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# 4. Stigma and Discrimination: The Situation of People Living with HIV and their Carers

*'Recognizing that, in accordance with the Universal Declaration of Human Rights, the ideal of free human beings enjoying civil and political freedom and freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his civil and political rights, as well as his economic, social and cultural rights...'*

- Preamble: International Covenant on Civil and Political Rights

*'Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world...'*

- Preamble: Universal Declaration of Human Rights

Stigma and discrimination have haunted the response to both HIV and to AIDS since the emergence of the epidemic.<sup>1</sup> This is as true of the Commonwealth as of the rest of the world, especially in societies with weak or non-existent legal frameworks offering human rights protections and programmes that support access to justice. Jonathan Mann (1987) famously predicted three phases of the epidemic that was unfolding in the early 1990s: first the wave of HIV, then the second wave of AIDS, and third, the epidemic of stigma, discrimination and denial. Recent data from the Stigma Index confirm its persistence.<sup>2</sup>

So too do the testimonials collected for this study. Just three country examples can illustrate the trends:

## 1. Jamaica

'Initially he got along very well with individuals that live in the yard but as he got sick they started treating him badly not talking to him, scorning him, not hanging out with him as they usually did. There were times when he would try to make it to the bathroom to go use the toilet and was unable to make it because he was weak and as such he would sometimes filth on himself on his way, so there were times when I had to come home and get him from outside and

take him in. He was scorn[ed] because people knew. People started talking how is it that he is losing weight, is the batty man [homosexual] etc. It was also the fact that it would be the gay disease and is because of our nastiness so.’ - L

## 2. Papua New Guinea

‘We were in [the hospital] emergency [room] and she was very weak, she said she couldn’t hold on anymore. She said “Look after my children”. K died in the hospital. We brought her body back to the village. Only the immediate family went close to the body to mourn her but many didn’t want to touch her. Only we touched her and cried over the body. Like with her husband, people were too scared to come close. They stood around but very few came close. Some came to pay respect while most came out of curiosity. (...) During the time of caring no one came to give me or the family a helping hand. We had no support’ - Alice

‘My daughter B was living at home with me when she got sick. I took her to the Barracks clinic which is about a mile from our house. They said she had malaria and pneumonia. It was only later I heard from others that she had HIV/AIDS. I took her to the AIDS clinic. I was not scared, my heart did not fear, nor did I turn away from her. I would take her where she needed to go. Whatever she wanted me to do I would do for her if I could. Many times she would get angry and cry and feel sad and depressed that people were talking about her, the gossip really affected her. She would cry and tell me that she didn’t have this “sickness” and wonder why people were saying she had. She was scared and angry. She felt that people were just labelling her for nothing. ...No-one helped me through this difficult time. I did it alone. Our traditional ways are that we help each other out during times of sickness but for some reason this time no one came, maybe they were scared.’ - Ruth

## 3. Bangladesh

‘Today I could not do any work properly due to my HIV infection because people rebuke me or neglect me. I worked in seven to eight houses as a maidservant when I was free from HIV. I cannot do heavy work after having infection of HIV.’ - Hamida

Despite the extensive analysis of stigma – and the arguably less extensive programming that has tried to address it, as seen in the chapters on the hospital and the prison in this volume stigma appears consistently across the interviews as a starkly defining feature of living with HIV and caring for people living with HIV. The contours of stigma remain the same as they have been for a decade or more: the association of HIV with contagion and contamination that is both physical and moral in its association and identification with groups already outcast or considered second class by dominant social norms.

The preambles of the UDHR and ICCPR each remind States that recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family form the foundation of freedom, justice and peace in the world. But just as the texts of the international human rights instruments make clear State obligations, so the caregivers' testimonies attest to the omnipresent and debilitating facet of coping with a diagnosis of HIV in the absence of State protections.

Across developing countries of the Commonwealth, stigma, discrimination and the hard work of care-giving situations is exacerbated by the absence of treatment, the presence of misdiagnosis or the absence of any diagnosis at all.

Alice describes looking after her sister and brother-in-law in Papua New Guinea in terms familiar to the AIDS response since the 1980s and still the reality in many parts of the developing world where access to medicines standard in the developed world remains denied with devastating consequences:

'When we were caring for them it was so very hard. Their eyes were hollow and the eyeballs were bulging out. It was a very bad sickness. They were naturally big people and they lost so much weight, they looked like living bones. They were big people. They were not sick that long but if you looked at them they looked like they had been sick a long time. The sores made life very hard for them. Their skin was always itchy. We would try to soothe it with warm water but it didn't help very much.'

