfriend and their two children, aged 13 and 6, and she seemed to be torn between a desire to keep her nephew and send him to a home. She could not accommodate him fully in her small apartment and so he slept with her parents and his grandparents who lived close by. The other female participant was a mother of six children. Her oldest, a boy of 14 was a haemophiliac who had contracted HIV at the age of seven after a blood transfusion. He was now extremely ill, had developed brain tumours and was receiving both anti retroviral and anti psychotic drugs.

The infected parents in the sample were all women between the ages of 20 and 58 and those who were willing to share their experiences had remarkably similar stories to tell of being infected by a boyfriend/husband; of being deserted and/or widowed. One had an infected five year old. The eight mothers had 25 children among them ranging in age from nine months to 21 years. Some had had themselves tested on learning of their partners' condition. Other participants had found out about their condition in the process of preparing to migrate; on becoming pregnant or in seeking treatment for repeated yeast infections.

There were 35 HIV positive orphans in care in two homes in the island. Twenty-three were in a home designed for infants and all but three were between the ages of two and five. These were the victims of mother to child transmission and had been abandoned and found

living under desperate conditions. Most were being treated with anti retroviral drugs. The others at this home were three teenagers about to be transferred to a smaller facility which housed 12 children aged ten to fifteen. The teenagers were infected by sexual encounters.

Disclosure

In a society in which there are preconceived stereotypes regarding HIV/AIDS the diagnosis immediately induces the fear of negative moral judgements; of being rejected and abandoned; of being subject to isolation and even violence. There was little doubt that among all the participating parents the psychosocial outweighed the physiological implications of the disease:

“It is me alone. I need a job. I come here (CHARES) and the Jamaica AIDS Support. I have been begging all around and can’t get a job. Sometimes I say to myself ‘Look what I have come to! That is what bothers me.’”

The fear of rejection induces secrecy and the need to keep the secret leads to feelings of isolation. The overwhelming impression gained from the discussions with the parents was that they were alone and that they had no option than to rely on their own resources. For most, disclosing their status was out of the question and much of the discussion revolved around the effect disclosure would have on their lives and the lives of their children. If their lives were to assume a semblance of normality and if their children were to be accepted in schools, their status had to be kept a secret.

HIV/AIDS has created a crisis in family life. It was interesting that the only instance in which a voluntary decision was taken by a parent either to reveal the child’s status to the child in question or the parents’ status to their children, was in the case of the child who had been infected by a blood transfusion. Disclosure may reveal information about a parent’s sexual orientation, drug use or marital infidelity. It therefore reflected on the entire family. There may also be guilt about transmission. However, when the disease was transmitted by a blood transfusion the family was absolved of blame and the stigma that is associated with sexual transmission (Herek and Capitanio, 1999). Therefore the entire community could be told of the status of this young boy and what was remarkable in the context of the Jamaican society was that the community was reported to be protective of him. It was not that the community had a liberal position on the issue. This young boy occupied a special place:

“If you come to (Community) and ask for him, they have to find out why you want him and if you have bad intentions they will kill you.”

To disclose the child’s status in this case was to make a statement of the state of health care in the island. In every other case, participants feared community and/or family rejection. The two male parents of infected children were, at the time of the discussions, struggling with the problem of how and when to inform the children of their status. In one case, in order to explain the visits to the clinic and the use of the medication, the child as well as other members of the family had been told that he had cancer. This was not an illness that

could reflect on the family. The social issues associated with the diagnosis of HIV/AIDS made disclosure a far more complex issue. The deception met with the approval of other parents, for the affected children as well as other children in the family had to be spared the problems consequent upon disclosure.

