

AIDS and the community

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Introduction – themes

I have been asked to address the topic of AIDS and the community. I will be making some general observations about AIDS and communities; the issue for this symposium is the extent to which these observations apply to Papua New Guinea. My remarks will be confined to four categories:

- What are the direct effects on communities of HIV/AIDS?
- How have communities responded?
- What strategies might communities employ to deal with HIV/AIDS?
- The challenge to survive and the interdependence of community and individual.

‘AIDS and the community’ is a broad topic which may well mean that I will say things that others have also said, but perhaps this is a good idea. We human beings are very good at silencing the threatening voices around us, particularly when the threat touches, as is the case with AIDS, on the sensitive questions and fears within each of us about our own living and dying.

The direct effects on communities of HIV/AIDS

Let me begin by naming the threats, the direct effects on communities of HIV/AIDS.

It has been noted that transmission of HIV/AIDS in the developing world is mainly by heterosexual contact, and from mothers to babies. The claim has been made that AIDS has the capacity to reverse population growth in developing countries. While this is an hypothesis that only the future will prove or disprove, the economic and personal costs to nations and communities are clear now. The greatest impact of the disease has been on the

younger, economically productive generations.

In some African countries heavily dependent on agriculture HIV/AIDS has decimated village populations. With the young people weakened or already dead, the question of who will plant the next crops becomes urgent. Chances of an alternative labour force are remote. A reduced farming labour force threatens a serious inability by the nation to provide its own food staples. This suggests a vicious downward spiral of disease, economic nonproductivity, food shortages, malnutrition and death. Papua New Guinea may be some way from this scenario but 85% of its people live in villages and depend on their own labour for food.

Meanwhile, the same economically productive younger generation is also sexually active and the parents of the next generation. Where children have already been born to an HIV-positive parent or parents the chances are very high that those children will also be HIV positive. When their parents die the burden of their care, education and health must be borne by someone. If the grandparents are themselves not living, or are unable or unwilling to cope, who will care for these children? Even if the family or community group still has the capacity to assume the burden of care the very real fact is that each remaining productive person becomes responsible for a higher number of dependants.

It does not seem realistic to expect that this burden can continue to be stretched within community groupings without threat to a system already under heavy pressure from the cash economy and urban drift. Can the government fill the gap and pay the bills for increased diagnoses, reporting, treatments? Can already overstretched medical and educational resources cope? An ailing population, economic downturn, and increased

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pressure on medical services resulting in new financial crises is not a formula for a healthy community.

I want to make one particular point here about women and HIV/AIDS. In AIDS Update 1994 (1:4) the following comment appears:

“Biologically, epidemiologically and socially women are more vulnerable to HIV than are men. Their generally subordinate role in the family and society renders them especially at risk of HIV infection. While this lower status differs from country to country, its universal effect is to restrict women’s ability to protect themselves from the sexual transmission of HIV. This ability is further limited by women’s inferior legal rights and their lack of access to appropriate health care, education and social services.”

The WHO/UNDP 1994 report, *Women and AIDS: Agenda for Action* (2:6-7), supports this thesis when it says that in many societies,

“males are expected to initiate relationships, and sexual assertiveness in women is often stigmatized or punished. The gender power differential is compounded by age differences. Women typically marry or have sex with older men, who have been sexually active longer and hence are more likely to have become infected themselves. In countries with high HIV infection rates, men justify the selection of young adolescent girls, even female children, on the grounds that they are less likely to be infected with HIV/AIDS.”

In communities where men are reluctant to use condoms and women are powerless to negotiate safe sex practices with them both women and men are at risk. There is strong anecdotal evidence suggesting that it is men who refuse to use condoms. At the same time I am also aware of anecdotal support for the opposite theory: it is women who dislike condoms, not men. Indeed, in one community in Papua New Guinea members of an admirably active women’s group told me that they oppose the use of condoms because they believe a ‘no condom’ policy will keep their men faithful and at home. Is this a real prospect

or mere wishful thinking? In fact, whatever the reality of willing condom use, these communities face a sad possibility: the men may already be infected anyway, leaving the women still exposed to infection, and dependent on the faithfulness of their men.

In addition, the serious community problem of rape or sexual assault puts women at an even greater risk and cannot be ignored. The most likely result would seem to be more and more HIV-positive women and babies.

A further threatening effect on the community is the link between HIV/AIDS and other sexually transmitted diseases and the spread of tuberculosis. These links have been discussed in other papers so I will confine myself to repeating simply that both tuberculosis and STDs are already major health problems in Papua New Guinea. There is also an excessive population growth, which is a genuine concern, but reducing the number of fertile women of childbearing age in Papua New Guinea by exposure to HIV/AIDS is not the way to solve it.

How communities have responded to the HIV/AIDS threat

The most basic problems are fear and lack of knowledge. Wherever HIV/AIDS is found fear and ignorance have stirred up the least good and noble, the most mean and dishonourable qualities in human beings.

Ignorance leaves people vulnerable to their own fears, imagination and folklore, which will rule powerfully regardless of any grounding in truth. If people do not know, in a way they can understand and accept, the ‘**how**’ of HIV/AIDS transmission then it is very easy to suspect mosquitoes, toilet seats, sneezing, coughing, shared eating utensils and so on. It is even easier to blame, to stigmatize, to look for scapegoats, to suspend reason at times, in order to protect oneself from the feared enemy.

