

01/12/1997

## Orphans in a world with AIDS

Sharon A. Bong

IT is politically insensitive to use the label "innocent AIDS victims" because it reinforces the stigmatisation of persons both infected and affected by HIV/AIDS - the biased implication being that the guilty minority deserve to be infected and die.

But in this instance, I have to differ. Amid the overwhelming HIV/AIDS pandemic, countless are victimised.

I have in particular the young in mind - babies and children below 18 years of age. It is precisely because facts are cold and statistics, faceless, that these children remain ignored, despised and further abused. And they represent our future.

However, four children from that invisible mass have identities. For they have been orphaned by AIDS. Their father passed away this year, three years after the demise of the children's mother whom he had infected. He was 37 and she 26.

Vijay, 13, Siva, 12, Mala, 11 and Kumari, 6 (not their real names) were understandably guarded to the point of being defensive. I decided for the moment not to broach their prolonged anguish of losing one parent soon after the other. Their maternal grandmother, whom they affectionately call Kupu, had assumed both the burden and privilege of nurturing them.

Instead, the children shared their daily preoccupations, detailing activities from dawn to dusk. Kupu is the first to rise and the last to retire, typical of primary care-givers in most families. The children predictably take her for granted. She cooks and cleans for them, and disciplines them because she loves them.

They are not encouraged to lepak after school as they are still impressionable. Even Kupu is unable to maintain peace when these siblings are at war with each other.

"At four, I study as I am afraid that my uncle would beat me," admits Vijay who will be in Form One next year. This uncle, their late mother's younger brother, financially supports them. He stretches his income of approximately RM700 a month to feed and clothe his nephews and nieces. But his job as a lorry driver is sporadic, thus an insecure one.

At his sister's deathbed, he promised her that he would not get married until her children were self-sufficient. At this point, Kupu breaks down at the memory of her loving daughter who, at 16, had eloped with her "husband" and had suffered his violence, amid five pregnancies.

The eldest boy, aged 14, who is mentally retarded, was placed in a welfare home by his father to alleviate the social-economic pressures of bringing up these children.

Home in its physical form is a zinc-roof house with wooden walls, well-kept but susceptible to flooding during thunderstorms. Kupu and her brood remain indebted to their kind neighbour who had sold them the land (albeit illegally). The children rarely watch television. That luxury is reserved for their uncle. But Kumari, the youngest, spends her days dancing to music from the radio.

"Saya sayang semua. Itu sudah biasa (I love them all. I'm used to it)," Kupu remarks as she looks indulgently at the children who were, at this point, to my relief, less reticent and more playful.

The daily struggle of this extended family in making ends meet, in preserving their fragile unity and threatened existence, is shrouded in a haze of figures.

UNAIDS, the Joint United Nations Programme in HIV/AIDS, reports that by the end of 1997, a million children under the age of 15 are expected to be living with HIV, over 90 per cent of them in developing countries.

The United States Census Bureau estimates that by the year 2010, if the spread of HIV is not contained, AIDS may increase infant mortality by as much as 75 per cent and mortality in children under five by more than 100 per cent in those regions most affected by the disease.

Have we in Malaysia an HIV/AIDS epidemic?

According to the Malaysian AIDS Council (MAC), reported HIV and AIDS cases from 1985 to September 1997 total 22,899 and 1,236 respectively. HIV-infected children below 13 years number 77 (0.3 per cent), whilst those aged between 13 and 19, 436 (1.9 per cent).

Correspondingly, children with AIDS aged below 13 and those between ages 13 and 19, account for 20 (1.6 per cent) and 4 (0.3 per cent) respectively. As such, there have been 16 deaths of children aged below 13 (1.6 per cent) and of those aged between 13 and 19, four deaths (0.4 per cent).

These grim statistics seemingly suggest that children with HIV/AIDS are adequately monitored. Absent are parallel epidemiology of children affected by HIV/AIDS (those orphaned for instance) and children living in the shadow of HIV risk (through sexual abuse, sex trade, consensual sex with peers, drug use, displacement and detention).

All is not well with us, both globally and locally. It is time to dispense with a holier-than-thou attitude that deems Malaysians as insulated from the above social malaise that plagues our Asian neighbours.

MAC president and chairperson of the Malaysian AIDS Foundation Marina Mahathir concurs that "there is no support for children per se, aside from concentrating on the 46 cases of HIV infected babies. We are not thinking of affected children, those living and coping with parents with HIV/AIDS, as deeply as we should.

"We, particularly the relevant ministries, are obviously not ready for children orphaned by AIDS, who by virtue of the stigma, are already disadvantaged."

Public sensitisation to their plight (and that of other affected children), is tortuously slow but critical. For Kupu and her grandchildren, their coping mechanisms are aided by Hospice Cahaya, the palliative caring arm of MAC. The hospice is in the process of drafting a funding proposal to MAC, as well as procuring financial relief through the SOCSO and EPF savings of the children's late father.

The children are subject to social exclusion. Prasanna Mohandas of the hospice relates to us a barber's refusal to give Vijay and Siva a hair-cut for fear of being infected with HIV, where such a risk is minimal even if the boys were HIV-positive.

Clearly, such discrimination is misinformed and compounded by fear, ignorance and prejudice. "There is so much conspiracy of silence (that cripples)," asserts Barbara Yen, medical social worker with University Hospital.

"Infected parents are so fearful that they cut off links with available social support systems, thus depriving themselves of such resources. In fact, these parents become so protective of their children that their fears (of being identified thus stigmatised by friends and strangers) are passed on to the latter.

Orphanages should remain the final resort for them, states UNAIDS, can be culturally inappropriate, can serve as a "magnet for stigmatisation" and inadvertently become a form of institutionalised care which thrives on dependency.

The following 1997 World AIDS Campaign objectives by the Joint United

Nations Programme on HIV/AIDS (UNAIDS) aim to empower children, their families and their communities:

- \* better understanding of the magnitude and diversity of the impact of HIV/AIDS;

- \* stronger commitment, improved policies and increased action for preventing HIV infection and minimising the epidemic's impact;

- \* increased and improved access to quality education and relevant information on the prevention and care of HIV/AIDS; and

- \* greater understanding of the interaction between children's rights, human rights and HIV/AIDS;

These well-meaning resolutions tend to numb the more cynical among us who have become disillusioned with the disparity between rhetoric and committed action.

Vijay, Siva, Mala and Kumari believe they have a future for they collectively aspire to become policemen and doctors. For their sakes and countless other infected and affected children, responsible living, a compassionate heart and courage in confronting our fears and ignorance are valid starting points.

(END)