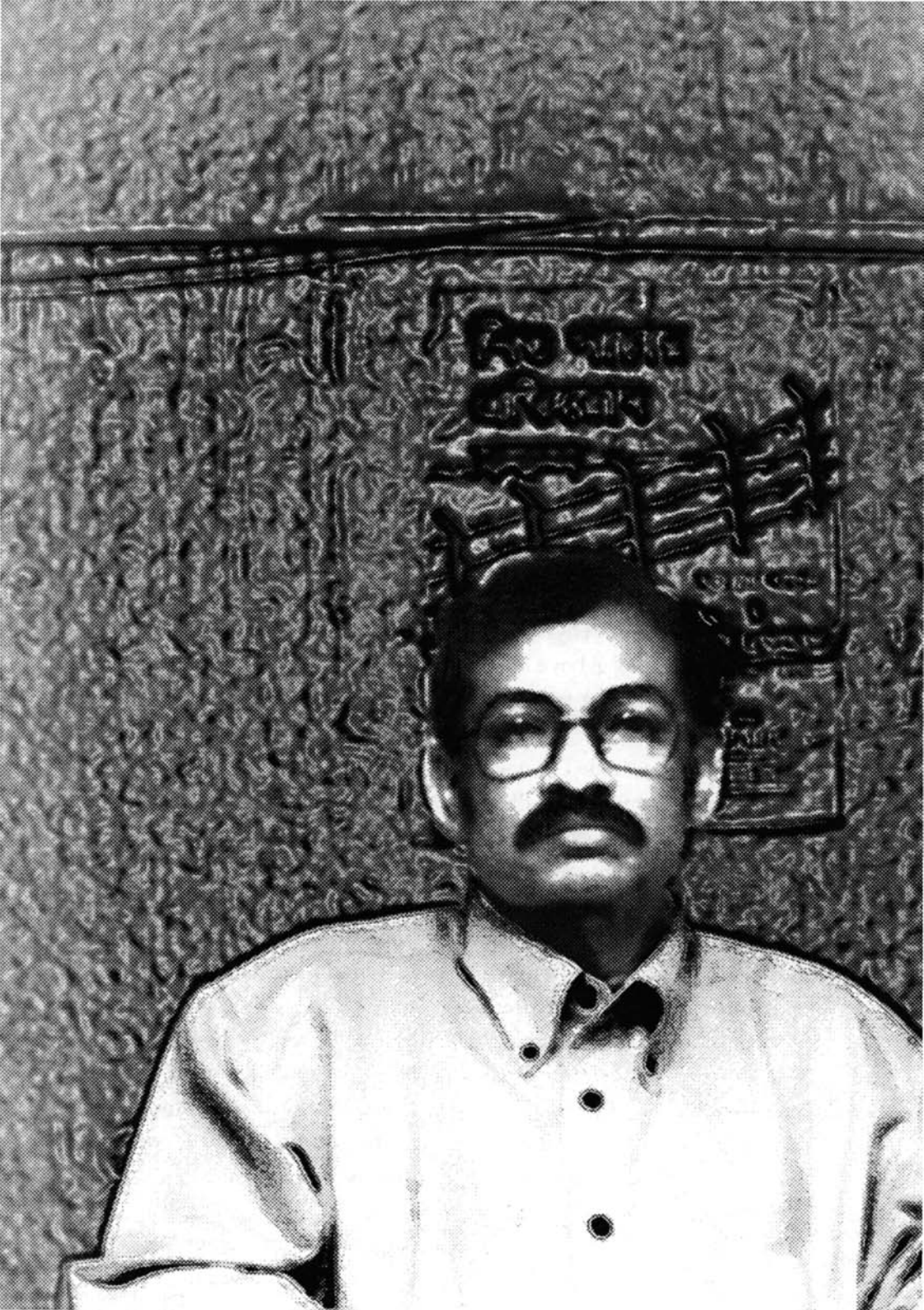

Chapter Five

'I Know I am a Woman of Worth'

I am reminded of Robert Benigni's portrayal in his Oscar winning film *Life is Beautiful.* Tough, disturbing circumstances in a concentration camp and yet life could be beautiful. That, of course, was on celluloid. The focus moves to Mexico – real life, real women and a real life threat – a virus called AIDS. The report of the community-based research entitled, 'Mexican Women and the HIV/AIDS Epidemic; the intersection of Gender, Power and HIV/AIDS in Mexico', has significantly delved into what the researchers have called 'lives of challenge and achievement'.

