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## **Hoping or Discounting the Future**

A New Perspective on the Transmission  
of HIV/AIDS

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### **Abstract**

Public policy debates, about HIV and prevention policy, have tended to occupy one of two extreme positions derived from either rational choice and or structuralists theories. This paper argues that the concept of hope may offer a way through this policy and paradigmatic log-jam. Hope is an individually measurable concept, which serves to link the ecological concept of risk environment with that of individual choices. It may be extended into broader understandings of the social epidemiology of some other infectious diseases. Use of an operationalized concept of hope also offers a possible way forward for rapid community diagnosis and participation in policy development, because it is immediately and intuitively accessible at three often separated levels: the individual actor, the researcher and those acting in the policy arena. The power of hope as an addition to our analytical armoury suggests that where there is hope, which requires structures and other resources if it is to be effective, then individual behaviour change in response to rational argument is possible. Where hope and resources are absent, behaviour change messages are less likely to be effective and other structural interventions, such as micro-finance, are found not only to provide income but also to offer hope. Incorporation of this variable is likely to strengthen efforts to achieve behavioural change.

Keywords: hope, health, poverty

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## 1 Introduction

The HIV/AIDS epidemic is one of the most serious epidemic events to affect human beings since the middle ages. It can be characterized as a very long wave event as the duration of the epidemic probably extends over many decades, and one observer has suggested that the natural history of the disease pathogen together with its epidemiological expression points toward an epidemic lasting at least 120 years.<sup>1</sup> Indeed, it is probably more accurate to describe this event as an ‘endemic’ rather than as an epidemic, given that the latter term is more aptly applied to acute outbreaks of infectious disease which are contained within a human life span. HIV/AIDS extends far beyond a single human life span.

The simple fact is that there is no one Human Immunodeficiency Virus and no one HIV epidemic. Instead, HIV is a group of closely related viruses and its epidemiological manifestation depends on the particularities of human societies, social relations and cultures at different times and in different places. Perhaps best thought of as a large clan, HIV falls into three main sub groups, HIV-0, HIV-1 and HIV-2. These sub-clans are not equally aggressive and when we speak of ‘HIV’ we usually mean the group of immunodeficiency viruses referred to by the label ‘HIV-1’. HIV-0 is a rare infection which seems to appear when someone already has another HIV infection, usually HIV-1; HIV-2 is altogether less virulent and has a longer life cycle than HIV-1 and appears to be poorly adapted to transmission via heterosexual sex. It has remained quite geographically localized in parts of West Africa. The HIV-1 epidemic is itself a multiple epidemic arising from the spread of a complex family of HIV-1 types, subtypes and strains (often called ‘clades’) around the world. These clades have established themselves in different geographical niches. The HIV epidemic thus exhibits diversity at the microscopic level. It is also diverse in the way that it appears epidemiologically in different parts of the world.

In the most general terms the differences between epidemics originate in the dominant ways that human body fluids are transferred between individuals producing the following conventionally used types of ‘pure’ types: blood and blood products as in transfusion related epidemics; intravenous drug use epidemics; sexually transmitted epidemics. Any of these may be combined, thus for example sexually transmitted epidemics may span the full range of human sexual activities and be combined with intravenous drug use. It is well known that the first epidemic identified was sexually transmitted between men in Europe and North America (Centers 1981) (Gottlieb et al. 1981) but that subsequently the driving force of the global HIV epidemic has been heterosexual transmission. And the largest epidemics in terms of percentage of people infected is currently in Africa while the largest numbers infected in any single country are to be found in India where around 5.7 million (range 3.4–9.4 million) people were estimated to be carrying the virus at the end of 2005 (UNAIDS 2006).

Most prevention efforts in relation to HIV have been based on standard models of individual behaviour change. However, it is evident that people do not change their behaviour in any simple way in response to health messages. In this paper it is suggested that between the message and its adoption lies an important variable which modulates the degree to which a message may be acted upon. This variable is hope. It is

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<sup>1</sup> Personal communication from Sir Roy Anderson, Imperial College, London.

a variable which has the major advantage of linking individual's capability of responding to health messages to the social, cultural and economic circumstances in which they live their lives. In other words, the concept of hope may be an important corrective to those who claim the problem of behaviour change is solely about individual decisions and also to others who argue that structural interventions must precede people's ability to respond to prevention messages. Hope links individual behaviour and social structure together and hints at a genuine social epidemiology of HIV prevention.