As a caregiver, the hardest things are the two most basic:

'Our hardest thing about caring is the carrying, the urination, the diarrhoea. The hardest thing was that. Another hard area in any sickness is food, trying to find food. People would see us and ask "Aren't you scared sharing food?" We would say no. The big thing was food and cleaning them. Food was a big issue and we tried hard. People who are working probably find it easier but we in the village really struggle.'

So too says Ruth, the mother looking after her dying daughter:

‘At that time I bought so many clothes from the second hand because she was soiling them and I wouldn’t have enough time to wash them and no one wanted to touch her clothes. They thought they would get sick if they touched her clothes.’

Alice takes her emaciated and dying sister to the hospital in Papua New Guinea, only to be told that it must be tuberculosis. After her sister has died, Alice takes the body home, only to be shunned by her community even in her grief:

‘We brought her body back to the village. Only the immediate family went close to the body to mourn her but many didn’t want to touch her. Only we touched her and cried over the body. Like with her husband, people were too scared to come close. They stood around but very few came close. Some came to pay respect while most came out of curiosity.’

For Ruth, caring for her daughter, the story of the misdiagnosis is almost the same:

‘My daughter was living at home with me when she got sick. I took her to the Barracks clinic which is about a mile from our house. They said she had malaria and pneumonia. It was only later I heard from others that she had HIV/AIDS. I took her to the AIDS clinic. I was not scared, my heart did not fear, nor did I turn away from her. I would take her where she needed to go.’

As her body breaks down in the absence of anti-retroviral treatment, and with the weight of stigma and gossip. Her mother tries to shield her, but it is a powerful combination:

‘Whatever she wanted me to do I would do for her if I could. Many times she would get angry and cry and feel sad and depressed that people were talking about her, the gossip really affected her. She would cry and tell me that she didn’t have this “sickness” and wonder why people were saying she had. She was scared and angry. She felt that people were just labelling her for nothing.’

AIDS gives families and communities permission to break down traditional social support systems that are generally attributed to promotion of social cohesion within communities. Ruth’s isolation from her family, community and government support is also palpable:

‘When she died I sent messages to my family to ask them to come and help me. I wanted to know whether we would prepare her for burial in one of their houses or here in our house. Nobody came. I washed her and dressed her on my own and waited, a solitary figure beside her body. I found this really hard as normally there would be the support of family during times of grief and mourning. I was asking “God you have taken her and I have nothing. Will there be someone to help me bury my child?” My other children joined me and we mourned together.’

Finally, someone from the community steps in:

‘At about 12 midnight someone came and said it was time to bring the body outside. I asked for help, for someone to help me put her body into the coffin. No one wanted to touch her. Only one lady came forward and with her help I lifted her body into the coffin. She was light, like a baby. They closed and nailed shut the lid on the coffin and carried her down to the ground. She was buried under cover of darkness. A burial shrouded by shame.’

This harsh reality is not an isolated incident they alone face, however, despite what these fragments of two Papua New Guinea women’s stories would suggest. In ending her interview for this research, Alice makes an important point. ‘There are others in the village you should talk to’, she says.

‘They have also looked after their loved one on their own. People are scared. There is no reason for this. Sicknesses, no matter what they are, are still sicknesses. When people get malaria, we look after them, when people get TB, we look after them. It is all the same. Someone is sick and we do what we can to make them better again.’

Alice knows that many others in her village have lost loved ones to AIDS in the absence of any acknowledgment of State responsibility or even accountability. The stigma gives community members permission to break social norms not once but repeatedly, undermining the social cohesion that has become the tradition for communities supporting their members in times of difficulty and grief caused by illness in the absence of any signs of social programmes. The State appears only after the fact, as noted earlier, to deliver a workshop and to debrief Ruth.

‘Where were they when she was alive? Now that she was dead, they wanted to know everything! I never found any kind of support in the way of counselling, nothing. I didn’t know where to go. Maybe the people living in the town area, the working ones know. I didn’t.’

In the end, for both women, isolation from family support is combined with their commitment to ensuring their dying sister and daughter have someone to be with them as the virus destroys their immune systems and their bodies spiral out of control. Ruth speaks for both of them when she reminds us that:

‘Normally family would be there for support. People to bring food, help care for her. This is what we do when people are sick and or dying. Why was this different? Why was I left to care for her on my own? I am not complaining, but I was angry at how my family were not there for us in our time of need.’

