Stigma in the context of development

A Christian response to the HIV pandemic

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PROGRESSIO

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The person who has the leprous disease shall wear torn clothes and let the hair of his head be dishevelled; and he shall cover his upper lip and cry out "Unclean! Unclean!" He shall remain unclean as long as he has the disease; he is unclean. His dwelling shall be outside the camp.
(Leviticus 13:45-6)

Silence kills, stigma kills. We should not want those living with HIV to be the modern equivalent of the biblical leper who had to carry a bell and a sign saying, "I am unclean."
(Archbishop Desmond Tutu, July 2004)

Stigma and belief

In November 2001, church leaders from sub-Saharan Africa met in Nairobi to explore the possibility of a coordinated, ecumenical response to the HIV epidemic. As the discussions on care, treatment, education and prevention proceeded, it became increasingly clear that the major barrier to the churches' existing efforts was the stigma attached to HIV. "Today," participants agreed, "churches are being obliged to acknowledge that we have – however unwittingly – contributed both actively and passively to the spread of the virus." (WCC 2001, p3) The following statement, unanimously endorsed, has come to be regarded as something of a turning point in the history of the global response to the epidemic:

> For the churches, the most powerful contribution we can make to combating HIV transmission is the eradication of stigma and discrimination.... Given the extreme urgency of the situation, and the conviction that the churches do have a distinctive role to play in the response to the epidemic, what is needed is a rethinking of our mission, and the transformation of our structures and ways of working. (WCC 2001, p2)

Christians protest, reasonably, that church clinics, mission hospitals and primary health care centres were pioneers in caring for people with HIV and AIDS. Some of the earliest home-based care and orphan programmes were developed and supported by churches and other faith-based organisations, and are today internationally respected examples of good practice. By the turn of the millennium, it was estimated that the Roman Catholic Church alone supported over 25 per cent of all home-based care in the world (Barragan 2005[1]). Given this shining record, how could people suggest that churches and other religious organisations were contributing to the *escalation*

of the epidemic, rather than its *prevention?*

To throw light on this question we need to look at what we actually mean when we talk about 'the Church'. Many church-related hospitals and clinics are justifiably proud of their record in opening their doors to people whom the world rejected. In doing so they are mirroring Jesus' own special concern for the poor and outcast. It is a matter of history, though, that the health work that has been such a powerful dimension of Christian mission has generally been conducted through semi-autonomous, often very effective organisations run by medical or health care professionals.

The stigmatisation and discrimination that are undermining HIV prevention are closer to home than that. They operate 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 among its members and within the communities it serves. Martha, for example, is an HIV worker for a diocesan home-based care programme in Kenya; but she does not tell anyone at church that this is what she does because she is afraid of being shunned and avoided. In Thailand, Yupa's husband, a popular church leader, dies of an HIV-related illness, and Yupa finds that she is also HIV-positive. She is excluded from the church, his family freezes her out, and she is filled with self-loathing and wants to die (Paterson 1996). In a South African township, Lydia is pregnant. She suspects her husband is HIV-positive, but she doesn't dare ask, and now she is worried about herself, and about the baby. Simple, free treatment to prevent mother to child transmission of the virus is available locally, but first she must have an HIV test. In the end, she decides not to go back for the result: she is afraid of being victimised by the community and expelled from the church if the diagnosis is positive, and that fear is more awful to her than the prospect of delivering an HIV-positive child.

HIV is a virus. Therefore it should be treated as a *public health issue*, drawing on up-to-date approaches to treatment and prevention. That seems logical enough. But we are not talking about science here, we are talking about meaning. Churches have often constructed HIV not as a public health issue but as a *moral issue*, the most appropriate responses being judgement, condemnation, and the exclusion from the community of the HIV-positive person and those 'contaminated' ones with whom he or she is associated. HIV, because it has been held to be something evil and dangerous that enters a community from outside, has often been shrouded in silence, denial or rejection. The experiences of Martha, Yupa and Lydia highlight the stigmatising 'meanings' attached to HIV and AIDS, which in turn attach themselves to all who are associated with the epidemic.