## **2 How to prevent HIV transmission**

The debate over prevention of sexual transmission of HIV has been deadlocked between ABC rational choice theorists and the supporters of PEPFAR in particular who are proponents of the simple rational choice model based on individual choice, deriving from the traditional health education stance that seeks to change the behaviours, views and attitudes of single individuals. Didactic interventions using the ABC strategy build on the basic behaviour change model. In contrast stand 'structuralists' who argue that structural poverty and disempowerment create the circumstances where individuals become susceptible to HIV infection. They further argue that fractured short-term responses to HIV can help drive the problem. With concepts like risk environment (Barnett and Blaikie 1992), this school of thought takes into account a more complicated and complex picture in the socioeconomic and environmental interventions it supports, which are usually long-term and intended ultimately to set the stage for individuals to make choices based on rational choice theory (Sen 1999) but from the security of a longer time perspective.

It can be seen that in fact both sides of the debate rely on the rational choice theory at one stage or another (Sen 1999). However, neither side manages to address the fact that the dominant theory does not account for why observed behaviour often differs from rational analysis. In other words, why do many people who are evidently fully apprised of the risks of unprotected sex continue to take risks which, as they know from empirical observation in hyper-epidemic societies particularly of southern Africa, are likely to lead to infection, illness and death. It must be concluded either that rational choice theory does not provide an adequate explanation for sexual behaviours or that the rational choices that people are making do not revolve around a rationality of long term personal survival but rather something else.

The sad fact is that in spite of the scope and magnitude of research relating to HIV prevention, there is no adequate theoretical apparatus to link individuals to social structure other than through concepts such as coercion and rational choice. Coercion is unacceptable and also very inefficient, but has been effective in some particular circumstances. This is the case for large-scale testing in the former Soviet Union and other such HIV prevention initiatives (Barnett, Whiteside, Khodakevich, Kruglov and Steshenko 2000). However, there are examples – like the quarantining of HIV infected people in Cuba – where coercion at a very early stage of the epidemic helped bring about desired policy results – namely a controlled epidemic. To use the example of family planning, exceptions in the use of some kind of coercion apply to few countries at certain points in time especially if you consider varying degrees of coercion and limited protection of free and informed choice.

Both sides in the current debate – a debate closely tied up with the US President’s US\$15bn Emergency Programme for AIDS Relief (PEPFAR) which has placed great emphasis on moral aspects of prevention, particularly on the abstinence component of the ABC<sup>2</sup> paradigm – endeavour to prove they are right with calls for ‘evidence-based policy’. Unfortunately this term is easily manipulated in this context. Thus:

- a) It is unclear what counts as evidence and over what period. In other words, when is ‘prevention’ deemed to have been successful?
- b) In poor countries, lack of information inevitably makes mathematical modelling necessary with its limitations of proxy representation of complex variables.
- c) Evidence can be created,<sup>3</sup> selected (Berger 2000; Schneider 2002) interpreted (Parkhurst 2002) and monitored and evaluated in various ways. Even when evidence has shown interventions to be effective, the intervention may not translate successfully into other settings.
- d) As in the case of the index case, Uganda, which is most often associated with ABC, it is difficult to sustain the argument for a direct and simple link between past policy interventions and observed outcomes. The ‘Uganda miracle’ could also be due to diffuse, diverse changes within Ugandan communities. Evidence that abstinence-only educational programmes were a significant factor in Uganda between 1988 and 1995 does not even exist (Singh et al. 2003). What is more, implications for programmes within Uganda, let alone for other settings, may be limited now. Prevention fatigue could also help explain recent reports of rising HIV incidence and prevalence.
- e) As for socioeconomic and environmental interventions, their long-term nature and wider scope makes it even harder to control for confounding. It may also make it difficult to read evidence of specific interventions given that they are couched within development policy interventions that have been around for over 50 years in one form or another. One important exception to this is the IMAGE intervention in South Africa (Pronyk et al. 2006).

This means that a way forward may be to find a way to account for differences between actual observed behaviour and behaviour based on best outcome according to economic theory. This disconnect has existed even before increased morbidity and mortality of productive generation of adults lost to HIV/AIDS started turning development models based on macro-economic theory on its head. The way forward should also address at least some of the shortcomings of evidence alluded to above and help transcend the debate between the two main camps by focusing on common denominators.

So, what alters possibilities for rational choices? How does knowledge about risk become authoritative? How can we understand individual susceptibility to infection, epidemiological observations of the social distribution of patterns of infection and, finally, devise workable policy interventions?

