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Essay 4

## **Risk-increasing context or individual behavior?**

Gideon Byamugisha

The following is an essay from the book *HIV Prevention: A Global Theological Conversation*, edited by Gillian Paterson. We encourage you to download the full text or order a single complimentary copy from:

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**Ecumenical Advocacy Alliance, Geneva**

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## Essay 4

# **Risk-increasing context or individual behavior?**

Gideon Byamugisha

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### **1. The real question**

You see the trouble we are in, how Jerusalem lies in ruins with its gates burnt. Come let us rebuild the walls of Jerusalem, so that we may no longer suffer disgrace. *Nehemiah 2:17*

In talking about HIV prevention, the question we have to ask is: 'Why do people get HIV?'. Why, with all that we know, and all the billions of words that have been said or published on the subject, does the challenge of HIV transmission remain so intractable? How come the world, in its wisdom, has not found a way to stop AIDS? How can we 'rebuild the walls of Jerusalem', and say a decisive 'No!' to the 'disgrace' that is suffered by those who live in it?

I am suggesting in this paper that one important answer lies in the way we see and understand the issue of HIV transmission, and what the virus has come to mean. Because how we see and understand the epidemic affects the kinds of responses we try to encourage. It affects the way we see our own place in the epidemic. And it affects where we lay the responsibility for change.

So the question we have to ask is: in talking about prevention, should we be asking about individual behavior, over which a man or woman, boy or girl may have or may not have a measure of control (given the socio-economic, cultural, educational, political, psychological, motivational, service and skill factors surrounding him or her)? Or are we talking about the overall environment in which the man or woman, boy or girl find themselves - the environment that either makes safe behaviors and practices easier to adopt and to maintain or makes them difficult to adopt and to maintain? Should we be addressing risky *behavior*, or should we be addressing risk-increasing *contexts* or should we be giving both risky behavior and risky environments equal attention?

I want to suggest that it is not possible to try and answer this question without first understanding something about stigma (or what the prophet Nehemiah calls 'disgrace'); that is, without first learning to perceive the way stigma sabotages and silences honest dialogue about the contextual dimensions of HIV transmission, and the way it paralyzes people who fear that they themselves or one or more loved ones may have HIV.

One difficulty about HIV prevention is that only about 15 per cent of all HIV positive people know their status. Because of the fear of the possibility of facing a quick agonizing death or else of being stigmatized, rejected, discriminated against, isolated or abandoned, many do not want to know. Many of those who dare to know are, for the same reasons, very hesitant to disclose their HIV positive status. Those who venture to disclose do so too late for effective HIV prevention, care and treatment to take place: often because they do not seek help until it is too late for medical interventions to make a difference in blocking new HIV transmissions and in preventing and postponing death.

Fear of stigma leads to individual and collective denial that there is a problem. As a result, people who secretly fear they may be HIV positive (and societies which have sufficient reasons to believe that they could be at risk) do not take measures to prevent the virus being transmit-

ted from one person to the other. This includes, for example, pregnant women, who may fear stigma more than they fear the possibility of transmitting the virus to an unborn child, as well as nations/communities which may fear loss of pride and business more than they fear the possibility of losing millions of people to a disease that is, in the absence of stigma, preventable and manageable.

Families, communities and nations which stigmatize those who are living with or affected by HIV or AIDS are not just stigmatizing individuals: they are in practice silencing the whole dialogue, within the community, from which a culture of prevention might grow and develop.

Societal stigma may be based on the irrational fear of contagion, or on concern about resources: which can be dealt with on a rational, factual basis. It may be based on an association between HIV infection and behavior, judged by community members to be 'immoral', or 'deviant', such as sex before or outside marriage, prostitution, drug abuse or homosexuality. AIDS may be associated with lack of faith in God and God's miracle healing powers; with inability to pray or pray well; or with punishment for sin, more especially sex-related sins.

An understanding of the sources and manifestations of stigma at individual, family, local community, national and global level is crucial to the argument of this paper. Stigma leads people and societies to make simplistic moral judgements, devoid of serious reflection and analysis, about people's capacity for behavior change. Seen through the lens of stigma, which arises out of connecting HIV infection with sexual immorality, looseness and debased-ness, the possible reality that someone could have *'failed to change to safe behavior'* is quickly and inaccurately translated into the perception that they have *'refused to change to safe behavior'*. But the key difference is that a *failure* to change is the result of constraining variables within someone's socio-economic, cultural, educational and political *environment*. In order to understand why this is the case, it is necessary to initiate an exploration of what we mean by 'community'.

## **2. What is community?**

We use the word ‘community’ a lot, but it is not at all clear what we mean by it. Is it a place ‘where two or three are gathered together?’ Can any form of human association be classified as ‘community’? Is my community defined by my city, or my neighborhood, or my church, or my extended family? Or is it defined by something else entirely? Do I belong to more than one community, each with its own social and cultural norms: such as my peer-group and my workplace?