Infected parents had a similar problem with disclosure. There was no instance in which the diagnosis was discussed with a child because the parent was ready to share the information. In one case, the child, at the age of four, had been present when the doctor revealed the diagnosis to the parent and even at that age, demanded an explanation of what it was since it meant that they could not migrate. In every other instance where the parents' status was known, disclosure was forced by the actions of others. For the most part, participants were taking great pains to keep their status a secret from their children, many of them teenagers. In the case where the mother had passed on the virus to her five year old, the child's status was also a secret. The secrecy involved attempts to hide medication, side effects and, in one case, the frequent doctor's appointments. They gave several explanations for their behaviour. To one parent, the timing was a critical element:

“When I decided to tell my son, he was doing his GSAT (primary level examinations). Now my daughter is doing CXC (secondary level examinations).”

Others seem to be approaching disclosure as a process in which, initially, they test their children's reaction to a hypothetical situation. So far, they had not been encouraged by the responses to these advances or by comments which suggested that their children had adopted the attitudes of the society:

“I can't tell him because I hear him talking some things.”

“Sometimes I want to tell him but he says some things. I've tried to tell him but it doesn't work.”

Above all, parents could not disclose because they had difficulty coping with their own illness and the felt need to keep their status a secret robbed them of the mechanisms that would make coping easier. They could not share their secret with their friends and members of their families. In some cases there was an absolute lack of trust in the ability of family members to respect confidentiality.

“Not even my mother”

“Me neither. I don't trust her”

“My mother doesn't know. It is between me and my God.”

This attitude was strengthened by the experiences of those who had shared their secret. The 'closeness' which formerly existed within the family had disappeared. The family, one participant said, doesn't 'use it against me' only because they were afraid that it would become known to the community and that they too would be affected. The mother of one

woman had found out but behaved as if she didn't know. The decision to hide the problem that had reshaped and overshadowed their lives protected them from the pain of rejection but, as with women in similar circumstances elsewhere (Crandall and Coleman, 1992), it led to isolation and robbed them of the support networks that had the capacity to assist them in working through their feelings of fear. One of the infected participants acknowledged support from an aunt and her three sisters.

However, it was apparent from the discussions that it was difficult to hide such a devastating illness from older children and that the attempt itself could create unexpected tensions. All the participants were convinced that the withdrawal and depression of a 17 year old girl, her declining performance in school were explained by the anxiety experienced because she knew that her father had died of AIDS and suspected that her mother and infant brother were infected, as indeed they were. She did not have and was probably hesitant to seek the information that would have allowed her to make sense of the situation. In addition, there was always the possibility that the right to make the decision as to how and the child should receive the information could be taken from the parent and the child receive the information in a non-supportive manner. One of the eight infected parents was forced to disclose her status to her children when the cause of her husband's death was revealed to her son. One of the twins was told of his status by an angry and probably grieving grandfather:

'He told him that his mother had AIDS and died and that he has it and will die too...He didn't want him there...I noticed that he looked withdrawn...and I explained it fully. I told him he doesn't have AIDS but HIV which doesn't have to develop into AIDS...'

"I told my brother that I was positive and he told a friend...The information get into the primary school and my children were abused. I couldn't walk on the street. I was so ashamed of myself.

Even then this mother could not admit the truth:

"All I told them was that everyone was going to die. Even me."

The Effects of Disclosure

The very strong support among participants for keeping the infection a secret sprang from their own experiences and the impact disclosure had had on their lives and the lives of their children. The National Policy advises that while a parent may choose not to disclose the status of a child to the school, it might be in the interest of the child to do so to a responsible person. However, the fear of discrimination and loss of privacy outweighed the potential benefits of disclosure. An education for their children in the public school system was only possible if their HIV status remained a secret. The adoptive parent had this to say:

"I told the Principal (about the child's illness) and he gave me the run around. The argument was that I was late with registration...I called the Ministry of

Education...which intervened.... For two and a half hours (the Principal) had me waiting...He made me complete a medical form and put on it that he is positive...The teachers were told. I went to (a Private School) and told the Principal. She told me that she had to speak to the Board and came back and told me 'yes'.