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<sup>2</sup> ABC – Abstain, Be faithful, and if that fails, use a Condom.

<sup>3</sup> Risk factors can be dependent on questionnaire design, for example, as documented by Carswell et al. 1989 and Serwadda et al. (1992).

### 3 Hope

Hope or hopelessness could provide a means to break through the impasse. The ability of people to realize their ambitions, to have ambitions and to visualize ways to achieve them are factors that enable or constrain the potential success of HIV prevention. Hope values the future; hopelessness discounts the future. Considering HIV prevention in particular from an empowerment/rights approach using a new variable based on Snyder's concept of hope could be one way systematically to discuss the famous statement by Max Weber that 'all action is rational from the point of view of the person who acts' (Weber 1964). This would be a way forward which took proper account of the social nature of epidemiological analyses (Krieger 2001).

Hope could account for a number of observed characteristics of the epidemic that do not fit neatly into either of the existing dominant approaches which have been outlined, in particular, the now widely recognized fact that HIV transmission is poorly if at all related to poverty (Gillespie et al. 2007; Piot et al. 2007), but may be related to levels and forms of social, economic and cultural inequality. As a conceptually distinct and operationalizable variable, hope provides the possibility of measuring and explaining in more local terms ways in which ecologies ensure determine the regulation of risk to the individual via individuals and groups of individuals and, in this, provide an outline for understanding differing potential for behaviour change. Surveys of relative hope levels in and between communities might be a way forward for identifying high-risk environments. As opposed to more global indices, for example the GDI and GEM,<sup>4</sup> the benefit of measuring hope could be that it could be more sensitive to geographical variation and, in this, help target HIV prevention.

Snyder's definition of hope encompasses what are essentially pragmatic and measurable elements: mental attitude ('cognitive set'), vision of future ('goal directed'), and practical way of achieving envisaged goals via consideration of agency ('individual and communal action') and pathways ('pragmatic consideration of how to act'). This definition echoes the language of empowerment in the sense of the capability to make meaningful choices with control over resources (physical, human, intellectual and financial) and to have agency and achievements (Kabeer 1999). Like empowerment, Snyder's concept of hope is a stronger concept than participation. It also encompasses both groups and individuals. Moreover, it can be argued that hope like empowerment, which has consistently been shown to be an important precondition for safer sex (Campbell and MacPhail 2002), can help measure the imbalance of power between men and women and address discrimination based on gender. In the process, it can also take into account the different needs of men and women.

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<sup>4</sup> Gender-related development index (GDI) consists of indicators compare female against male: (1) life expectancy at birth, (2) adult literacy and GER, and (3) estimated income. Gender empowerment measure (GEM) compares female to male (1) share of seats in parliament, (2) positions as legislators/senior officials, managers/professional and technical positions, (3) estimated earned income.

#### 4 Poverty, HIV prevalence and hope

The disease rarely has a homogenous impact on the population. Hope could help shed light on the widely-documented interplay of poverty, inequality and HIV and specifically on the determinants behind health-related behaviour in order to explain who is impoverished and why. The relationships are more complex than equations stating that urban HIV seroprevalence increases as (a) GNP per capital declines and (b) income inequality rises as measured by the GINI coefficient. Poverty can be a major determinant, but this is not always the case (Bloom et al. 2002). The poverty-prevalence-link may be dependent on time, stage of the epidemic and male:female ratio.

A halting conceptual attempt to resolve the conundrum rests on the possibility that while income and wealth are important in explaining some of the infection pathway, another very component is the degree of social cohesion with the Gini coefficient as a possible proxy for this. The argument is that income disparity often results in poor social cohesion and increases opportunities for transactional sex. Investigating social cohesion can provide a tool for social change and gendered power relations, in particular. Power matters, because people without power are less likely to exercise control over vital aspects of their lives and to take charge of their health and seek health-enhancing behaviours<sup>5</sup> (Wilkinson 1996). If they also lack hope then their relative powerlessness will combine with this to discount the future and thus expose them to sexually related risks (Barnett, Whiteside and Decosas 2000). Use of the term social cohesion suggests that the pathway for individual infection runs through social capital.