It is because religious institutions are so prone to this kind of stigmatisation that health professionals often describe them as 'hard to work with'.[2]

Churches are communities whose sense of their own identity tends to be formed by a particular set of moral convictions. The majority of their members may not (in practice) live up to these moral convictions, but they are nevertheless the ones who dictate the 'official code' by which the community understands itself. The person with HIV challenges those convictions, and also the hypocrisy they conceal, in a way that the majority finds intolerable. Therefore he or she must be punished, encouraged to keep silent or, like the scapegoat of classical mythology, driven out. It is this anthropological view of Christian community that led to the widely quoted (but little understood) claim that "the Body of Christ has AIDS".

Jesus encountered this dynamic in the incident of the woman discovered in adultery. Here, he did not focus on the woman's alleged sin, but on the sins of the stigmatisers themselves. "Let anyone among you who is without sin be the first to throw a stone at her," says Jesus (John 8:7). It was not the (invisible) male partner in the adultery who was to be stoned: it was the woman, who in that culture would have had little choice about where, when and with whom she had sex. Was she to blame for what had happened, or was she a victim? Was she a sinner, or was she a scapegoat for the sin of others? These are the kinds of questions we are led to ask in the context of a reflection on HIV-related stigma.

Stigma and silence

Many church leaders, today, are actively promoting the open involvement of people living with HIV in the life of their churches, encouraging organisations that represent HIV-positive people, and intervening to prevent stigmatisation and discrimination when it comes to their attention. Others, though, try to enforce a culture of silence around HIV. From all over the world come stories of HIV-positive clergy being told by their bishops either to resign or to keep their status a secret. In a recent study of HIV-positive women in KwaZulu Natal, fewer than 30 per cent said they were able to talk to their pastor or priest (Gennrich et al 2005). Bernard, in Tanzania, told me: "I would like to talk to my priest, but he would condemn me. AIDS is not a nice thing to mention to a man of God." (Paterson 2003, p4) Until very recently, it was unknown for AIDS to be disclosed as a cause of death at funerals: indeed it is still extremely unusual, even in parts of sub-Saharan Africa where clergy find themselves conducting several funerals a week for people who have died of HIV-related illnesses. Thus when Nelson Mandela's son Makgatho died in 2005, he took the brave step of asking journalists to attend the funeral and then, with his wife and other children at his side, of talking to them about it. He said:

> Let us give publicity to HIV/AIDS and not hide it, because the only way of making it appear to be a normal illness just like TB, like cancer, is always to come out and say somebody has died because of HIV.[3]

Disclosure, though, carries its own risks. In KwaZulu Natal, Gugu Dlamini was beaten to death in December 1998, by her own community, because she spoke out, at a World AIDS Day event, about her HIV status. In Jamaica, Brian Williamson, Jamaica's leading gay rights activist and HIV campaigner, was murdered in his home, his body mutilated by multiple knife wounds. A crowd gathered outside the crime scene, celebrating Williamson's murder, laughing and calling out, "let's get them one at a time", "that's what you get for sin", "let's kill all of them". (Human Rights Watch 2004) In an urban hospital in North India, Anu was turned out of her bed in the maternity unit, and left to deliver her own baby on a storeroom floor. In a hospital in Zambia, nursing staff insist that a geographically separate HIV clinic is set up for health care workers, in case they are seen by their patients to be going to a public HIV clinic. In Guatemala City, Eduardo travels to another district to dispose of the packaging from his antiretroviral medications, because he is afraid somebody in his family will spot them in his dustbin. In Britain, Philomena has been HIV-positive from birth. Told by her adoptive mother of the little girl's condition, her school's head teacher was sympathetic. The news leaked out, and parents threatened to remove their children if Philomena stayed at the school.