The children in question did not know of their illness or of the negotiations that were taking place over their entry into the school system. In this sense they were more fortunate than the affected children. The haemophiliac boy had been withdrawn from the school system because the brain tumours were affecting his behaviour. He, however, had siblings in school:

"I made the mistake of telling the Vice Principal and my other son was beaten ...by students and ill treated by the teacher....That made him fail GSAT. He was told 'Your brother has AIDS and you must have it too. I don't want any AIDS victim here.' I was so upset...I reported it to the Principal but nothing was done....I had to move him."

The effect on the girl who had been told of her mother's condition at the age of four was interesting. The participant felt that she had to prepare her daughter to be stronger than she was, to have the self esteem that would enable her to avoid the mistakes her mother had made. She had to be able to look after herself. So that by the age of five, the participant said, her daughter was able to cook and wash and to make positive decisions. Today, at the age of 14, the roles are reversed. The daughter has become the parent and it is she who insists on secrecy.

"...it is feeding back on me now. She questions everything...I can't tell her to do anything. Not only me. She is the same at school..."

The child has had to assume an adult role and this has taken its toll. At the time of the discussions the child was receiving professional counselling

School Performance

Most of the parents believed that their children were not performing well in school and this held for both .the infected and affected. To the parents, the work of the affected 'fluctuated'; the children 'did not appear to have much interest' in school; they were depressed and withdrawn:

"...she was bright but everything is going down....She goes to school but her mind is not there. If I had money, I would send her to a professional."

"Recently, my son was in a corner by himself. He doesn't talk about it. I know he is bleeding inside."

“Now, all my daughter’s marks are low. I wonder if I did the right thing in telling her that her father died from it. It’s worrying me a lot.”

The parents of the infected were almost unanimous in their belief that their children were not coping academically:

“...he goes to a slow learning school.”

“We have been taking them to Mico Teachers’ College (for special education). Both are slow learners.”

“I notice that he is not learning anything...he doesn’t know all the letters of the alphabet...I went to the school and they asked him to repeat Seventh Grade.”

Evidence suggests that the virus can interrupt in-utero brain development, cause a decrease in cognitive function and a resulting decline in academic performance (Nozyce *et al.*, 1995; Gay, Armstrong and Cohen, 1995). But poor school performance was reported by parents of those children who were not infected by the virus and it may be that the young children were depressed by knowledge of their parents’ condition or by uncertainty of their parents’ status. One parent placed the blame on the shortcomings of the public school system rather than the virus. For, removed to a private school, his adopted son who was formerly labelled slow:

...” now excels. He is one of 12 students and two teachers...”

Poverty also excludes

There was also the problem of the financial burden of the disease. Many were unemployed and even those who were employed had difficulties in meeting the cost of the subsidized drugs and the type of food which were essential to their health and that of the infected children. Luckily, the parents were not in need of anti retroviral drugs and looked extremely healthy. The health problems mentioned by a few were unrelated to the virus. But they all found the cost of the food which, they said, were responsible for their appearance, extremely burdensome. The mother of the haemophiliac child spoke at length of the problems associated with living on her husband’s earnings of J\$7,000 (~US\$115) a fortnight, meeting the needs of six children; purchasing the special food needed by the child as well as the anti retroviral and anti psychotic drugs. She also had to pay the cost of the damage he inflicted on property in the community. When the drugs are to be purchased, she said, the rest of the family must go without proper food. The financial problems experienced by most parents affected attendance at school. Choices had to be made and the medication for the infected was given priority:

“I have bills, three children to school...daughter’s bus fare, son’s bus fare. I wonder how I do it. Sometimes there is no food.”

“It they go to school this week, they can’t go next week.”

“Meeting expenses is more stressful than the sickness itself.”

Irregular attendance at school, poor diets and the general poverty of the socio-economic environment are other conditions that must be factored into the explanation of poor school performances.

