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Unshackling our mindsets

Sharon A. Bong

"I AM a person with AIDS and this is my story."

Maznan with his sons, Zainal and Zainon (not their real names), aged seven and nine respectively, poignantly recounts how they were systematically ostracised by their community in a northern State. And then relocated through the intervention of the Malaysian AIDS Council (MAC) at Rumah Pengasih, a therapeutic rehabilitation programme.

"I discovered I was infected seven years ago when I donated blood. Immediately upon confirmation (through blood tests), I brought my wife and sons to be tested for HIV. My wife and younger son tested HIV positive. I had infected them.

"A year and three months ago, my wife died. I was by her side. Since then, my sons and I have been homeless. Renting rooms didn't work out as landlords eventually found out about my condition.

"I lost my job as a staff member of a hospital. I tried all means to earn a living. I was a security guard for a primary school but was fired by the PIBG (parent-teacher association). Washing cars and being a pump attendant didn't work out too.

"Coming from a small town, people gossip to the extent that we were not even served food at stalls. As a final resort, we sought refuge at the masjid.

"I had hoped that those who came to pray would be sympathetic. But no one bothered to give us any donation, or enquire about our welfare. Not even when my sons fell ill as a result of having to sleep in the rain.

"I pleaded with the State's Welfare Department to provide alternative shelter and other provisions. I couldn't bear it any longer at the masjid." (He breaks down at this point.) "There were too many lies being spread about us. The villagers even resorted to spraying us with insecticides, treating us like vermin.

"Once when I sought treatment at the hospital, a matron pasted a notice over my bed to announce to passers-by that I was HIV positive. I was so ashamed. I was thankful to a doctor who removed it.

"I tried many times but unsuccessfully to see the Menteri Besar to tell him of our suffering. I do not doubt his leadership. But those at the bottom ranks treated us badly. We were not allowed an audience with him.

"I thank God every day that my sons and I are at Rumah Pengasih. The doctors here take the trouble to explain the nature of our infection to us. Previously, my sons could not understand why other children treated them so badly. We finally feel accepted and have made friends."

Maznan's coping strategy in the face of such alienation has been an unflagging devotion to God. That has preserved his sanity in the face of tribulations which he accepts as God's will. His commitment to his sons is his reason to endure and persevere.

Haji Mohd Yunus Pathi Mohd, the director of Rumah Pengasih, MAC's representative in "rescuing" Maznan and his sons, admonishes purportedly religious people who have behaved reprehensibly by being judgmental, thus irresponsible and callous.

"God is compassionate and does not impose suffering for the hell of it. Human beings do not have the right to be doubly cruel. For affliction is punishment enough and the afflicted have been purified," professes Datin Paduka Marina Mahathir, president of MAC and chairperson of the Malaysian AIDS Foundation.

She stresses the urgent need for preventive, not merely curative measures. The relocation of Maznan and his sons was necessitated by the inhumane living conditions they were subjected to. It was much more expedient to physically transport them to Rumah Pengasih (Jalan Syers, Kuala Lumpur), than to re-educate their community of abusers, she explained.

Such interventive strategies however justifiable, may unwittingly perpetuate the vicious cycle of ignorance and damnation, which translates into a kind of "ethnic cleansing". For those, whom these issues remain an abstraction, would rather purge PWH/A (persons with HIV and AIDS) from their midst and consciences.

"Value every life, honour every death" is this year's theme for the 14th International AIDS Memorial Day (IAMD) to be celebrated on May 4. The concerted efforts of activists such as the Malaysian AIDS Council in sensitising bigoted members of the Malaysian public against PWH/A is unavoidably, a tireless one.

From the first HIV case detected in 1986, there is to date a total of 19,019 PWH/A. And 498 infected people have since died.

Publicity campaigns include a three-day awareness and mobilisation programme at Central Market in Kuala Lumpur today, an AIDS Film Festival to be screened at the British Council (May 2 and 3) and an exhibition of art therapy work by PWH/A at Galeriwan in Bangsar, Kuala Lumpur (May 3-10).

The highlight is the International AIDS Memorial Night 1997 Concert at Dataran Merdeka (May 4), to be commemorated by Culture, Arts and Tourism Minister Datuk Sabbaruddin Chik. All events are open to the public. Admission is free.

Parallel efforts are the 1997 AIDS Memorial and Mobilisation Day at Ipoh Town Hall (May 4) by Health Minister Datuk Chua Jui Meng and a nationwide campaign to counsel doctors on the impartial and sensitive treatment of PWH/A to be launched by the Malaysian Medical Association (MMA).

The initiative to be pro-active, in shedding one's stigmatisation of PWH/A, should be the collective responsibility of all. Neither should one fall into the other extreme of romanticising their plight.

My lasting impressions of the above encounter is that of Maznan's fortitude in sharing his story in spite of his vulnerability to public exposure, hostility and repulsion. And the maturity of Zainon for whom religion is a favourite subject in school despite the sanctimonious attitudes of their previous community, particularly their extended family who were first to reject them.

Especially heart-rending is young Zainal's ambition to be a policeman when he grows up.

Let us unshackle our mindsets from fear and hatred of those whose suffering should move us to compassion and strength, inspire us to hope.

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