Stories such as these demonstrate the fear that HIV evokes; the ignorance that often accompanies it; the extreme violence that may characterise the group response to it; the association between HIV-related stigma and the stigmatisation of other marginalised groups; the self-stigma and self-loathing that can be associated with a positive diagnosis; the social alienation that can be part of the experience; the silence and denial that prevent individuals from accessing help and groups from developing appropriate responses; the self-justifying righteousness of the stigmatisers; and the stigmatisation that pervades health services. The Revd Canon Gideon Byamugisha was one of the first ordained clergy to declare openly that he was HIV-positive. He says:

> It is now common knowledge that in HIV/AIDS it is not the condition itself that hurts most … but the stigma and the possibility of rejection and discrimination, misunderstanding and loss of trust that HIV-positive people have to deal with.[4]

What stigma does is to set people apart: the HIV-positive from the HIV-negative, the clean from the unclean, and above all 'them' from 'us'. It provides a good conscience for treating the feared 'other' as less than human. It allows us to condone suffering by convincing ourselves that it is somehow deserved, and boost our sense of our own inviolability and virtue at the same time. For the history of disease speaks again and again of the association between disease and sin. It speaks of disease (especially sexual disease) as a punishment from God or the gods. It speaks of disease that is basically *deserved*. And the fact that you or I are not officially 'sick' proves that we, therefore, are good, deserving, and by implication, in favour with God and our fellow humans.

HIV-related stigma is connected with the (primitive) link between sexuality and defilement. Paul Ricoeur's analysis of this ancient connection makes an essential contribution to our understanding by pointing out the tendency of cultural codes to apply negative judgements to even the most 'morally neutral' *sexual* behaviour, while comparing these with "the silence of the same ritual codes with regard to *lying, theft* and sometimes *homicide*" (Ricoeur 1969, p28). Christian ethics has a responsibility for helping people move on from pre-Christian understandings of sin which lead to the stigmatisation of sex and sexuality.

It is considerations such as the above that led to the adoption of 'stigma eradication' as a priority for churches. As the church leaders in Nairobi confessed:

> Our tendency to exclude others, our interpretation of the scriptures and our theology of sin have all combined to promote the stigmatisation, exclusion and suffering of people with HIV or AIDS. This has undermined the effectiveness of care, education and prevention efforts and inflicted additional suffering on those already affected by HIV. (WCC 2001, p2)

Stigma is contextual

The Greek word 'stigma' applied originally to the branding of slaves, a stigma (or sign) being literally burned into their flesh as a permanent sign not just of their excluded status but also of the identity of their owners. We regard such practices with horror today, but for the Greeks it was a natural consequence of the way they viewed their culture. They believed (and for the early Christians, their scriptures confirmed their belief) that some people were slaves and some were not and that this was the right and proper way for things to be. Maintaining the boundary between slaves and free people was part of the unwritten code that determined what it meant to be a full member

of that particular culture. People who broke that code could be seen as jeopardising civilisation itself, as St Paul was well aware when he pleaded with his friend Philemon to accept the freed slave, Onesimus.

Within a culture, the role of organised religion is generally to reinforce and ritualise such boundaries and taboos, and to place them in the context of a supernatural order. The inferior status of women, the taboos that surround homosexuality, and the various purity laws that surround sex, personal hygiene, ethnicity and so on are not just 'things most people do': they are part of the sub-consciously held value systems which are such vital ingredients of the glue that holds communities together. People talk with fear about crossing such boundaries, as if doing so is against nature, against the divine, or likely to bring down the vengeance of the gods upon them.

When the Canaanite woman implored Jesus to help her daughter, Jesus' instinctive reaction was that it was "not fair to take the children's food and throw it to the dogs" (Mark 7:27). This story shows Jesus struggling with the taboos that defined what it meant to be a Jew at that time. For the gospel is subversive precisely *because* it leads people to question some of their most treasured beliefs, to reveal the face of God that already exists within cultures, and to stand up against injustice and abusive structures of power. But this is not done without a struggle. Stigmatising beliefs are embedded in the lives of communities and the consciousness of their members. They are used to endorse the power structures and hierarchies that make those communities tick. Stigma is engraved on people's identity at the deepest level. Stigmatised and stigmatisers: both groups are complicit in what James Alison describes as "the profound 'do not *be*' which the social and ecclesiastical voice speaks to us" (Alison 2001, p39). Both groups have internalised the silent rule-books that set the parameters of what it means to be human.