Orphans in Care

Parents/guardians had the option of keeping the status of their children a secret but this was more difficult in situations where children were living in institutions devoted to the care of infected orphans of AIDS. At the moment, the youngest children are being schooled on site. However, the Director of the institution freely acknowledged that the children were simply being kept occupied and no real education was taking place. There was a need for them to enter the public system. The dilemma is that a very protective Director would like to arrange for their education in a manner that would not force disclosure. She rejected the Primary school nearby on the grounds that it would be impossible to hide the status of the children. In spite of the protective wall that has been built around these children, they are already asking questions about their status.

The teenagers who lived in the home were in schools where their status was not known. They lived with self stigma, in fear of disclosure and rejection and for these reasons, had made no friends at school and hid from visitors to the home. The secrecy protected them from rejection but not from the stress of isolation. The twelve children who lived in the home for teenagers were not in school at the time of the interview and the institution had no means of providing an education for them and in the prevailing climate saw no immediate solution.

The School Environment

A. The Kingston Metropolitan Area

The community in which group interviews were conducted among Basic and Primary School teachers was a low-income community in which more than a half of the householders lived in informal housing and unemployment was in excess of 60 percent. This community had been targeted for intervention in an early study conducted by researchers at the University of the West Indies (UWI) and it became known that there was a pocket of HIV/AIDS infected persons. The Headmaster of the Primary school was an enlightened individual who had been involved in Jamaica Teachers' Association workshops on the issue and, in informal discussions, he expressed a strong belief that that the children of the affected had a right to an education and to be educated with the healthy. Probably because of this attitude, he described a relationship with the community in which HIV/AIDS infected parents were able

to inform him of their condition and to give him the assurance that their children would be frequently tested for the virus.

Some of the infected parents were known to the teachers. In some cases the parents themselves had informed the teachers. In other cases, the teachers said that they just knew:

“I met a parent who said she was infected. Her child is in Grade 2.”

“When I was teaching in the Infants’ Department there was a child whose father died of AIDS and the mother has it.”

‘...her children are tested regularly.’

They explained that an epidemic of this sort should be expected in the community because of the pervasive poverty. Mothers do not work and are dependent on men. They do not have control over their lives. Moreover, they suspected that some of the children in the school were also infected and there was a long discussion among themselves during which they calculated the time of death of the parents and the ages of the children of those parents.

“I was wondering if one in my class is infected because she is four. Her father died a couple of years ago. Her mother has it and she was born during that period.”

They discussed the fact that several of the children - in one case, five – were brothers and sisters but did not share both parents and that in some cases, the parents had died of AIDS.

The suspicion and knowledge, they said, made no difference to the manner in which they interacted with the parents and the children:

“...She comes to pay for the children’s lunch. To me she looks well, and I treat her the same.”

They described what they referred to as an ‘understanding spirit’ in the school which explained why parents were not ‘intimidated’ and why they were able to disclose the nature of the illness. Infected children just needed ‘more attention and more love.’ They attributed this spirit to the attitude of the school Principal.

Disclosure

The teachers were disturbed, however, that they had to guess at the status of the children. They felt that they ought to be told and their position was based on two factors, one of which was clearly articulated. They felt that at any one time there were large numbers of children in the schools with cuts and bruises and that in poor environments, these took a long time to heal.

“Some of the parents don’t pay attention and so they get infected. Some have to wear slippers to school when they get a cut because it won’t get better....”

The children were involved in contact sports and under these circumstances; they felt, there was an increased risk of transmission. It was not that they should be barred from involvement in contact sports but they needed to be carefully supervised. In the same way, they needed to be carefully monitored in the class room where they could be cut by sharp edges and nails. Generally, there was a fear of coming in contact with infected blood. But the infected children also needed to be protected from the healthy:

“If I sneeze on somebody who has AIDS, they could die of a cold because their immune system is being eaten away everyday.”