The personal narratives collected for this study lay bare the daily realities of the poor when AIDS enters the household as an additional

shock that catapults the family house into deeper poverty. Hamida in Bangladesh says of the time before she and her husband got sick:

‘That time I was in good position. Family was happy. I need to wake up early in the morning and prepare food for family members. Then prepare myself to go office and also taking food for lunch. After returning to residence I again prepare food for dinner and do care my child as well as other members.’

But Hamida is caring for a husband who is struggling with a drug addiction:

‘In that time he [her husband] was picking up waste paper from street and managed his drug habit by selling the papers. He could not contribute to maintain the family. I maintained the family by the income of mine and my son. Some time he gives me 40 to 50 taka from his daily income to maintain the family expense. But when he has no money to take drug for his addiction than he claims money from me and I am bound to pay him.’

HIV enters the household first through him and then her own infection, which undermines her ability to work: ‘after having infection by HIV I feel very weak’ she says. Her own physical deterioration combines with the unchecked and unredressed social stigma and discrimination. Nevertheless, the burden of care falls to her: ‘Still now I am working to maintain family’ she says. Under the combination of her own ill health, discrimination from employers, her husband’s efforts to eke out a subsistence life that mostly supports his drug addiction, the household processes begin to break down:

‘I was not able to continue my son’s education but my daughter is going to school by staying with my sister’s house. My son is working for helping the family. If I don’t work then where do we get the food. I am the only daughter of my family and always being upset by thinking what will happen to my children in absence of me. Who will take care of them and who will provide them food?’

## **Wives and husbands and children**

All the caregivers speak of their fear of who will look after their loved ones if their own bodies give in, and they labour long and hard, denying their own failing health. Alice’s sister’s story in Papua New Guinea echoes the experience of Hamida in Bangladesh – breakdown of the family and household.

‘We were living life day to day and then K’s husband got what looked like scabies on him. It spread everywhere. We took him to the doctor but by then it was like it had gone under his skin

and into his body too. We went to the skin doctor at the hospital and get medicine and cream. It didn't get better, his skin was looking worse and then his joints started to lock and he could walk properly, finally he couldn't walk at all. He was losing a lot of weight. We went to Three Mile and they admitted him at Port Moresby General Hospital. My sister looked after him and I watched the kids at home. The doctors discharged him and they came home. We returned to the village and he died here.'

After K's husband dies, K collapses:

'Once her husband died, K seemed to get weak very quickly. When looking after him she had stayed as strong as possible. I would do the heavy tasks like carrying the water for him to wash but she did the rest. She washed him, cleaned his sores and dressed him. My sister looked after her husband in the hospital while I looked after the children and when he was discharged they came here and we both cared for him. She was starting to get sick so needed help, so I helped her. I was trying to look after both of them. Only our elderly parents would come and see us, but they are old. While caring for him she got the scabies, he passed it on to her and she started getting sick. The sores were spreading ... She would tell us and we would do what we could but the sores were getting bigger.'

It is K's funeral Alice describes above. K's children are left for Alice to raise, but it was K who was the breadwinner, whose illness threw the household into a poverty from which it has not recovered, where hunger is the daily reality. K's illness lasted just three months before she died.

For Hamida, who has been looking after her husband for three years, the hardest part is her husband's on-again off-again abuse:

'After doing whole day's work I feel very pain to serve my husband at midnight. When my husband burns cigarette randomly in the whole night and drowsing that is very much painful for me. During serving my husband some time he becomes angry due to addict. I do massage my husband legs, hands, body and also wash his clothes but if anything is wrong then he becomes cruel to me. It is really painful for me.'

What makes Hamida's situation far more bearable than Alice's or Ruth's is the presence of social support. Hamida is on ART, which is never even mentioned in the testimonies from Papua New Guinea. She has also been able to get assistance from CARE Bangladesh and Mukto Akash Bangladesh (MAB). The minimal support she gets for her health from MAB, combined with a toehold in the market economy through her office cleaning job, sustains her, she says, although she is still left to care for her husband when he comes home at midnight, and her son remains out of school.