The irony is, though, that it is often quite easy to see when other people hold stigmatising beliefs, while our own may go unnoticed, integrally connected as they are with our values, our relationships and our spirituality. Paul knows this when he says to Philemon: "Though I am bold enough in Christ to command you to do your duty, yet I would rather appeal to you on the basis of love." (Phil 1:8-9)

Since 2001, most global denominations have declared their determination to eradicate HIV-related stigma and discrimination. In the process, church leaders have found a spotlight thrown on judgemental attitudes, patriarchal traditions and structures, difficulties relating to sex and sexuality, the privileging of the truths of revelation over those which come from empirical disciplines, and the tendency of religion to reinforce rather than challenge cultural taboos. Such reflections do not simply call into question the way churches are organised. In December 2003, a group of leading academic theologians met in Windhoek, Namibia, for a UNAIDS-supported conference

focusing on HIV-related stigma. They concluded:

> If churches are to engage effectively with local, regional and international responses to the epidemic, then issues of stigma and discrimination have to be confronted not just at the level of church organisation and practice but also by Christian theology itself: at the level of what is taught in seminaries, what academic theologians think and write about, what the faithful believe and do, and what values inform the pastoral formation of pastors and lay people. (UNAIDS 2005, p6)

The next section explores some areas of theological and ethical dialogue that are important in addressing HIV-related stigma.

Stigma and Christian ethics

Caution is needed in generalising about the theological and ethical issues stigma raises. Stigma is contextual. For example, same-sex relationships are less stigmatised in – say – western Europe than they are in cultural contexts where the taboos are stronger, and where men having sex with men are criminalised by the law. To be a woman, or black, or disabled may be stigmatised in one context, but will be normal in another. On the other hand, experience shows that stigma can be reduced by legislation against discrimination, better information, and by challenging stigmatising attitudes in society. For example, in western Europe today, slavery (once taken for granted) has, in principle, been outlawed; and in the last 50 years the stigmatisation of men who have sex with men and of unmarried mothers and their children has massively reduced.

With those provisos, this section draws together some issues that emerge in most contextual analyses of HIV-related stigma. (The vital issue of *gender* is discussed in a separate paper in this Comment series, *Gender justice, theology, HIV prevention and healing: A holistic and community-centred ministry* by Nyambura Njroge.)

In this essay, we have already encountered the idea of HIV as a punishment for sexual sin. Of course, sex can be sinful. It is sinful when the circumstances in which it takes place are unjust, violent or exploitative. The silence that surrounds abusive sex is sinful, because it provides a safety zone where abuse can continue with impunity. The glorification and demonisation of sex are also sinful, because they create a rhetorical and fantasy world by which young people, in particular, are taken in. Abuse, violence, exploitation and the commodification of human beings are always sinful, wherever they occur. In sexual situations, they are of particular concern because of the silence that

surrounds sex, and because they imply that sex has somehow lost its connection with faithful, loving, trusting human relationships.

The stigmatisation of sexuality and disease is in part the heritage of the Christian tradition's ambivalence towards the human body in general. It is to be found, for example, in the purity laws of ancient Israel, the writings of St Paul and St Augustine, and the insights of the desert fathers. This ambivalence is part of the anthropology of Judaeo-Christian tradition. It has provided an entry point for fear of and loathing for bodies (particularly female bodies) and their functions, and for the cruelly negative meanings that have been attached to – for example – the bodies of slaves, 'fallen' women, people with leprosy, disfigurements or other disabilities, and so on. It has endorsed the abhorrence felt for the body's sexual desires, the simultaneous attraction and revulsion which women's bodies have sometimes excited, and the strand of belief that makes salvation dependent on 'mortifying the flesh'. It is easy to find body-negativities to criticise.

