

On the limited utility of KAP-style survey data in the practical epidemiology of AIDS, with reference to the AIDS epidemic in Chile*



Herbert L. Smith

*Population Studies Center and Department of Sociology, University of Pennsylvania,
3718 Locust Walk, Philadelphia, PA 19104-6298 USA*

Editorial note:

Herbert Smith raises some important issues in this article. Readers who are interested in contributing to a debate on social-science data collection in the AIDS area are encouraged to contact the Editors immediately.

Abstract

Population surveys concerning 'risk behaviours' thought to be related to the AIDS epidemic are many. Nevertheless, unfocused inquiry into diffuse behaviours in undifferentiated populations is not productive in low-seroprevalence populations, especially when the point is to design some form of intervention that might actually avert further infection. This is because of a failure to distinguish conceptually between the relevance of AIDS-related behavioural data for individuals and for populations. An illustration is drawn from the AIDS epidemic in Santiago, Chile, and an alternative perspective, based on extensive interviews with persons with AIDS and a survey of current HIV-surveillance and blood-screening programs, is described.

Introduction

The advent of the epidemic in acquired immune deficiency syndrome (AIDS) and the associated discovery of the human immunodeficiency virus (HIV) occasioned the realization that there were gaps in the social-science knowledge base pertinent to the epidemiology of the disease (Turner, Miller and Moses 1989). Homosexuality, bisexuality, and injectable drug use were characteristically studied under the rubric of deviance; and a large body of work on the sociology and demography of human fertility was developed with minimal direct study of sexual behaviour (Davis and Blake 1956; see Ryder 1973; Bongaarts and Potter 1983; Rindfuss and Morgan 1983). Efforts to redress this knowledge gap are many, and cannot be fairly reviewed here. Instead, I focus on one aspect of social science data-gathering that has emerged of late, namely, the tendency to gather attitudinal and behavioural data through population-based KAP-style surveys, and to make inferences from such data to the current prevalence and future course of the AIDS epidemic. By KAP-style surveys, I refer to questionnaire-elicited data from samples of individuals regarding knowledge, attitudes, behaviours and practices. Such surveys are legion in demography (for example, in the study of fertility and family planning

*This is a revised and abridged version of a paper entitled 'AIDS prevention research: population-based and epidemiological perspectives, as applied to the AIDS epidemic in Chile', by Herbert L. Smith, Nilda Peragallo, Ximena Ferrer S-G, Eileen T. Lake and Linda H. Aiken, and presented at the 1992 Annual Meeting of the Population Association of America, in Denver, Colorado. When I write in

[Population Council Inc. 1967; Hermalin, Entwisle and Myers 1985]) and health behaviour (for example, in the study of oral rehydration therapy [Yoder, Drew and Zhong 1989]), and have been seconded or adapted to topics associated with AIDS and the spread of HIV. For example, the US National Survey of Family Growth, hitherto primarily a fertility survey, added batteries of questions on knowledge of transmission of AIDS and behaviour modification attendant on the epidemic (McNally and Mosher 1991); and a substantial component of the World Health Organization's (WHO) Global Programme on AIDS (1989, 1990) was a large set of national studies, chiefly surveys, regarding AIDS-related knowledge, attitudes, beliefs, and practices. More typical are the restricted-population surveys of 'risk behaviours' routinely reported in, for example, abstracts appearing in Track D (Social and Behavioral Science) of the annual International Conferences on AIDS (Istituto Superiore di Sanit¹ 1991).*

This surge in data collection has probably improved our knowledge about the distribution of assorted practices and predilections in a variety of populations. It is less clear that such data are of great use in understanding the epidemiology of AIDS in a given population. This last remark arises from experience gained in seeking to develop effective interventions against AIDS in Santiago, Chile. The argument developed below is made primarily with reference to the Chilean AIDS epidemic, but is intended to apply, *mutatis mutandis*, to other populations as well.

This paper is organized as follows. I begin with a brief review of AIDS in Chile, with an emphasis on the nature of existing sources of information about the epidemic. This leads to a more general discussion, with Chilean examples, of the limitations of certain data-collection schemes, and corresponding analytic categories, with respect to the apprehension of information relevant for the design of intervention programs. The schemes and categories derive primarily from the aforementioned KAP-style behavioural surveys. In their stead, I sketch, in the following section, an alternative perspective gleaned from extensive interviews with several dozen of the known individuals with AIDS in Santiago, and a survey of the current HIV-surveillance and blood-screening programs in the Santiago area. I conclude with brief comments on the need to distinguish conceptually between the relevance of AIDS-related behavioural data for individuals and for populations.

Background

The AIDS epidemic in Chile appears to be at a fairly early stage, even in comparison to other South American countries (Quinn, Narain and Zacarias 1990). The first (five) AIDS cases in Chile were diagnosed and reported in 1984.¹ Official cases doubled annually up to 1987 and biannually up to 1991, when 163 cases were reported. Of the 507 cumulative AIDS diagnoses, 94 per cent were males. Most people diagnosed with AIDS were still alive in late February 1992, even those diagnosed as far

* the first person singular I refer to my own thoughts and arguments; when I write in the first person plural I refer to joint research activities with my earlier co-authors. In addition to my collaborators, I thank John Wilmoth, Susan Watkins and an anonymous reviewer for helpful comments on earlier versions; Jennifer Klocinski and Sharon Donovan for their help in the preparation of this paper; and the Center for Health Services and Policy Research, School of Nursing, University of Pennsylvania, and the *Centro Internacional de Investigaciones Collaborativas, Fundacion Arriaran*, Santiago for research support. The research was funded by the National Center for Nursing Research, of the US National Institutes of Health (NIH 5R01 NR02754-02), and the United States Agency for International Development, through Family Health International (#4021-6). The views expressed herein are my own, and may not reflect those of the aforementioned individuals, institutions and agencies.