## Multiple forms of stigma in Jamaica

When double and triple stigmas make the caregiver's role even more difficult, it becomes an additional affront to human dignity as understood and guaranteed by international human rights instruments and the way they have been interpreted in national law. In one of their judgments, the Canadian Court of Appeals for Ontario defines human dignity thus:

'Human dignity means that an individual or group feels self-respect and self-worth. It is concerned with physical and psychological integrity and empowerment. Human dignity is harmed by unfair treatment premised upon personal traits or circumstances which do not relate to individual needs, capacities, or merits.'<sup>3</sup>

If poverty is exacerbated by the arrival of AIDS in the family home in the cases of Bangladesh and Papua New Guinea, the household structure at the centre of the testimony from an urban Jamaican ghetto is even more tenuous because of sexual orientation, for here indignity endorsed by the State is a central factor.<sup>4</sup>

The man at the centre of the caregiver's story is never named, but he worked in the market selling among the other small traders. It is there, in the street and in other public places that his illness begins to manifest:

'...he had dizzy spells and sometimes I would wonder and asked him why was he passing out so often, he passed out a lot. He would pass out at the market, sometimes at home or maybe in the streets...'

The dizzy spells were accompanied by a frightening deterioration of his body: 'he had diarrhoea, loss weight, his eyes had sunken deep in his cheek bones, he was throwing up.' This was a marked difference from when he first moved into the tenement yard in which he was living:

'.. people were used to seeing him as a healthy person going about his business and going about his daily life and as time progressed he started looking unhealthy so to speak. He was very good with the neighbours especially the people in the yard because it was like a tenement yard setting. ... Initially he got along very well with individuals that live in the yard but as he got sick they started treating him badly, not talking to him, scorning him, not hanging out with him as they usually did so. ... [E]ven the immediate neighbours weren't paying much attention to him, they weren't talking to him much anymore. The challenge that I have looking back is that I could remember when he was up and about he used to assist them, like give somebody a banana or take a bread to somebody, but eventually they [abandoned] him; they went about their business.'

Once a source of economic support for his family, he began to stay alone in a one-room home until his condition deteriorated to the point where he could no longer manage alone. The diarrhoea and his weakness became



so extreme he could no longer hold his faeces on the walk from the house to the latrine:

‘There were times when, as a result of his weakening stage he was weak as a result of not eating, having weight loss he was weak as a result of that. There were times when he would try to make it to the bathroom to go use the toilet and was unable to make it because he was weak and as such he would sometimes filth on himself on his way, so there were times when I had to come home and get him from outside and take him in’.

The neighbours refused to help:

Interviewer: So the neighbours would leave him lying in the yard?

Interviewee: They wouldn’t pay him no mind; they wouldn’t pay him no mind.

So his caregiver, L, had to leave work to pick him up from where he is lying on the ground in his faeces, take him back into the house, clean his soiled body and clothes, and console him. Eventually, the strain of looking after his lover financially, physically and emotionally leads L to move in to the one room house where his lover has been trying to live alone with his deteriorating body:

‘What made me decide to move in with him was I couldn’t afford to see him in his filth not being able to go and use the bathroom as he would normally do. Not being able to prepare food and eat, and working within the field I know that those were also important.’

The need was great as his lover’s body deteriorated in a familiar description that nevertheless repeats itself across the Commonwealth, as if nothing had changed since the advent of ART:

‘He was throwing up, not eating, he lost a lot of weight, he was skin and bones. With that said I knew things were getting worst, his eyes were in a hole it was to the back of his head, his cheekbones were sunken so that in itself told me it was getting worst. He was having more frequent diarrhoea, he was dehydrated, I knew it was getting worst.’

L was determined to bring his lover solace and help him die with dignity. He took the few dollars he earned a month and used it to try and feed the two of them while they are living together, despite the fact that suffering from thrush meant the meal ended up being vomited again. Once that happened, the food was gone but not the hunger or the need for nutrition:

‘So he starve because if you ain’t eating what was available, when he did eat he throw up so there was nothing else to give him so he stayed hungry. I am sure that he might have been hungry many times and not share it with me because he didn’t want me to be worried about what he would eat, and what was happening to him.’

This is Jamaica, however, and the community did not accept the couple's living arrangements, even though their neighbour was clearly dying:

'...before he died I moved out because things had gotten real bad in terms of the community because this was in Spanish Town and because people were talking! And the neighbours were talking. I had to make the decision as to what, do I live with him and continue to take care of him and deal with the issues of the fear of being attack as well as being verbally attack or do I move out and do it on a visitation basis? ... [P]eople were [calling] us "batty man." "How is it that two men were living together?"'