“It was for this reason that they needed ‘more love and more attention.’

But there was another reason that was more implied than actually stated. The fact that they suspected that there were HIV positive children in the school did not affect their attitude to them. Familiarity with the condition had brought with it a measure of acceptance. One teacher actually said that just as they had been informed of the presence of a child with juvenile diabetes, they ought to be informed of the presence of the HIV positive child. It was ignorance of the fact that put them at risk.

There was a concerted effort to transmit this positive attitude to the student body. Guidance classes formed a part of the curriculum for Grades 2 through 6 and this was the medium for exposing the children to the issues surrounding HIV/AIDS and other sexually transmitted diseases. There was satisfaction with the impact of the programme on the attitude of the children who benefited from the programme:

“Some began to draw pictures to express how they feel after class and one boy wrote, ‘Corey is my friend. He has AIDS. I would still hug Corey and he would still be my friend.’”

However, the Guidance Counsellor felt that it was a pity that guidance time did not cover all grades and that so little time was devoted to the subject. There were she felt, some unhealthy tendencies among the children which could be addressed in the class room:

“Sometimes the children tease children whose parents had died of AIDS. I’ve had to call in more than one of them and explain, and talk to them. So I would say that education is an ongoing process.”

The biggest challenge they had to face was the attitude of the parents of healthy children. The teachers were sure that there would be complaints about the presence of infected children in the class room. But even this, they felt, could be overcome with the right approach. Parents are young. They go to dances; listen to songs; they put DJs on pedestals and they saw this as the best medium for putting positive ideas on HIV/AIDS across to the population.

In the meantime they all felt that they could benefit from more information especially on how to take care of HIV positive children while avoiding infection.

Basic Schools

Basic school teachers are not at all informed and the lively discussions which characterised other sessions were absent. The problem stemmed from a huge knowledge gap:

“Can you get it from mosquitoes?”

Attitudes were expressed verbally and in a body language which suggested that some attention must be paid to what for many children, is the first level of entry to the school system. The teachers did not live in the area and did not know the community. They appeared to be disturbed over questions and issues that they were forced to consider for the first time:

‘This makes me think ...that they (the children) need to get check ups. I could have one and don’t know.’

They were not prepared to teach infected children and they gave no response when asked whether they were unprepared in the sense that they were unwilling or lacked the knowledge. It was clear, however, that they needed very basic information on transmission – assurance that mosquitoes are not vectors and that the virus cannot be absorbed through unbroken skin, for example.

Rural Parish

Group sessions were held with teachers in one Primary and one High School outside the KMA. The groups comprised ten teachers each and, in the High School the teachers were drawn from a range of subject areas – English Language, Literature, Drama, Home Economics, French, Spanish and the sciences. In both schools the Guidance Counsellors were included.

Teachers’ Fears

Teachers had very strongly held ideas which they did not hesitate to express and at times it required a tremendous effort on the part of the Moderator to keep the discussion on track. The attitude in both schools to the disease was essentially the same but some of the strongest views were expressed by teachers in the secondary system. For the most part, they were unwilling to share space with affected children:

‘I believe that Cuba has set a good precedent. We should build a large compound, nice and spacious with cute little cottages, and once they have it, they must go there.’

‘...it may not be fair, but a compound would be a loving environment where there would be people around who understand what it is like to have the disease. Almost like group counselling.’

“Quarantine! We can’t allow sympathy to override an issue like this...”

‘And let us not be like the Americans who say, well, they have rights so we must **embrace them...It is a burden that they have to walk about** with the hope that nobody finds out. If they are quarantined they will be with people who they can relate to. This is absolutely the best thing you can do for them.’

‘Mental retards are separated. So what is the difference!’

‘We should have a place where these people can go...They would be considered heroes.’

