‘Talk to them freely about this disease…’
1. Part of the solution, or part of the problem?

In November 2001, a group of African church leaders met, in Nairobi, to draw up an ecumenical plan of action for responding to the HIV/AIDS epidemic. Their conclusion was this. ‘For the churches,’ they said, ‘the most powerful contribution we can make to combating HIV transmission is the eradication of stigma and discrimination.’

Christians claim to find this puzzling. In the earliest years of the HIV epidemic, most government health services were afraid to treat patients with HIV. By contrast, many church clinics, mission hospitals and primary health care centres refused stigma by pioneering the care of people with AIDS. Some of the earliest home-based care and orphan programs were developed and supported by churches and other faith-based organizations. Many of these are internationally respected, today, as examples of good practice. Given this shining record in the field of care, why should the escalation of the epidemic be accompanied by accusations that religious organizations contribute to the spread of the disease rather than its prevention?

The answer takes us to the heart of the Church’s identity and self-understanding. It is a historical fact that the churches’ health work has generally been conducted, at arm’s length, through semi-autonomous organizations run on secular lines by medical or health care professionals. At that level, church hospitals and clinics (echoing Christ’s own special concern for the poor and outcast) can be proud of their record in opening their doors to people whom the world rejected. But the stigmatization and discrimination that is undermining HIV prevention is much closer to home than that. It operates at the level of human community, local culture, and the way in which the day-to-day life of the worshipping, praying, believing church relates to the forces of life and death that are played out in those arenas. By denying truth, institutional churches have all too often sided with the forces of death that exist within cultures. By reinforcing silence and denial, they often fail to take a stand for the forces of life.

A South African theologian described the death of his cousin. When he knew he was dying, and the family discussed the funeral with him, the young man said he wanted them to tell the truth, that he had died of AIDS. ‘So at the funeral, my grandmother walked to the front of the church and laid her hand on my cousin’s coffin, and said, “My grandson no longer has to suffer with AIDS.” Then, with her hand still on his coffin, she turned to the pulpit and said to the preacher who was about to preach to the people gathered in the church, “Now… talk to them freely about this disease. To us it is not a shame.”’

2. What is stigma?

The idea of social stigma generally refers to any attribute that marks the bearer as culturally unacceptable or inferior. Stigma can be associated with a physical condition or disfigurement, a moral blemish, membership in a despised social group, or simply being ‘different’. The afflicted person is cast out of the social community and is made to feel of little worth. As a result, people who are stigmatised experience guilt, shame and rejection: feelings they may accept with a fatalism that stops them seeking help or trying to change things.
Anthropologists observe that stigma is often interpreted as punishment[^2], visited on a particular individual or group as just retribution for violating community norms. The stigmatised person may also be held responsible for real or imagined ills that afflict the community, which can only be cleansed by the expulsion or isolation of the polluting influence. Their continued presence can become a threat to the survival of the whole group. Exclusion, victimisation and scapegoating follow, further justified by the belief that those who are ‘different’ are less than human, and do not feel things as ‘normal’ people do. Their suffering is inevitable: they have sinned, and now they pose a threat to a divinely ordained order. In punishing them, human beings are only doing what the gods themselves demand.

As a result, those who discriminate and exclude may see themselves as occupying the moral high ground, their own perfection enhanced by the so-called ‘blemishes’ observed in the stigmatised person or group. The existence of such categories of outsiders is useful, because it boosts the self-image of the majority, and enables the hysterical hounding of minorities to appear virtuous. By such means, ordinary, god-fearing people have – with a good conscience – been able to participate in the slave trade, the holocaust, apartheid and ethnic cleansing; the victimisation of sexual minorities, beggars, illegitimate children, the disabled and the mentally ill; the lynching of saints, mystics and geniuses[^3].

This process is highly contagious, and very difficult for individual members of a community to resist. When the mob was baying for the death of Christ, the male disciples fled in terror. Even Peter, who loved Jesus so much, was blinded by the contagious violence of the crowd and aligned himself with the murderers rather than the victim. Only the (stigmatised) women were left. From the cross, knowing how blinded we are by the norms, values and the political aspirations of our times, Jesus said it all. ‘Father, forgive them,’ he said. ‘They don’t know what they are doing.’[^4]

### 3. ‘Don’t tell the neighbours…’

**Luke’s Story**

For many years, Luke was a pastor in a mainstream church in a rural area of Kenya. Few people knew much about AIDS, and when they were told, they didn’t believe. Then in 1999, when his three children were 10, 7 and 4, his wife died. The death certificate said tuberculosis, but in the hospital they told Luke that it might be AIDS. He should really be tested himself. “On the day I received the result, I was about to die,” he says. Desperate for advice and comfort, he went and told his bishop.