L had already been physically attacked and then expelled from college for being gay. Moreover, like Hamida and K, he had contracted HIV from the partner for whom he was now caring. He realised he was looking at himself in the future and wondered who would look after him when his time came.

Finally, the pressure from the community and from his own fears of what might happen to him came to a head:

'What made me decide to move out was as a result of the external community pressure I couldn't deal with that. In addition to that I was also dealing with my own, for want of a better word, personal demons because I was probably saying, oh my gosh if I should test positive tomorrow is this how am I going to be living, and so it was complex.'

L began secretly sleeping at the office where he worked while doing his best to continue caring for his dying lover.

'I paid it [the rent] still but it was still difficult, it was just too much for me to be there looking at it, looking at him dying so I would pay, I would visit him now and then and sleep at my office - I would get into trouble for that - eventually I lost my job.'

Eventually his employers found out about his sleeping arrangements and, knowing nothing of what he was struggling with at home, fired him. Because of the double stigma of AIDS and homosexuality, he had nowhere to live:

'I was no longer able to live with him and take care of the emotional and health needs and I started sleeping at my office, it would be the office or the street and I was eventually fired. Protocol... office procedure... I was told on several occasions that I could not be sleeping at the office. Well I did not say why I was sleeping at the office, eventually I lost my job. So in losing my job it became practically that he was on his own too. How we managed, I had another friend in Kingston who I would take from him to give to him, and the reason why I paused, that friend died in November as well.'

L began squatting in an abandoned house with a group of gay men who were also homeless, until being homeless, HIV-positive and unemployed himself takes its toll and he can no longer be there for his lover as he once was. Three or four days after L's last visit he hears his lover is dead:

'I did not even know when he went into the hospital. I remember that ... one day and someone called me and told me that my friend had died and I said, oh, and they said yes he was on Ward 9 and at that time at KPH Ward 9 was where persons with HIV were being kept or being bedded and I remember I was crying and people were being sympathetic but I was just crying, it was overwhelming.'

Because he was not family, his lover's mother reappeared and claimed the body, gave him a pauper's funeral, and took what little he had left behind. His lover now dead, L remained homeless and on the move:

'It [squatting in the derelict building with other homeless gay men] went on for a long time. A year and half or a year until, eventually I said, by this time my partner had died, I said to myself I can't live like this anymore, reflecting on the fact I might end up dying like him and being treated as how he was treated. I said I could not do that so I went back home to Duncans [in rural Jamaica], I spent another two or three months in Duncans. In the community people were talking about my sexuality, they were calling me names. I moved from one place to another ... and then eventually I went to [another rural community] and started doing some yard work and then eventually I got the opportunity of coming to America to study.'

L subsequently successfully claimed asylum in the United States on the basis of his sexuality and lives in Massachusetts.

## Notes

1. The literature is extensive. See, for example, Parker and Aggleton 2002; UNESCO 2003; or Cameron 2009.
2. The Stigma Index is a collaborative project between the Global Network of People Living with HIV (GNP+), the International Community of Women living with HIV (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS. The index is being used around the world to measure the stigma experienced by people living with HIV. To read more, see: [www.stigmaindex.org/](http://www.stigmaindex.org/) In this research we highlight stigma for carers, which is different from that experienced by HIV-positive persons.
3. Court of Appeal for Ontario, McMurtry C.J.O., Macpherson and Gillese J. J .A. between: Hedy Halpern and Colleen Rogers, Michael Leshner and Michael Stark, Aloysius Pittman and Thomas Allworth, Dawn Onishenko and Julie Erbland, Carolyn Rowe and Carolyn Moffatt, Barbara Mcdowall

and Gail Donnelly, Alison Kemper and Joyce Barnett - and - Attorney General of Canada, the Attorney General of Ontario, and Novina Wong, the Clerk of the City of Toronto - and - Egale Canada Inc., Metropolitan Community Church of Toronto, the Interfaith Coalition on Marriage and Family, the Association for marriage and the family in Ontario, Canadian Coalition of liberal rabbis for same-sex marriage, and Canadian Human Rights Commission (date: 20030610; docket: c39172 and c39174)

4. For an analysis of the legal environment and HIV, see Commonwealth HIV and AIDS Action Group and International HIV/AIDS Alliance 2010.