The teachers were fearful for themselves, for the children in their charge and concerned about the effects of negative attitudes on the infected children. In the session in the high school there was frequent reference to the uniqueness of the disease. Even for a dreaded disease such as cancer, there was some hope for a cure, they said, but not for HIV/AIDS and since they were all sexually active, they were all at risk.

‘I am so afraid that I would not go for a test’.

‘Even the doctors are afraid. Some of them don’t want to take blood.’

They were not simply afraid of the ravages of the disease. Heap and Simpson (2004) comment on the capacity of the epidemic to create metaphors of a society’s ‘dis-ease’ with itself. Its early association with homosexuals in an homophobic society has created a situation in which men felt the need to distance themselves from the affected and in which the diagnosis of HIV/AIDS raised questions about sexual preferences. In this context also, a clear distinction was made between cancer which, like AIDS had the potential to cause loss of life and HIV/AIDS which stigmatised.

‘When someone has it, the first question you hear is, how did you get it? If it is cancer, we do not ask that.’

‘When a man has AIDS...most people feel that he was involved in some homosexual activity.’

HIV/AIDS therefore, provoked a type of irrational fear to the extent, they said, that an affected person standing nearby compromised their manhood. ‘That is the fear.’

They also expressed concern for the safety of the unaffected children and they introduced one aspect that was not discussed in the focus groups in the KMA and that was, the problems of

controlling sexual activity in the school. The primary school teachers said that they had to keep a careful watch on the children in grades 4 and 5 and this observation sparked an interesting debate over the need to know who is infected, an issue that was also keenly debated in the high school. Is the teacher who knows in a better position to protect the student who may not know? What does a teacher do if he sees a student known to be infected 'checking' a girl who doesn't know? Can they trust the infected to be careful or to reveal his status to a partner? Wouldn't everyone be safer if there is full disclosure? There was some anxiety here also for the infected child in an unaccepting school environment.

The teachers were anxious to avoid giving the impression that they were heartless and uncaring. They cared but:

'We are just afraid. When we watch these programmes we cry. But we still will not go and shake the hands of someone with it...'

'It is like being beside a man-eating lion and somebody telling you it won't eat you.'

Schooling the Infected

The overwhelming majority believed that the children deserved an education but that they should not be taught with the healthy. They suggested home schooling. A few found themselves in position in which they were uncomfortable with both inclusion and exclusion if only because only those known to be infected would be excluded. One primary school teacher initially recommended segregation but confessed that during the discussion she had become increasingly uncomfortable with that view. If there were a code regulating the kind of physical contact that could take place between teachers and students, she said, then both infected and healthy could be treated in the same way. Her problem was that she wanted no physical contact with the affected but did not want them to feel that they were being treated differently. Two teachers said that they would accept infected children into the school without reservation. Those who recommended home schooling said that their attitude would be the same if their children were infected. Their presence in school would put others at risk and the stigmatization would be bad for their psychological health. But one teacher could not see the point of home schooling when the children did not have long to live anyway.

When asked for their reaction, as parents if one of their children's class mates was known to have the infection, they said that they would request immediate transfer for their children. Further, there would be a mass exodus from the schools should parents learn of the presence of an infected child. However, in both types of schools the attitude of the teachers to the possibility of having to work with an infected peer or to have an infected teacher teach their children was markedly different. A majority could see no problem and felt that it would be important to give that teacher their full support. Only a few were ambivalent. That difference was explained by the fact that they saw teachers as responsible adults who, knowing that they were infected would take the necessary precautions. They had no objections to eating or sharing a bathroom with them. Those who were ambivalent related tales of vindictiveness and deliberate attempts to spread the infection. One high school

teacher, however, accused his fellow participants of hypocrisy. He reminded them of the teacher who was suspected of having AIDS and had died during the previous year.

‘...there is a bed that he used to rest on and nobody will go near it.’