The fact is, though, that ours is an incarnational faith, and it is in the context of our bodies that we experience our struggles to live in a Christ-like way. "My body is my good and my evil," says Brazilian feminist theologian Ivone Gebara (Gebara 2002, p58). It is perhaps more helpful, therefore, to focus on the person of Christ. Jesus' life and ministry were intensely physical. He was a teacher and healer, concerned with the social, spiritual and physical dimensions of the lives he encountered and changed during his ministry. Even after death, he remained an embodied presence. Accounts of the post-Resurrection appearances stress the highly physical nature of Jesus' presence with his friends: the wounds on his hands and feet, his hunger, his bodily companionship among them on the beach or the road. To fail to honour our own and other people's bodies is to fail to honour the incarnate God-with-us.

The experience of HIV is characterised by a struggle between truth and silence, and the need (for religious people, particularly) to find a language in which taboo issues may be discussed. The taboos that silence talk of sex and sexuality do not make people more moral: instead, they provide a safety zone for abuse by ensuring that the shock experienced when such things are spoken of relates less to the acts themselves than to the fact of their being mentioned at all. Thus sexual activities become, literally, 'inconceivable' since there are no usable words in which they can be conceived *of*, and therefore no usable concepts in which information may be framed and transmitted. Language itself, in consequence, becomes a hiding place for sexual abuse and exploitation. For example, we know that a culture of violence against women is associated with high levels of HIV transmission. So are situations in which men have unprotected sex with men. But if women's sexuality is denied, and if homosexual men are forced to keep their sexuality a secret, then how is this vulnerability ever to be addressed or healed?

Part of the problem is that much of the stigma associated with HIV has its roots in fear and ignorance. People (especially young people) need accurate, comprehensive education about transmission, how to stay healthy and how to build non-trivial relationships. HIV is a virus and not a sin, so information itself should be in simple, literal language, and not dressed up as morality. Further, individualistic messages may not be enough. If stigma and taboo are woven into the fabric of communities, cultures and peer groups, then individuals are unlikely to maintain changed attitudes and behaviour unless the process of change is 'owned' by the communities and the peer groups to which they belong: a crucial insight for a development agency that is concerned with prevention.

A further ethical issue is "the virus of global economic injustice",[5] closely tied up with assumptions about ethnicity, which underpins crippling poverty in much of the developing world and in some parts of the West. Of course impoverishment and ethnicity do not in themselves cause HIV infection: the virus has manifestly affected both rich and poor, black and white. However, poverty does leave people economically poor, marginalised, hungry, illiterate and unable to raise healthy families, with inadequate access to healthcare services or advice on how to protect themselves and insufficient motivation to do so. It is in the absence of grounds for hope, or of the economic space to take control of their own lives, that people so often turn to transactional sex or drug abuse. The danger of HIV may seem a minor issue, with far-off consequences, in comparison with the urgent need to keep one's children alive till next week. It is the stigmatising (if unacknowledged) assumption that poor people are somehow 'less-than-human' or at least 'different from us' that allows us to live at peace with ourselves in a world where such inequalities exist.

Epidemiologists have observed the frequency with which infectious diseases strike already-stigmatised sections of society. Particularly vulnerable to HIV transmission are groups which have traditionally faced religious marginalisation, discrimination, exclusion or persecution, notably sex workers, injecting drug users, refugees and internally displaced people, and men who have sex with men. A holistic approach to HIV prevention makes it absolutely essential that vulnerability is not criminalised, that the vulnerable are not also invisible, and that society's victims are not treated as sinners but are welcomed into our church communities.

