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People with AIDS tell their stories

Reviewed by Sarah Sabaratnam

HIDDEN VOICES

True Malaysian Experiences of AIDS

Edited by Marina Mahathir and Wan Zawawi Ibrahim

(Malaysian AIDS Council, 158 pages)

PEOPLE living with HIV or AIDS (PLWHA) are the best to show us how to care for them. But few of us have the benefit of encountering them. Which is why Hidden Voices - True Malaysian Experiences of AIDS is a useful and enlightening book.

It enables PLWHAs to speak up, with "no interpretation and no sacrifice to their privacy". It also focuses on care-givers and allows us a peek into their hearts and minds.

Most of its stories are tragic and upsetting. Like Nadia's. She was raped by her husband's drug-addict friends, and her letter, the first featured in the book, is full of thoughts of regret and death.

You come away thinking the situation is totally hopeless, but in the next chapter you feel her strength through her poem and her desire to go on so that she can help others of similar fate.

Benjamin, an ex-drug addict, writes of how he lived after learning he was HIV positive:

"The only bed I had was made of cement, my mattress was a piece of cardboard. I don't know how to tell you how I lived. I let go of all responsibility for being a human being; I didn't bathe, I didn't brush my teeth, I didn't care. I had a little corner, just beside a staircase, and there was a garbage chute where all the people in the flats threw down their rubbish. I slept just beside that dump."

Benjamin's story is one of the more personalised, insightful and descriptive ones here.

Mak Som tells how she is coping with the fact that her eldest son, formerly a drug addict, is HIV positive. Kartini, the senior manager of Pink Triangle, relates her experience of caring for young Basariah, from the time the latter was undergoing treatment for TB to her last breath. Basariah used to be a sex worker and drug user.

Hidden Voices is touching, timely and necessary. However, it does not measure up to Wise Before Their Time, edited by Ann Richardson and Dietmar Bolle, the first ever compilation of PLWHA voices from all over the world.

One weakness in Hidden Voices is that some of the voices are not guided or focused. As you read through the stories, you have many questions, but they are not answered, or are answered very late in the text.

For instance, Linda talks about her health, her confusion and her trauma, and how she found strength in God.

You keep asking: How did she get it? What were her initial thoughts when she found out? Who did she tell?

Linda mentions that she was a nurse when she discovered her affliction. You wonder: Did she get the virus accidentally, while working as a nurse? The answers are not forthcoming.

In the next chapter, where her sister Rose speaks, you deduce that perhaps Linda was infected by her husband. But Rose is merely speculative: "I know my sister very well. I am not taking sides, but I know she would have got it from her husband and not from somebody else."

Wise Before Their Time compiles brief autobiographies of delegates who attended the Fifth International Conference for People with HIV and AIDS,

held from September 11-15, 1991.

One of the strengths of this book is that its voices are not presented as those of "victims". Instead, they speak of the joys of life, the values to which they have been drawn, and how their lives and perspectives have changed since infection.

The preface has a short introduction on HIV/AIDS. The stories are international in scope, with voices coming from India, Sweden, Mexico and further.

They tell of people from diverse backgrounds - homosexuals, ordinary folk, even a child infected by her mother, who acquired the virus from her husband.

This variety is not found in *Hidden Voices*, which focuses very much on those who have been involved, in one way or another, with Pink Triangle or Positive Living. Most of them were either former sex workers and addicts, or their relatives.

In *Wise Before Their Time*, interviews complement and expand on what participants have written. This gives focus and sequence to the accounts. Each chapter has a specific theme. Chapter 2, for example, has 13 individuals relating how they felt when they discovered they were HIV positive, the first persons they told the fact to, and how those people reacted.

Chapter 3 describes the day-to-day experience of living with HIV; the following chapter follows complex relationships with partners, parents, children and friends.

The first chapter has four complete stories, each different from the other, yet similar in many ways. Prejudice, fears, determination and relationships are recurring themes. Because the stories are thematic, you get a clear idea of what it means to live with HIV/AIDS.

The book shows the determination of PLWHAs. "I've spent my life breaking out of closets and I'm not about to be shut up into another closet called HIV." It explores the difficulty of breaking the news: "One effect of telling people is that relationships can change."

PLWHAs talk about how they don't want to be treated. "Often, they treat me as a child, 'Oh, poor Monika.' I don't want to be treated like that." And how they have changed: "I think my life has gained much more depth. I have changed from being closed to wanting to be open or be opening ... Just having the opportunity to look at things I would never have looked at in a different life, I don't know ... it's like a chance or a challenge. But it's hard work."

Some of the stories, like Daisy's, are so personal and vivid that you cry and cry. Daisy died when she was 21 months old, nine months after being diagnosed. Her story is related by her mother.

Unfortunately, *Wise Before Their Time* is out of print, according to Amazon.com. *Hidden Voices* is the closest, vital alternative.

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