The objective of this reflection on ‘community’ is for members of a community to learn to:

- appreciate and reduce their individual and collective risk and vulnerability to HIV;
- promote positive prevention among individuals, families, communities and nations living with HIV;
- integrate HIV and AIDS related issues in liturgy and worship in such a way as to facilitate (or enhance) theological reflection, task-focused praying and practical action for accelerated HIV prevention;
- reflect on how such a church/community praxis can be strengthened and scaled up for increased HIV prevention.

So before we can define what we mean by a ‘risk-increasing community’ or start discussing what risks are carried by the culture of our own communities, we need to be sure that we know what we are talking about, and that we are all talking about the same thing. And, having done that, we need to reflect – in the context of the particular community with which we are concerned - on the community practices, traditions, values, attitudes and happenings that add to the problems of HIV and how these can be used to change situations in community. The question is: how can community activity be scaled up to address the challenges? And in addressing

that question, one must also ask oneself: what (other) community activities need to be scaled *down* if that is to happen?

Of course every community is unique; but also there are a number of community level factors that can help explain the rapid spread of HIV, or the difficulty of containing the epidemic. Any review of factors influencing individual or collective community competence or incompetence in HIV prevention should therefore reflect the following:

- a) *The availability or scarcity of accurate, adequate and unbiased information* regarding HIV and AIDS and how HIV is and is not spread; information about all possible modes of transmission and all possible means of prevention; and what individuals, families, communities and nations can do to minimise risk and contain HIV.
- b) *The attitudes of community members* towards both HIV and to people living with the virus. Are they positive or negative, empowering or disempowering? Do they encourage vigilance and spirited action for accelerated HIV prevention, care and treatment; or do they cause paralysing fear, stigma, shame, denial, discrimination, inaction or mis-action? Do they foster openness, counselling, testing, sero-status disclosure and positive prevention; or do they foster the kinds of rejection, harassment, mistreatment and discrimination that drive the epidemic underground?
- c) *The presence or absence of skills* for self-protection among community members. Do community members know how to negotiate abstinence or safe sex with their current or potential sexual partners? Do they know how to store, use and dispose of condoms correctly? Are they able to read and check their expiry dates? Do they have the competence, self-belief and self-motivation to demand VCT, safe injections, safe circumcision, safe blood transfusion or the enrolment of women into mother to child transmission prevention programmes?

- d) *The availability or scarcity of health related services for self-protection.* Are HIV prevention services available, and if so, are they accessible? Examples include voluntary counselling and testing (VCT), treatment to prevent mother to child transmission (PMTCT), condom supply, safe maternity and delivery services, safe surgery, safe dentistry, safe blood transfusion and safe circumcision.
- e) *The presence or absence of supportive environments.* Examples would be those that make safe behavior and practices widely acceptable, popular, easy to adopt and routine, while making unsafe behavior unacceptable, unpopular, difficult to practice and rare. Factors in this would be psychological, socio-economic, spiritual, cultural, educational or political; they would be expressed in family, local community, national and global level policies, and in programmes and partnerships aimed at bringing about safer, healthier, fairer and more prosperous relationships.
- f) *The amount of HIV circulating in the community.* The HIV prevalence in a certain community may determine whether individual behavior or practice (which may appear to be 'acceptable', 'lawful' or 'right') is actually, in that context, 'unsafe'. On the other hand, local prevalence may determine whether a behavior or practice regarded as 'unlawful', 'unacceptable' or 'wrong' by the community is actually 'low-risk' or 'risk-free'.
- g) *The community members' frequency or infrequency of exposure to HIV* through unsafe sex, unsafe maternity and child delivery services, unsafe circumcision, unsafe injections and other skin piercing, penetrating or cutting practices and other happenings (voluntary or involuntary) that take place at community level.
- h) *The condition of sexual organs,* for example the absence or presence of sores, cuts, abrasions, whether a man has been circumcised or not and whether the sexual organs (especially of the girls) have matured to withstand/manage the wear and tear during sex.

- i) *The gender of the community member at risk of infection (positive men are more efficient transmitters of HIV to women than positive women are to men).*
- j) *The general health and competence of immune system and other variables of the members at risk.*<sup>1</sup>

From the above, we are now in position to appreciate what is meant by an 'HIV risk-prone' or 'vulnerable' community where members do not just *refuse* to adopt safer and healthier behaviors and practices but in most cases *fail* due to the environmental factors at play in the context of accurate information acquisition, appropriate attitudes formation, skills building and service provision for effective self-protection against HIV and AIDS.