Life with HIV/AIDS can be beautiful. This is what work in Mexico is beginning to highlight. The results of a participatory community-based research in this Central American country have been quite revealing. Forty-six women living with HIV/AIDS were interviewed separately and in groups. With ages ranging from 22 years to 54 years, this group of positive women with positive approaches represented a range of experiences, a spectrum of perceptions and motley of feelings. Nineteen were married or living with a partner, 12 were widowed and 15 women were single or separated. All had at least 6 years of formal education, with 7 having reached university level. Most of the women interviewed described a process of growing self-value and self care in spite of their commitment to taking care of their male partners and their children.

I value my life more and I try not to expose myself to getting sick. I see my life with more caring eyes. I think life is beautiful. I take care and value myself more as a woman because I know I am going to live longer and I am well . . . I love myself more.

I know I am a woman of worth. I exercise more and try not to become depressed. I take care of my health and my son's health. He is not infected.

I know that there are no victims or guilty parties. This happened to me and I have to know how to live with dignity and quality of life. I am more careful about what I eat, I don't drink, I smoke less. When I am not depressed, that is.

I take care of myself first. Before I thought of my family first, but now I understand that if I am well, they will be too. I value myself much more. I think, now that I know I have HIV, all of us need to value our body and our feelings.

These voices seem to indicate that women are coping exceptionally well with an otherwise rather debilitating disease – debilitating socially, economically, physically and emotionally.

Changes in her emotional life

What filled me with amazement as I read and re-read these quotations was that this level of self-esteem was not common in the general population in Mexico. And I say this from empirical, not anecdotal, knowledge. A comparative survey with 211 respondents in five provinces of the country covering rural and urban population used a self-esteem index to measure this aspect. Only 27.7 per cent of the women and 45.4 per cent of the men had a high self-esteem. More women (68.6 per cent) than men (43.1 per cent) had low self-esteem.

An index to measure depression was also used, based on an instrument that had been validated and used extensively in Mexico. Over twice

as many women as men were severely depressed (28.6 per cent of women and 13.3 per cent of men). Women also had a higher proportion of moderate depression (54.5 per cent) as compared to men (38.8 per cent). In general, the conclusion reached was that a general lack of self-esteem and a depressed emotional state made negotiation of safer sexual practices much more difficult for women. This no doubt increased their vulnerability to HIV/AIDS in Mexico.

However, as we worked with a sample of women who were all infected with HIV/AIDS, the percentages of the depressed and the dejected seemed to be much lower in this sample of women who for all practical purposes were facing a much tougher set of circumstances. The women living with HIV/AIDS in Mexico, unlike the women living with the virus in some other countries, were depicting a higher level of self-esteem and confidence. As brought out in the table below, 36 out of the 46 women interviewed said that they took greater care of themselves and 14 out of the 46 women said that they valued themselves much more. Only 5 out of the 46 said that they did not take care of themselves and three out of the 46 said that they felt depressed due to rejection.

Table 1

Change	Number
Takes care of herself more	36
Values herself more	14
Values life more	5
Is careful to prevent infection of others	5
Takes care of herself less	5
Becomes depressed due to rejection	3
Has difficulty finding a partner	3
Has lost independence or become isolated	2

The question, therefore, that kept arising was how was it that Mexican women were displaying an increased level of self-esteem once they were diagnosed as HIV-positive?