Thus the focus on stigma calls us to take a new look at the theological meaning of community. We should not expect our churches to be safe havens from the world, where we can shut the doors and expect not to be morally challenged. Jesus said to God: "I am not asking you to take them out of the world, but I ask you to protect them from the evil one." (John 17:13) A friend who lives in London's East End once said to me: "Because I'm gay, the Church

has always had difficulties in accepting me. But you've no idea how much they love me now that I have AIDS." An HIV-friendly church is not *just* one where people with HIV are welcome: it is one where those who are most vulnerable to transmission (often rejected by 'the world') are also welcome.

I have left children to the end. Of the 40 million people in the world who have HIV, 2.3 million are children. Many millions more have lost one or both parents to AIDS, and are growing up either in child-headed households, with grandparents or other family members, or in the loose gangs of street children one encounters in every capital in the developing world. These children are some of the most vulnerable human beings on earth, neglected, frequently abused, often – as they grow up – resorting to transactional sex or drug-trafficking in order to survive. But they too are part of the Body of Christ – the body of the One who said to his disciples: "Let the little children come to me; do not stop them; for it is to such as these that the kingdom of God belongs." (Mark 10:14)

'God shows no particularity'[6]

One of the reasons why religious people find it so difficult to get to grips with the idea of stigma is that it is so often linked to what they believe about the nature of God, and about God's relationship with the world. At Horeb, God speaks to Moses from a burning bush and reveals God's identity to the children of Israel. "I am what I am," says God; or (more literally) "I will be what I will be." (Ex 3:1-15) Yahweh is calling the people to liberation; promising they will no longer be enslaved foreigners and strangers but free beings, at home in the land which has been promised to them. However, the very idea of 'chosen' people heading for a promised land that will then belong to *them* (and not to the people who already live there) carries the suggestion of exclusiveness and violence. Therefore the image of God that comes to us through the scriptures, as well as being the Creator God rejoicing in diversity, also contains the potential for God to be 'seen' as excluding, violent, judgmental or hemmed in by taboos and by laws that dictate who is in and who is out (Lev 19). It is this strand in our understanding of God, the voice of this God ringing in our heads, that authorises the exclusion of 'the other' from human community: exclusion that is further justified when we succeed in associating otherness with sin.

However, judgementalism and moralisation cannot survive an honest reflection on the 'good news' of the gospel story. Conceived out of wedlock, Jesus' life was a challenge to the taboos and stigmatising attitudes of his culture. In his death, a stigmatised no-person, outside the walls that marked the boundaries of human society, he embraced stigma and the sin that is associated with it, and he moved beyond them. For the Cross is not the end.

Beyond the Cross are the empty tomb, the Resurrection, and the ongoing life in the spirit.

It is through the birth, life, death and resurrection of Christ that the 'I AM' tradition is redeemed and the non-stigmatising nature of the incarnate God most fully revealed. "I am the resurrection and the life," says Jesus. (John 11:25) "I am the way, the truth and the life." (John 14:6) "I am the light of the world." (John 8:12) "Before Abraham was, I am," he said (John 8:58): a statement so intensely provocative that his audience wanted to stone him. For God is not outside the world, judging it. On the contrary, it is in Christ himself that God's good, diverse, beloved and grace-filled Creation is brought to fruition. The meaning of the incarnation is that God is here in the thick of it: born, living, suffering and dying alongside the excluded and the stigmatised ones and those who (like Him) stand with them. It is Christ incarnate, Christ rejected by his own, who was, is and will be, in his own being, the ultimate, embodied 'no' to the 'othering' and stigma that exist in our cultures, our churches, our institutions and communities, and – let's face it – in all our hearts.

Notes

1 Based on a global survey of Catholic Bishops Conferences.

2 It should be noted that there is a growing body of research revealing health services themselves as the generators of HIV-related stigma.

3 Reported in The Guardian, London, 7 January 2005.

4 Canon Gideon is founder of the African Network of Religious Leaders living with or affected by HIV or AIDS, ANERELA+.

5 A phrase used at a conference in Pretoria in 1998 by Nigerian Catholic theologian Teresa Okure.

6 Acts 10:34.

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