“You are a disgrace to the Church,” said the bishop. “You will not tell anybody you have this sickness, and if you want to retain your ministry, you will marry again soon so that people are not suspicious.” But that, says Luke, would have been killing. He refused to marry, and was duly fired. This was the worst time of his life. His children were victimised at school and made to sit separately, with other ‘AIDS children’. He had no job and no money. “If it hadn’t been for the kids, I would have killed myself,” he says. Then an AIDS counsellor saved him by offering sensible advice and real options. Today, Luke is a pastor in an independent African church. He has not married again, but he has friends, he is accepted, and he knows his ministry is of great value to those he serves. “Every time I stand in the pulpit and say I have AIDS,” he says, “I know that I am making a small dent in the way people think, and maybe giving hope to other people.”

**Yupa’s story**

Yupa’s husband was a leader in a local church in Chiang Mai, Thailand. When he started to be sick a lot, Yupa thought it was just exhaustion, but the doctor suggested a blood test, and then that Yupa...
should have one too. Both were HIV positive. Yupa cared lovingly for her husband until he died her arms, in his sleep.

From having been a respectable woman, a church leader’s wife, Yupa became an outcast. Her husband’s family rejected her, and she was told she was no longer welcome in her church. God was punishing her, and she should avoid the presence of god-fearing Christians. Her family received death threats, and people would look the other way if she met them in the street. “At that time I lived like a demented person,” she said. But then Yupa met some people who gave her sensible advice. She realized she had to take responsibility for herself.

Yupa became a volunteer with a support group for people with HIV/AIDS. “I feel so loved and valued now,” she says. “My work is important. For me, every moment in every day has meaning and value and purpose. But I am happy that my husband died before he learned the shallowness of his church’s claim to be loving and compassionate.”

Linda May’s story
Linda May was born in Maryland USA. In high school, most of her evenings were spent on youth activities at the church, and that was where she met Ed. One terrible day, he came round to the house and told her he was HIV positive. She should have a test, he said. She hasn’t seen him since. Her mother took her to a clinic fifty miles away, where she wouldn’t be recognised. The result came back positive, and her father has not spoken to her since.

The minister at church told her that she would be damned forever, and then preached publicly about her sinfulness. The parents of the other kids said they would withdraw their own children from youth clubs unless she left. At home, she has her own cutlery and plates and bedding. When people come round, she is sent to her room. She knows that if she becomes ill, she will have the best medical care her parents can afford, but at 16, she feels her life is over.

Bernard’s story
Bernard is a Catholic, an elder of the church, living in a poor area on the outskirts of a Tanzanian city. He thinks he may have AIDS. He doesn’t know what to do. He could go to the testing centre in town, but what then? There is a Catholic clinic nearby, but suppose someone recognizes him there? If people think he has HIV, he’ll probably lose his job. Bernard has two wives, and five children. What of them? He knows where to get condoms, but that is a sin, and anyway then the women would guess. Discovery might mean the whole family being ostracised. He would like to talk to a priest, but then he would lose his position in the church. Anyway, nobody talks about such things in church: AIDS is not a nice thing to mention to a man of God. So Bernard carries on as before, getting sicker and more desperate, and dreading the moment when he gets too sick to go on pretending.

4. Challenging respectability

These four stories are familiar ones to anyone working in the field of HIV/AIDS. In each case, their churches have contributed more to the problem that the solution. But why? It is not just that people have a misplaced fear of physical infection. The virus seems to make them nervous in less tangible but more far-reaching ways than that. It’s almost as if it shows people their own vulnerability, their own mortality, and they don’t want to know. The fact that HIV is sexually transmitted makes people feel particularly vulnerable. It’s an admission of the sexuality of the infected person, a confirmation of the secret fear that sex really is something nasty and dangerous, an endorsement of all the ambiguity people may feel about their own sexuality but don’t acknowledge. It is a challenge to their own respectability, and that of the Church as its embodiment.
The Revd Canon Gideon Byamugisha, of the Namirembe Diocese of the Anglican Church of Uganda, is living openly with AIDS. He says, ‘It is now common knowledge that in HIV/AIDS, it is not the condition itself that hurts most (because many other diseases and conditions lead to serious suffering and death), but the stigma and the possibility of rejection and discrimination, misunderstanding and loss of trust that HIV positive people have to deal with.’

5. From Caring Church to healing community

One of the glories of Christian tradition has been its concern for those who suffer. In some of the poorest places in the world, the church has pioneered the provision of health, education and training, hospices for the dying and shelter for the orphans. It is in the context of this ‘caring church’ that the leadership role taken by Christian health professionals in the care of people with HIV must be seen.