Compassion by the community

The answers surfaced as we delved into the rich body of information that this participatory research provided. Whereas rejection and prejudice towards people living with HIV/AIDS was common, Mexico could simultaneously boast of a show of compassion and solidarity by the community towards people living with HIV/AIDS. A number of respondents in this study mentioned solidarity from family neighbours and friends. One woman described the show of solidarity she received from her neighbour. 'My neighbours all talk to me, encouraging me. They ask me if I am going to the doctor. When my husband died, since I wasn't working, they gave me milk for my son. They came over to talk; they invite me to their homes and come over for lunch to my house. They ask me to watch their kids for them. At first I was afraid they would reject me. I even thought they would chase me out of the neighbourhood, but it was exactly the opposite.' The tables below bring out the levels of rejection and social inclusion in the Mexican community towards people living with HIV/AIDS. Out of a sample of 46, 18 women had to face rejection by the community. However, what is heartening to note is that an almost equal number of people living with HIV/AIDS – about 15 in number – had also experienced a fair amount of social inclusion and solidarity in the face of the debilitating disease. This finding was different from the findings in some other countries where compassion by the community is an exception rather than a rule.

Table 2. Rejection encountered by people living with HIV/AIDS*

Offensive comments	5
None, because they don't know her diagnosis	4
Stigma related to homosexuality	3
From her partner's family (towards her)	2
From her family, towards her partner	1
Rejection by nurses	1
No one donated blood when her husband needed it	1
Someone was forced to move out of the community	1

* These included reactions the women themselves encountered, or which they observed in relation to others

Table 3. Solidarity shown towards people living with HIV/AIDS in the woman's community

From the seropositive woman's own family	4
Support from NGOs	3
Support from neighbours	2
General support and solidarity from the community	2
Existence of a home for seropositive people without their family's support	1
Recommendations by friends of which doctors to go to	1
Support from the husbands family	1
Support from affected and infected people	1

Access to counselling services

Another kind of support which was a source of resilience to women in Mexico was the availability of and access to treatment, along with counselling services. In most countries, receiving the diagnosis is the most difficult moment for the patient because it is done without providing

adequate information about the disease. Health providers have little training and skills in counselling. They are, at best, able to provide some very basic clinical information. The doctors or nurses somehow find it difficult even to hide their own prejudices relating to this epidemic. 'When I went to the hospital . . . the nurses put in the I.V. (intravenous equipment) and they said something like "I am going to take a bath right away."'

Counselling for HIV/AIDS is predicated on a number of principles and values including confidentiality, privileged communication and interpersonal relationship between the counsellor and the client. Besides, counsellors and health care providers need to be equipped with well-presented and accurate information on non-clinical issues related to HIV/AIDS, for example – how can a woman take her HIV status back to the community? Who should she tell without losing love and support? How will she be able to break an abusive relationship in order to deal with her disease in an empowered fashion?

During the data collection process, one woman described her experience: 'The diagnosis was difficult, principally because I knew that it was a fatal disease but I knew nothing about the process. But as the very sensitive doctor gave me the result he said to me, "Don't worry, not everything is lost".' People living with HIV/AIDS need to know that not everything is lost if they contract the virus.

Access to medicines

In Mexico, there is an enabling policy environment in relation to the health care of people living with HIV/AIDS. It is due to this that the governmental health services, especially the Mexican Institute of Social Security, as well as the Ministry of Health, provide the essential service of distribution of anti-retroviral medications to people living with HIV/AIDS. Over half the women interviewed during this research had access to social security services, which meant that they would have

access to the anti-retroviral treatment – an access that is still a dream for large numbers of women living in Asia, Africa and in many other countries of Latin America and the Caribbean. This access has undoubtedly increased the hope and the self-esteem of women living with HIV/AIDS in Mexico. Receiving information about managing HIV/AIDS through medication and self care, and in general the hope of living quite a while after the diagnosis, is of fundamental importance. However, at this juncture, it is necessary to point out that a matter of concern expressed by the researchers was that 13 out of the 46 women interviewed were not receiving anti-retroviral treatment of any kind. This occurred when neither the woman nor her partner were formally employed and so were not covered by social security benefits. The study has pointed out the need that access to medication for people living with HIV/AIDS needs to be de-linked from their employment status as this would otherwise enshrine economic inequalities and gender biases, leaving large masses of the population disadvantaged, especially as the epidemic progresses and matures in the country.

Thus, what is critical is to provide women with access to resources which can enable them to fight stress and depression and to procure adequate treatment so that their vulnerability is reduced. In fact, access to treatment and care where available is making the HIV infection a chronic disease that can be controlled for increasing periods of time.