Participants were asked whether more information and education would allay their fears. Most of the teachers felt that they had enough information on the subject but there was a great deal of scepticism among Primary school teachers about the reliability of the information that they received. They were careful to explain that in saying that they did not trust the information received from the Ministry of Health, they were not criticizing the Ministry but making a statement about medical knowledge. HIV/AIDS was first presented to them as a ‘gay’ disease. Today, it is affecting heterosexuals. They feared that in time they may be told that they could ‘get it through their pores.’

If formal education gave an advantage then the level of accommodation should have been highest in the High School where most of the teachers had University Degrees. Instead, the views of a segment of this group were among the most intransigent. There was one instance in which information seemed to have made a difference. One of the Guidance Counsellors at the High School felt that she had to make a deliberate effort to overcome her prejudiced if she were to perform efficiently:

‘As a Guidance Counselor, I had to do reading on HIV/AIDS and its management....This research was also influenced by an experience I had when I was hugged by someone with the disease and I itched for months. I said to myself that it cannot be like this. I need to be able to reach a point where I can counsel somebody with it. So, I had to read.’

She did not say whether she had overcome her fears but she was able to counsel.

Putting a human face on HIV/AIDS

What seemed to have made a real difference is contact with people with HIV/AIDS. Those teachers who had met persons with HIV/AIDS held the more liberal views.

‘I met someone with AIDS....He came to a function to give a talk and when he finished, he said that he had the disease. I hugged him, and in my mind I was worried because he was sweating a lot. Overcoming that fear has helped me because the main problem is fear.’

‘I have had the opportunity to share with people who are living with AIDS. Some have died....With drugs they are living longer. They want to be loved just like everybody else.’

This is what accounts for the marked difference between the attitudes of the Primary School teachers in the high prevalence area in the KMA and their more highly educated counterparts in the High School. They had survived contact.

CONCLUSIONS AND RECOMMENDATIONS

With medication children with HIV/AIDS will live longer and must be given tools to lead a productive life. They should be educated alongside healthy children. But the challenges to the instilling of non-discriminatory attitudes as outlined in the National Policy are tremendous. To avoid stigmatisation and discrimination, many parents opt for non-disclosure. They hide their status and that of their children. They hide their status from their children and the children's HIV status from the infected and affected children.

Disclosing a diagnosis is not an easy task and parents need emotional support. They do not feel that they could trust members of their own family, the institution that traditionally was relied on to perform this function. Therefore they are cut off from the most important sources of social support. Some of the children in the study were teenagers and secrecy becomes increasingly difficult as children age. Although there can be no set rules as to what age a child should be told of his or a parent's status, the study has shown that there are risks associated with continuing secrecy. Disclosure is necessary if only for long term planning and to increase the likelihood of success of the plans.

Some are not given the choice between disclosing and not disclosing. The death of parents will increase the number of affected orphans in care and these children will have to enter the school system. While legal protection must form an essential component of a country's response to discrimination and stigma, discrimination can and does occur in spite of protective legislation. Efforts must be made to create more positive attitudes to those affected by the disease and ultimately, the goal must be the creation of a safe, informed, caring school environment. This is still a distant goal. This study suggests that putting a human face on HIV/AIDS can dispel misinformation and generate empathy. Those in the study who reported contact with people with HIV/AIDS had more favourable attitudes and no objections to interacting with them in a classroom situation. Opportunities must be created in which the public can interact either directly or vicariously with the affected. Experience elsewhere has shown that this can reduce stigma and prejudice (Brown *et al.*, 2003).

But stigma is double edged. Children living with HIV/AIDS must cope with being stigmatized by the community. They must also learn to overcome the shame felt in response to the reaction of others to their plight or the self stigma. There is a loss of confidence and esteem and a tendency to separate themselves from society, reinforcing their social exclusion. The affected children also can benefit if more adults living with AIDS become involved in the public education programme; if they are exposed to the diversity of the epidemic. Beyond this a special attempt must be made to develop intervention programmes to deal with self stigma among children with HIV.

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