But HIV care and prevention are not primarily medical issues: indeed, the continued escalation of HIV represents a devastating failure for modern medicine. HIV is to do with sex, with addiction with premature death, with human relationships: all profound and universal human experiences, located at the core of human family and community life. In theory a church should be ideally placed to engage with such matters, intimately involved as it is in the lives of people and communities. But the fact is that churches cannot address HIV/AIDS without first breaking the silence that surrounds issues of sex, drug addiction, sin and death. This, they find, challenges them not as the managers of health, education and poverty-reduction programmes, but at the very core of what they proclaim and believe: in their theology, their language, their liturgy and the way they interpret their scriptures.

A further challenge comes from the Church’s traditional teachings on ethical matters. Jesus was extremely wary of religion that is defined by moral codes and rules. Christ’s free gift to our world is grace, and the unconditional love of God. And yet many churches have greeted the issue of HIV/AIDS with thundering moral denunciations, and by victimizing and excluding those who are known to be living with HIV and their families. You have sinned, say their leaders: you deserve to die. When the Church takes this view, it is indeed more part of the problem that part of the solution. In effect it is saying, ‘Go away, you who labour and are heavy-laden. There is no rest for you here.’

It is not the caring church that is speaking here. This is the church as moralist, dogma carrier and judge. This is the church so traumatised by the practical problems that it turns a blind eye to the fact that HIV exists in its own body, erecting walls of silence and denial around AIDS and other sexually transmitted infections. This is the church that dismisses priests and pastors when they tell the truth about their HIV status; the church that rejects and abuses widows and children who threaten its façade of respectability; the church that makes it impossible for Bernard and hundreds of thousands of others to react responsibly to the fear that they may have HIV.

Churches may believe that they are AIDS-free zones, and they may bolster that belief by denying evidence to the contrary. They are wrong, though. AIDS exists within the body of the church. In an area where adult HIV prevalence locally is 30%, then it is also likely to be around 30% among Christian congregations. There are numerous stories of pastors, known to be infected themselves, who pray ‘for those fallen ones who are sick with AIDS and seek forgiveness’, or preach hell-and-damnation sermons against ‘immoral behaviour that leads to AIDS’. It is their own they are stigmatising here, and themselves, but they will not admit it.
When churches seek to become healing communities, the first challenge they face is in naming the truth. The conspiracy of silence is a powerful thing. Where bishops or clergy have died of AIDS, churches have fought to conceal it. Everybody may know that a family member has AIDS, but it still requires courage to admit it in public. Priests and pastors may fail to face the challenge because they do not know the facts. Above all, churches are afraid that in becoming more open and accepting about sexual matters, they will be undermining their commitment to faithful, permanent and trusting human relationships.

Ending stigma demands strong, sensitive, truthful and well-informed leadership. It demands that the Church shatters the conspiracy of silence and admits to the presence of AIDS in its midst; and that churches go out of their way to nurture and encourage those who have HIV, because they are the most valuable potential resource they can have in the struggle against AIDS. It demands a re-evaluation of the morality the church is teaching, and the way it is preached to the young. It demands analysis of the ways in which the church, in all cultures, has taken sides in the battle between life and death, and a willingness to discern new lessons about how it can choose life. It is in choosing life that Christian hope is born. Life, hope and truth: these, and not stigmatisation and exclusion, are the foundational values of the healing community we pray the Church can be.

6. Seven suggestions for combating stigma

• Stop seeing AIDS as an ‘us’ and ‘them’ issue: AIDS is in the Church
• Base education on people’s real experience, not on wishful thinking
• Encourage theological and ethical reflection on HIV/AIDS
• Welcome people living with HIV/AIDS as a valuable resource
• Build welcoming, non-stigmatising communities
• Break the conspiracy of silence
• ‘Now talk to them freely about this disease…..’

(Endnotes)
2 Revd Prof. Maake Masango, quoted in WCC document (see above)
3 A keynote work on this was Erving Goffman’s Stigma: Notes on the Management of Spoiled Identity, New Jersey, Prentice Hall 1963, Penguin Books 1990
5 Rene Girard: I See Satan Fall Like Lightning Maryknoll Orbis Books
6 For a discussion of this, see James Williams, The Bible, Violence and the Sacred, Valley Forge Pa, Trinity Press, 1995
7 See 1. above

(Credits)
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*Inclusion of persons in photos should not be construed as indicating their health status.

As part of her ongoing work in this field, Ms. Paterson is interested to hear from you about your own experience, and to find ways of sharing ideas and thinking more widely. Please get in touch with her at stigmamail@aol.com and let her know how you have used this discussion paper.

UNAIDS supported the writing of this article, as part of efforts to stimulate debate on the roles of specific communities in fighting HIV/AIDS and stigma and discrimination within the context of the World AIDS Campaign. For further information about UNAIDS please visit www.unaids.org.