'I am a woman.' 'I think life is beautiful.' These sentences continue to amaze me. The picture in my mind had been quite different. Today, my mind is filled with impressions that resurface again and again as I read the report. I remember I had heard women with HIV, not so long ago, say in one country of South Asia, 'To be alone and dying, yet to care for one's own HIV-infected child is a tragedy, the dimensions of which few of us can truly comprehend', and 'some people are imprisoned for life because they are HIV-positive'. 'As positive women, we are probably dealing with multiple losses and how difficult that can be whilst at the same time we

are coping with the possibility of our own shattered life spans.' Women in Mexico were coping much better with the epidemic.

No doubt, this conclusion that I was drawing was based on empirical averages and did hide a lot of disparities. Nevertheless, as I looked at the sample of the study, the reasons for this 'more positive positivity' were clearer. Women who participated in the study came from all income levels. The sample was taken with the intention of overcoming any biases relating to economic disparities. The sample included women from the formal sector, from the informal sector, with low incomes as well as high incomes. Over half the women had paid employment, about one-third had additional jobs (other than their primary employment) which were usually informal and part time. About one-quarter of the sample had to quit working due to some cause related to their HIV status, either because they became sick frequently or because they migrated from a rural area to a state capital to obtain better medical services. Three women lost their jobs because of discrimination but did receive a pension and medical treatment through the social security health care system.

Access to employment

Simultaneously, analysis of the sample and the results of the study also revealed that in Mexico women living with HIV/AIDS could lead lives of dignity, positivity and enrichment, even in the most disturbing and life threatening circumstances, because a number of them were gainfully employed. About 60 per cent of the respondents had paid employment and another 25–30 per cent had work in the informal sector.

It seems from the above that the key to enable women to ride the waves of the epidemic is for policy-makers and planners to ensure that women continue to be visible in the labour market. Women's economic empowerment, manifested through their work participation rate, will need to somehow be increased to enable more women to join in the crescendo – 'I am a woman of worth'.

Table 4

Situation	Number
Women with employment	27
Women with an additional job	17
Women who stopped working due to living with HIV/AIDS	12
Women who lost their jobs due to discrimination	3
Women who began to work due to reasons related to living with HIV/AIDS	6
Someone else in the family began working related to living with HIV/AIDS	3*
Someone else in the family began working related to living with HIV/AIDS	1**
Women with young children who also had access to day care (through their own employer or spouse)	Yes/ No

*Two male partners stopped working because of their own health problems, while one lost his job because of discrimination.

** The daughter of a woman who was interviewed, who was 16 years old, left school after finishing junior high school and began working to help support the family.

The task is not easy, for the macroeconomic environment that we are facing today is producing a growth of joblessness in the wake of structural adjustment policies. People living with HIV/AIDS will continue to need jobs and so policy-makers and planners will need to look again at the criteria for selection that they had hitherto outlined for income generating programmes. These will now need to somehow include the needs of people living with HIV/AIDS and one way could be to include household dependency ratios as a key element in the selection of participants for income-generating and economic empowerment programmes. In fact, learning from the experiences of our partners and neighbours and building on the lessons already generated, it becomes imperative to remind ourselves of a warning from a well-known development worker who is now a political figure from Thailand, Mr Jon Unphakorn who as early as 1993 remarked, 'The main roots of the HIV/AIDS situation in Thailand lie in

the extremely successful national development policies of the last three decades, which have focused on a rapid economic growth at the expense of all other considerations. This has brought about a widespread increase in economic and social disparities, a group of jobless citizens, a rapid depletion of natural resources and the wholesale disintegration and degradation of the rural society with its traditional qualities of economic and environmental self survivability, family and community cohesion and an in-built social welfare system.'

The ways in which we respond to the epidemic now will influence the ways in which women will participate and contribute to development in this twenty-first century. But national development will be conditional on human survival and on the survival of those who reproduce and nurture the human race. This, in fact, needs to be the primary focus of our attention today. The work in Mexico has shown us that women with HIV believe that life has to be lived and lived well, that it requires a will of steel and a resilience that makes a woman. Even when they are no more, the world will say, 'She died with dignity after teaching us what humanity is all about!'.