Fear is more complicated and more primal. Fear of infection stirs the fear of death in so many people. I know of one dedicated nursing sister working with the organization People Living with HIV/AIDS who hides the nature of her work from her parents. Their fear of infection is so powerful that she fears they

would ban her from their home and family if they knew. In the same way as the lepers of the ancient world were thrown out of the community, there are plenty of people in today's communities whose fear and ignorance lead them to suggest the same treatment of people living with HIV/AIDS.

The direct community result is discrimination, which is effectively rejection by the community. People living with HIV or AIDS face loss of housing, loss of jobs and the fear of rejection by family and friends if their positive status becomes known. Even where discrimination is banned by law subtle means have subverted the law. I knew one young man, a chef with a publicly owned catering facility, whose boss, while declaring compassionate support, drew up such demanding work rosters that this young man's health was seriously undermined and he was forced to resign before he was emotionally and psychologically ready to do so. The experience broke his spirit more than his health and he died very quickly.

I am very much aware that I have created a rather negative picture. At this point I want to acknowledge that, while HIV/AIDS has stirred the bad in humankind, it has also stirred generosity and compassion in people in many communities, including Papua New Guinea. But today we need to focus on the problems to be faced and solved rather than comforting ourselves with sentimental accounts of good deeds done.

Some years ago when I was involved in AIDS ministry, a young man told me he was going off the drug AZT because of the horrible headaches it induced. "Tell me what an AZT headache is like", I asked. "You know how sometimes when you eat icecream", he said, "the cold hits your teeth and shoots straight through your jaws and into your forehead. It *burns* and you want to scream ... and you think, 'I'll never eat icecream again'. Well, with AZT that pain hits your brain and your whole head. It burns worse than the icecream and you think you'll go mad if you can't get away from it."

Perhaps this story is a metaphor for what our communities need to experience to have some idea of the pain in their midst, and the threats to their own existence.

The strategies communities might employ to deal with HIV/AIDS

In England they used a slogan "Don't Get AIDS From Ignorance". People must be educated to understand the disease and the behaviours that will place them at risk. But in developing educational programs there will be some important ethical and moral issues to be addressed. These include:

- The need to strike a balance between arousing concern within the community on the one hand, and stirring up fear on the other.
- The need to clarify individual and community responsibilities and remove the blame factor.
- The need to stress that getting AIDS is not a punishment by God. This sadly still quite common idea says more about human projections of human fears than it does about God. It is bad theology and not Christian.
- The need, therefore, to stress the corollary that there are no 'innocent victims' of HIV/AIDS, only People Living with HIV or AIDS. It does not matter how people have become infected, only that they have and are likely to need the community's care. Speaking of 'innocence' is divisive and makes a value judgement.
- The need to fund programs to gather accurate data on regional knowledge, attitudes, beliefs and practices about health and sexual reproduction. Such research needs to examine gender differences, for example in attitudes to condom use, to test conflicting anecdotal reports and provide useful educational guidelines.
- The need to educate about sexual behaviour and the facts of reproduction.
- The need to respect human privacy and human rights. Fear may drive people to demand draconian laws to protect them from HIV/AIDS infection but the law has very limited use as an instrument of social change. Behaviours, attitudes and moral understanding cannot be changed quickly or by force.
- The need to maintain a sense of proportion: sexual activity may be a rare pleasure in an otherwise unhappy existence and there should be no suggestion that sexual expression is bad, immoral or shameful.

The challenge to survive and the interdependence of community and individual

I know that 'AIDS and the church' will be discussed by another speaker but, in a community such as Papua New Guinea which publicly espouses the Christian faith, 'AIDS and the community' also means 'AIDS and the church'. The community of Papua New Guinea is faced with the challenge to live the biblical imperatives of love, mercy, compassion and justice. Christianity is about relationships and relationships are what make community. Roman Catholic theologian Edouard Schillebeeckx once said, "People are the words God uses to tell God's story". The community is about us, the people who are the words of God.

The ancient Hebrews, ancestors of Judaism, Christianity and Islam, believed passionately that a person's individual identity was defined only by association with community. Rejection by the community was to be stripped of identity. A community is its individual members and containing or defeating HIV/AIDS will depend on absorbing the experience of all its members. This means, in part, listening to its members who are living with HIV or AIDS and, in part, facing the fears of all its members. We, the people, who are the words of God, can only begin to live fully when we embrace the shadows in our own lives, the shadows of our fear of our own dying. And it must also be remembered that a community is not only a physical grouping. It is also the spirit which unites its members. A community which turns against some of its members and rejects them from its presence is feeding upon its own soul. This would be a *community with AIDS*.

Conclusion

In conclusion let me say that the story God tells is one of living as well as dying. Its aim is not division and rejection from the community, but liberation and hope in the community.

Hope is not just a word. Hope is a need which has to be made to happen. In the words of Kim Benton, an HIV prevention officer in Australia, "That hope has to be spelt out, to be delivered, to be proclaimed in a way that embraces and warms and heartens and encourages, not alienates, compartmentalises, segments, isolates or pushes away" (3:125). It is the task of the people who are the words of God telling God's story in this community to spell out that hope with courage and fearlessness.

Further discussions of this theme may be found in 'AIDS: Insights from the Stockholm Conference', which includes responses on legal, social and economic aspects of the AIDS epidemic by Justice Michael Kirby, President of the New South Wales Court of Appeal and Commissioner of the International Commission of Jurists, and Mr Dennis Altman, Member of the Australian National AIDS Forum and Lecturer in Politics at La Trobe University, Victoria, Australia. Other useful and relevant sources are books edited by Cosstick (4) and Woodward (5). The World Health Organization provides assistance locally with its regular AIDS surveillance reports from the Central Public Health Laboratory in Port Moresby and globally through its program in Geneva (6).

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