Chapter Six

'She Died with Dignity after Teaching us what Humanity is All About'

'She died after passing her HIV to her husband.' This is an often-repeated sentence in Zimbabwe. The echoes can be heard in homes in workplaces and in graveyards, at times shrill, at times in a hushed whisper. The tone, though, is always accusatory.

The corollary to this statement, i.e. 'He died after passing HIV to his wife', is seldom heard, perhaps only in low whispers in support groups of women living with HIV/AIDS. I assumed the reason for this state of affairs lay in the fact that since time immemorial women have been blamed for the spread of STDs. The literature of the early 1990s pointed towards this analysis. Among certain groups in Thailand and Uganda, STDs were known as women's diseases. In Swahili, the word for STDs literally means 'disease of women'. Essays on HIV/AIDS written by Ugandan school children showed how deep the prejudice was rooted. In their writings, as early as 1992–93, 40 youngsters expressed the opinion that women were mainly responsible for spreading HIV, while only three named men. These views were held by girls as well as boys, highlighting the tendency of the 'victims' of prejudice to accept its assumption as natural.

In particular, female sex workers had almost universally been characterised as 'vectors' of the disease, a description that completely ignored the role played by the customer. In the USA, in the early stages of the epidemic, many men diagnosed with HIV blamed their infection on a female sex worker. Only when interviewed at length did they admit to injecting drugs or having sex with men. The harsh judgement extended even to women who were sick and dying. 'If you have AIDS, the society rejects you. When you die you will not even be missed because you have died of a shameful disease', a married woman in Zaire told researchers. 'They will not see that maybe she remained faithful while her husband has strayed.' Given the status of women in most societies, AIDS is doubly stigmatising for most women.

Women in the forefront

As I read the report on the community-based research undertaken by a team of researchers in Zimbabwe the sentence 'She died after passing her HIV to her husband' stood out as a disturbing paradox. Why is the death of a woman being echoed so much in a society where more men are dying because of HIV/AIDS? The study carried out amongst 412 respondents recorded that 109 had lost their spouses. Of these 101 (92.7 per cent) were women compared to 8 (7.3 per cent) who were men. And just five pages further into the report I found an answer to my query. Though more men were dying of the epidemic in Zimbabwe, it was the women who were at the forefront. The caregivers interviewed during the research noted that to enable a change of attitude of the community, a number of people living with HIV/AIDS were disclosing their status – a majority of these were women. Women accepted their HIV status and tried to ensure that the community knew. Men, however, preferred to die in silence. This courageous approach manifested itself in the composition of the support groups of people living with HIV/AIDS, where there were more women as compared to men. Women were in the forefront everywhere. A large

majority of the participants in income-generating projects for families affected by HIV/AIDS were also women.

Caring in the face of adversity

The profile of community caregivers also gave the epidemic a female face. As hospital infrastructure was proving to be inadequate and family institutions, both nuclear and extended, were burning out with the burden of disease and sickness, groups of caregivers from the community were springing up to respond to the needs of the hour. These caregiver groups were composed of the women of the community, young girls taken out of school to look after patients and some young boys too! With little or no resources available from the city council for the execution of their duties, these groups were improvising and responding on a day-to-day basis. In the absence of gloves and face masks, they were making do with empty plastic sugar packets. With no linen or soap available from the local government, they were straining their own household budgets to cope with the demands of the disease. From morning till evening they were bathing, feeding, cheering the sick, doing their laundry, talking about death to the children, helping in writing wills, and all this with no monetary remuneration whatsoever!

Wilson, living in the Insiza district of Zimbabwe, had been a charmer, a flirt. But then AIDS dulled his sparkle and confined him to his bed. That was when Sibongile Ndlovu increased her visits to his home, coming every day with food and caring for his bed sores. 'The whole skin on his side was coming off', she says 'and it filled his hut with a smell of sickness'. She persuaded the clinic to give her medicine and she rubbed the ointment on his raw bedsores every day for two months until he died. Four years have passed, but despite that ordeal Ndlovu is still caring for patients. How many has she assisted? 'Forty-two', she says, checking a tattered ledger with hand-written notes. How many have died? 'Sixteen.'

With little training in home-based care, these caregivers were in fact

working in 'high-risk environments', with little to protect themselves against infection. And yet when asked what they would prefer, given a choice – to continue caring for the person living with HIV/AIDS in the homes or to put them in institutions – the caregivers immediately responded that they preferred to take care of the patient in his/her home. This, they said, was because the HIV/AIDS patients were not receiving enough care in the hospitals.