### **3. Contextualising HIV and AIDS prevention in the Diocese of Namirembe, Uganda**

In the final section of this paper, I am going to focus on the context I know best, which is the church community in the Anglican Diocese of Namirembe, in Uganda. Here we have found that scaling up HIV and AIDS prevention involves both the empowerment of individuals to behave in a risk-free or less risky way and a careful analysis of the risk-increasing (and also risk-reducing) factors that are at work in our communities.

In doing this, we have learned to use the Bible in particular ways, notably as a lens for 'seeing' the reality of our lives in community, by starting with what is actually happening in our midst, and looking for resonance and dissonance between that reality and the Word of God. In doing this, we have discovered that there is a very big difference between what we know as 'acceptable, right, lawful, and faithful' in the eyes of God and what is known as 'safe' in the context of HIV and AIDS. In other words we are discovering and

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<sup>1</sup> Science is still exploring the mystery of people who remain negative despite regular exposure to HIV. It is now common scientific knowledge that HIV positive people with undetectable viral loads in their blood systems due to effective and impactful ARV treatment are not able to transmit the virus to others - even if they were to be tempted to.

frustrating the plans of the Evil One, recorded for our awareness, and taking heed of what is written in Nehemiah 4:11: 'Our enemies said: "They will not know, they will not see until we come in their midst, kill them and cause their work to cease"'

What are we doing in Namirembe to intensify HIV prevention?

*We are educating, encouraging and supporting community members to adopt safe practices through:*

- community awareness raising workshops, seminars and sermons;
- attitudinal change training events;
- skills building session for behavior change, positive living etc;
- counselling in pre marital and pre/post testing contexts;
- testimonies from HIV positive and personally affected community members;
- interpreting and re-interpreting scriptures to enhance understanding, in particular about sexual relations (see box);
- understanding that, when the Bible teaches: 'Drink water from your well/cistern', it does not go ahead to ask the questions: what type of water is in that well/cistern? Is it safe or unsafe water?

*We are supporting community members living with or vulnerable to HIV to live positively, to access treatment and care and to participate in HIV prevention programmes and activities, through:*

- loving, caring and being church;
- initiating and strengthening church-run and church-sponsored post-HIV-test clubs, home care programmes and referral services;

- campaigning for increased treatment programmes and funds through days of prayers to enhance solidarity;
- offering treatment in church run and church supported clinics and hospitals.

*We are encouraging, funding and multiplying voluntary, routine and stigma free counselling and testing by:*

- sponsoring mobile counselling and testing services to communities far from testing centres;
- subsidising the cost of HIV tests;
- offering testing and counselling services through church run clinics and hospitals.

*We are empowering children, young people, families and communities living with or vulnerable to HIV by:*

- running child-to-child peer education, 'Youth Alive', 'Daughters of the King', 'Minus One', programmes in Sunday schools, Youth Fellowships, Mothers' Union, Christian Women Fellowships and activities in parishes;
- giving leadership space to people living with HIV or AIDS;
- participating in national, regional and international action and advocacy agenda for accelerated HIV prevention.

### **The wise and foolish virgins of today**

It is not only sex outside of marriage that is 'foolish' and 'deadly' as Proverbs 5 and 7 teaches. In the context of HIV risk it is *all unprotected sexual intercourse with someone whose HIV status is not known as HIV negative, whether that*

*sex is in marriage or outside of it.* In the context of Matthew 25:1-13 and in the context of HIV, there can be 'foolish virgins', who marry without testing, who do not insist on condom use in a situation where a spouse's sero-status is not known as HIV negative, who do not guard against other routes of HIV infection beyond sex and who do not advocate for safer, healthier and fairer policies, programmes and practices in their socio-cultural, economic, spiritual and political environments. On the other hand, there are 'wise virgins' who know and appreciate that in the context of HIV risk and vulnerability, 'faithfulness' (as it is rightly taught in Proverbs 5:15) does not always translate into 'safeness' and that, in high HIV prevalence countries and communities, 'acceptable' and 'right' sexual behavior (i.e. having sex in marriage only) in unsafe public health environments may not be right *enough* or safe *enough* to protect someone against all the possible modes of HIV infection and transmission.

We believe that this multifaceted, comprehensive and truthful approach to prevention tackles unsafe, risky and life-reducing environments at family, local community, national and global level. It tackles it just as aggressively as it addresses unsafe, risky and life-reducing behaviors at individual level. In that way it puts into people's heads, hearts and hands the understanding, the skills and the competence they need, as individual men and women, boys and girls, in order to prevent the spread of HIV in their own environments; but, in addition, it will also result in the transformation of risk-increasing cultures into risk-reducing ones in all the sectors, levels and dimensions of our living. And in faith, we say, with the prophet Isaiah:

*For I am about to create new heavens and a new earth. The former things shall not be remembered or brought to mind.*

— Isaiah 65:17