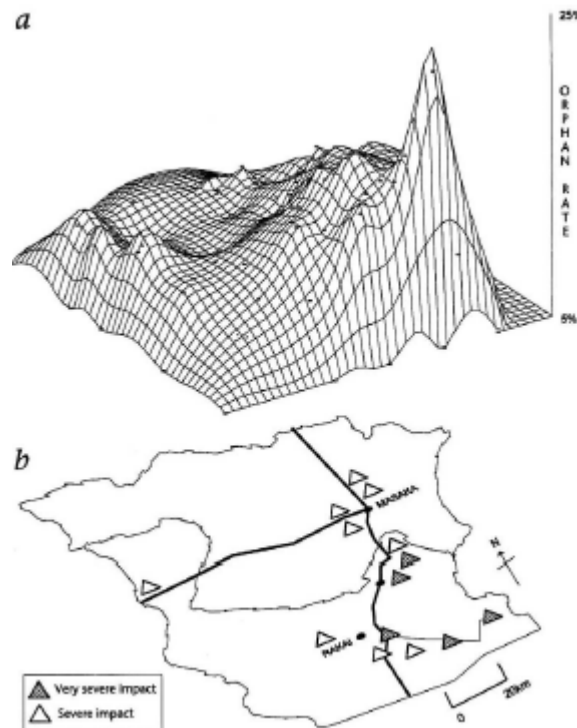
Social capital (as opposed to physical and human capital) describes the social framework, the bonds, customs, responsibilities and obligations of the members of a social network and has central tenants like trust, reciprocity, cooperation and the attainment of common goals. Social capital is significant to public health status in the sense that its social framework and key tenants are usually undermined or broken down when levels of poverty, inequality and mobility rise (Barnett and Blackwell 2005). Social capital is affected by chronic illness, death and orphaning through its impact on the host household (Harvey 2003). However, social capital explains little about how in any given structure of income/wealth inequality some are able to take advantage of those in need. This is particularly the case for gender relations and the trading of sexual favours (Collins and Rau 2000).

In 1997 Low-Beer et al. provided topographical plot (see Figure 1) of HIV seroprevalence as represented by orphaning events over time, laid over a map of south-western Uganda centered on Rakai District, where peaks and troughs were explained by a number of factors, some geographical to do with communications, some historical, to do with warfare. These troughs and peaks could also be linked to individual behaviours via hope, where higher or lower levels of individual hope may have been associated with longer or shorter time horizons in relation to the potential effects of then current sexual behaviour decisions. We cannot now know about this in relation to the situation in Rakai in the early 1990s, however, it would be of considerable use to test this hypothesis longitudinally in relation to current and future studies of sexual behaviour

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<sup>5</sup> Bandura (1996) quoted in Campbell and MacPhail (2002).

Figure 1. Comparison of geographical distribution of orphan rates with estimated demographic impacts of AIDS in Rakai and Masaka districts (from Low-Beer et al. 1997, op. cit.)



and HIV prevalence in southern Africa. Just such a test of this hypothesis forms part of a study of the SAFE project in Kasungu district, Malawi, now being undertaken by Professor Lance Weinhardt and his team from the Center for AIDS Intervention Research at the Medical College of Wisconsin.

Early work (Barnett and Blaikie 1992) in Uganda suggests that the situation in Rakai in 1989 could best be described through the concept of a 'risk environment' where sexual behaviour was seen not to be risky in itself but only in a particular environment. In other words, the behaviour was not intrinsically risky, rather the environment made it so. This gave rise to the notion of an ecology of risk, where risk was differentially distributed across a social or geographical space depending on the coming together of specific factors which made a particular activity 'risky' in a specific environment.

From the perspective of the current paper, hope is a conceptually distinct and operational variable which provides a possibility for measuring via individuals and groups of individuals ways in which ecologies of risk regulate risk to the individual and thus provide an outline for understanding differing potential for behaviour change (Snyder 1998, 2000; Snyder et al. 1991, 1999, 2000).

Deployed in this way, epidemiological surveys coupled with ethnographic observation and ultimately quantitative assessment of relative hope levels in and between communities might be a way forward for identifying high risk environments. This could then enable communities to be pinpointed in which further exploration of social and economic conditions leading to hopelessness could expose leads into effective policy and programme responses which could reverse the existing situation, point the way forward out of hopelessness – and thus exposure to infection.