Dr. Lulu Muhe, heading a paediatric section of a hospital in Africa, provided a stark description of the conditions in the hospitals. Working in a ward full of children living with HIV/AIDS, Dr. Muhe had his hands in the air. 'Shortage of gloves and disposable syringes? We don't even have enough new razor blades to shave the heads of children before setting up a drip. I don't think people have any conception of the conditions we are working under. We have to perform lumbar punctures and blood transfusions without gloves. And to top the shortages there is the workload, which is ever increasing. We get tired and then we get careless.' The laboratories lack the necessary equipment, reagents and skills to make effective diagnoses. Without proper diagnosis treatment becomes difficult and sickness is prolonged. For instance, 'we often don't know exactly what is causing the patient's diarrhoea'. The implications of this state of affairs for the women caregivers are enormous. In personal interviews, women have informed us that if the HIV/AIDS patient has diarrhoea, which is a common symptom, they need 23 buckets of water per day to keep him/her clean. Time-use studies have shown that on average a woman requires 45 minutes to fetch two buckets of water in the rural areas of Asia and Africa. Despite all these conditions, committed caregivers, in institutions or out of them, were doing all they could to relieve suffering and safeguard human dignity.

And as I read the report, my eyes blurred. I stood up in salutation and began to wonder once again – what is it that makes a woman? Courage and steadfastness, compassion and love, innovation, perseverance – the list could go on.

Will traditional structures revive?

It was interesting to note from the report that there are a number of traditional support structures that are now being revived to help communities cope with the epidemic. The 'Zun de Ramambo/Isiphala Senkosi' was cited as one of the practices which had died out but was being revived in some areas. According to this practice, the chief of a village or a tribe donated a piece of land for communal use. Villagers took turns to work on that piece of land. The produce was distributed to the destitute and the needy of the village. This practice, which had died with colonisation and the introduction of social welfare, was now being revived in some provinces of Zimbabwe such as Chirumangu and Tshelanyemba. The threads of revival of such a valuable practice are, however, still quite weak. A prerequisite to the successful implementation of this practice is a healthy work force, able to produce for the sick, the elderly and the orphaned. But the work force is in fact being depleted. As an indicative window on the situation in Zimbabwe, the respondents offered a dismal picture. 'More husbands run away from their homes in order to avoid the burden of care giving to the family. Male spouses are known to come back when the partner is showing signs of recovery. On the other hand, if he falls sick when he is away, he comes back for care to his wife and remains there until he dies.'

This situation was creating a 'negative income shock', as the researchers put it, in the Zimbabwean community. Negative income shock indicated such low levels of income reached by a household in a short span of time that they were left in a state of shock and helplessness. Of the 268 respondents who were experiencing this shock, 208 (77.6 per cent) were women. The major causes of the income shock were cited as HIV-related illness by 28 per cent of the respondents, death in the family by 23 per cent and inflation by 20 per cent or the respondents. Other causes of this income shock, quoted by a small percentage of the study participants, included unemployment and income loss through care

giving. If this was happening at the level of the household, the challenge that was arising was how could this be reduced or alleviated by the introduction of suitable measures at the macroeconomic level. In Zimbabwe the picture at the macro level was also very bleak and dismal. The plight of the households was in fact a reflection of the situation at the macro level.

Zimbabwe is one of the southern African countries that is severely affected by the HIV/AIDS epidemic, with a national adult prevalence rate of 25 per cent. The epidemic has already reversed hard won national health gains and continues to threaten the key development indicators of per capita income, life expectancy and literacy. Zimbabwe's economy today records a low economic growth rate of 2 per cent, a high double-digit inflation of 50 per cent and low capital access with interest rates as high as 45 per cent. A high unemployment rate of 40 per cent is therefore a natural consequence. With 250 people dying every day due to HIV/AIDS, life expectancy is hitting a low. Without HIV/AIDS, the average life expectancy in Africa in the year 2000 would have been 62 years. Instead it has fallen to 47 years. The combination of a deteriorating economic base and the onslaught of the AIDS epidemic has promoted a sharp increase in chronic poverty, that is increasingly becoming feminised.

Zimbabwe offers useful insights for countries on the threshold of the AIDS epidemic. Every indicator of development in this sub-Saharan nation is entangled with the mutating virus. The grip of the virus is pulling it back, away from progress, away from development, away from prosperity. By the year 2010 life expectancy in Zimbabwe will be less by 25 years. The child mortality rate will have been pushed up by 150 per cent. And in spite of these pulls and entanglements, the country has made progress in reducing poverty and in achieving a Human Poverty Index (HPI) value of 25 per cent. The HPI provides an aggregate human measure of the prevalence of poverty in a community. The HPI draws attention to deprivation in three essential elements of human life, namely longevity,

knowledge and a decent standard of living. The HPI also reveals deprivation that would be masked if poverty was measured only by income. The scales and indices of the UNDP Human Development Report of 1999 clearly show how, amidst such dire threats to development, the Zimbabweans are moving up in the human poverty index. This indicates that in spite of very little capital availability by way of incomes, and 50 per cent of the population being income poor, in viewing poverty from a broader perspective of longevity, knowledge and a decent standard of living only 25 per cent of the Zimbabweans are poor.

In the light of the epidemic these rather redeeming statistics, brought out in the Human Development Report, have been made possible by the work of the caregivers, the women of Zimbabwe, who move like the angels of care, the apparitions of strength who are in fact the shock absorbers. In Zimbabwe, therefore, the sentence 'She died after passing her HIV to her husband', will no longer be meaningful. Folklore will have it that 'she died with dignity after teaching us what humanity is all about'.