## 5 Hierarchy and powerlessness

Michael Marmot observed that chronic non-infectious illness seemed to be related to social position and that hierarchy was important in explaining the distribution of disease in British civil servants (Marmot 2003). This is now a classic study and Richard Wilkinson has extended these ideas into a general theory of the distribution of chronic disease in relation to social inequality (Wilkinson 1996). The essence of this hierarchical account of disease distribution is that people at the lower end of hierarchies over long periods often by definition lose hope of advancement, feel powerless and turn this inwards with resulting stress related illness. Given the degree to which identity is tied up with career and work for most people in rich countries, this should not surprise us, and indeed for many people, learning to live with limited aspirations is the corollary of coming to terms with the relatively high living standards provided in such societies. Some do not come to terms with this at all and suffer poor health, while others come to terms with it through excessive consumption (Martorell 2001). Such responses to lowly social position may be thought of as future discounting responses and a search for short-term satisfactions.<sup>6</sup>

The relation between this observation and HIV infection is that if we return to the topographical representation of the Ugandan epidemic circa 1986-9, then many people were taking decisions, including sexual decisions, which were concerned with survival rather than with longer-term goals.

## 6 So what of hope?

As a link between the pathogen, the individual, social and economic structures, hope offers the following analytical advantages:

- (a) It is measurable using fairly straightforward scales (Snyder et al. 1991; Babyak et al. 1993; Snyder et al. 1996; Snyder et al. 1997);
- (b) It is easily understood by politicians and others in a position to allocate resources;
- (c) It is understood by ordinary people who may be able to tell us directly what is required to restore hope and therefore directly inform policy.

Furthermore, it may turn out that, like happiness, levels of individual hope are not directly related only to income, although up to a certain point this is undoubtedly the case, but after that other factors such as the nature of government become of considerable importance (Frey and Stutzer 2002; Nettle 2005; Diener and Oishi 2000; Oswald 1997). That this is the case is implicitly recognized in the Human Development Index (HDI), which are generated from three components:

- (1) A long and healthy life, as measured by life expectancy at birth

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<sup>6</sup> Explored at great length from various perspective in Bernstein's three volumes: Bernstein (1971: vol. 1; 1973: vol. 2; 1975: vol. 3).

- (2) Knowledge, as measured by the adult literacy rate (with two-thirds weight) and the combined primary, secondary, and tertiary gross enrolment ratio (with one-third weight)
- (3) A decent standard of living, as measured by gross domestic product (GDP) per capita at purchasing power parity (PPP) in US\$.

Hope also has the following advantages:

- (1) We know that the HIV epidemic has become increasingly ‘feminized’ and many researchers and advocates have pointed out the importance of gender inequality in its spread. Some of this reflects IPV (intimate partner violence), some reflects the powerlessness of women in stable relationships where their male partners are unfaithful, but an unknown component also reflects the ways in which women deploy their sexuality as a part of a livelihood strategy in response to heavily discounted futures where circumstances of poverty and instability cause this to happen;
- (2) We know that the spread of intravenous drug use is rapid in the poorest groups in the US and Western Europe and that it has been very rapid in the former Soviet Union (Wodak 2006), in each case IVDUs occupy very low positions in the social hierarchy before they begin IVDU (Rhodes et al. 2005) and thus their lack of hope and discounting of the future can be argued to produce hopelessness, drug use and therefore elevated susceptibility to infection (Bernays et al. forthcoming).

It is certainly not being argued here that *all* HIV infection reflects relative hopelessness and it probably does not help us very much as a concept for explaining MSM epidemics in western Europe and North America where it has often been the highly articulate, educated and relatively prosperous who have become infected – and where notably the *individual* behaviour change model has been most effective, but never alone, always accompanied by structural factors which include collective action, solid funding support and government leadership.

Indeed, it is this case which really suggests the power of hope as an addition to our analytical armoury. Where there is hope (and this requires structures and other resources if it is to be effective), individual behaviour change in response to rational argument is possible; where hope and resources are absent, behaviour change messages are less likely to be effective and other structural interventions, such as micro-finance are found not only to provide income but also to offer hope. It is this that explains the possible decline in the conditions for HIV incidence in the IMAGE study (Pronyk et al. 2006; Kim et al. 2006).

## **7 Conclusion**

An approach incorporating hope provides new perspectives on each position in the debate. While it is particularly relevant to our understanding of HIV epidemics, it may also be appropriate for understanding the epidemiological and social processes operating in relation to some other infectious diseases, where while poverty and inequality are factors the link is not necessarily direct or obvious. Thus while the pathways between poverty and acute infections such as cholera is clear (although future

discounting may play a role in acquisition of cholera), we do not understand the processes associated with acquisition of many other infectious diseases where poverty and inequality are an issue. The idea may even have wider applications in assisting in the understanding of acquisition of these conditions and thus point to ways in which innovative social policy interventions might be generated based on sound epidemiological surveys and ethnographic observation, two kinds of evidence which are all too rarely combined.

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