¹ All data in this paragraph are drawn from unpublished tables and figures provided by the Chilean Ministry of Health, dated 25 February, 1992.

back as 1987. Seventy per cent of AIDS cases are concentrated in the Santiago metropolitan area; a secondary cluster of 20 per cent, larger relative to the population base, is found in the urban coastal region that includes Valparaíso and Viña-del-Mar. An additional 742 individuals have been confirmed positive for HIV infection. They were identified by a combination of notification by partners, self-selected testing, screening by the medical system, and testing of blood-bank donors. Discovery of asymptomatic HIV-positive cases has outstripped diagnoses of AIDS since 1989; in 1991, there were roughly twice as many new HIV-positive cases as AIDS cases.²

Fifty-one per cent of the 468 adult males diagnosed with AIDS are categorized as homosexual, 24 per cent as bisexual, and 13 per cent as heterosexual. The remainder are classified not by sexual orientation, but by apparent means of transmission (that is, they are haemophiliacs, transfusion recipients, injectable drug users and means not known [*desconocida*]). Women are primarily classified as heterosexual in the sense that they appear to have contracted the virus by sexual contact with a male. HIV-positive asymptomatics are not classified by sex in classifications of sexual orientation or means of transmission, nor are bisexuals distinguished from homosexuals, but it appears that asymptomatics are somewhat more likely to report being heterosexual. These classificatory exercises are of most interest with respect to the questions of whether there is one or more than one AIDS epidemic in Chile, and where the epidemic may be heading. Taken at face value, approximately half of the cases occur among individuals who are reported as something other than male homosexuals, and this in a country without much of an indigenous injectable drug culture.³ The large number of men classified as bisexual and heterosexual may be related to the same ambivalent definitions of homosexuality noted by Carrier (1989) for Mexico. The official classification scheme derives from a risk-assessment inventory that appears on the official medical-notification form, and the amount of inquiry underlying these classifications is likely to vary.

It is likely, of course, that there are many more HIV-positive individuals in Chile than have been detected, but the number is uncertain. Bernal (Bernal et al. 1988:257) advocates an estimation strategy based on two multipliers attributed to the WHO: first, AIDS cases are underreported by a factor of two; and secondly, for every sick person there are 50 to 100 infected individuals. The size of these multipliers, coupled with uncertainty about the base number of cases, has a destabilizing impact on estimates: in two papers published in the same year, the number of 'healthy carriers' is placed at, respectively, 10 to 20 thousand (Bernal et al. 1989:15) and 20 to 40 thousand (Bernal, Lukács and Bonacic 1989:127). These ephemeral estimates are adduced in support of a prescriptive intervention: 'a politics of AIDS education, teaching responsible sexuality, inspired by deep ethical and moral values' (Bernal et al. 1989:15). This may explain why they are not reconciled with one another nor, later, with

² Official tabulations distinguish between patients with AIDS and patients with HIV, sometimes referred to as 'carriers'. The distinction derives from a question on the official medical notification form (*Encuesta Epidemiológica de Caso de Infección por VIH/SIDA*), 'Does the patient have AIDS?'. Responses of 'yes' become AIDS patients, responses of 'no' become HIV-positive asymptomatics, or carriers. Discussion with physicians and health officials suggest that many persons diagnosed as HIV-positive asymptomatics in fact have symptoms that would lead to a diagnosis of AIDS were standard (for example, US Centers for Disease Control) definitions to be applied; and there is apparently no administrative mechanism for altering official data to reflect reclassifications as the disease progresses.

³ Most of the initial AIDS cases linked to drug use appear to involve comparatively high socioeconomic (SES) status individuals and/or those who have lived abroad. We have been told, however, that a major AIDS-care clinic in Santiago is now working with a cluster of low SES individuals who share needles in the intravenous injection of *pisco*, a popular local liquor.

1990 seropositivity rates of 0.25 per 1,000 blood donors, a group touted as 'very much representative of the general population' (Bernal 1990:143). Such seropositivity rates would imply approximately 2,000 HIV-infected persons, given eight million Chileans aged 15-64 in 1990.

In Chile, both knowledge-gathering about AIDS and opportunities for intervention are circumscribed by the country's recent political history. The transition from 17 years of authoritarian rule to democracy has so far been a success, but the shadow of the former regime is long. Chile remains a fundamentally conservative, Catholic nation, in which public discussion of sexual matters attendant on educational campaigns is highly controversial. The authoritarian period appears to have left a legacy of individual compliance and acquiescence in domains that elsewhere, for example, in the United States, are arrogated to personal privacy. This is in spite of recognition by the current government that strong respect for individual liberties is necessary to avoid the human-rights abuses of the previous regime. The opportunities and difficulties of dealing with the AIDS epidemic in a nascent democracy were clearly on the minds of those responsible for drafting the medium-range program of the national AIDS commission (*Comision Nacional de SIDA* [CONASIDA]):

The task [of the national AIDS commission] has arisen in the context of the return to democracy in the country. In some ways, it is possible to assume the challenge of the epidemic in conditions of greater openness and social discussion over the problems that matter to the nation, and with less censoring and restrictions than in the recent past. But the Program [of prevention and control of HIV infection] also occurs at a time when it is the responsibility of the State to reconstruct feelings toward social order, and to undertake this charge with serious legal and economic constraints (CONASIDA 1990:127).

Public discussions of homosexuality, youth sexuality, and condom use are now possible in Chile, but they wear on a frayed social fabric.

Thus data-gathering efforts attendant on the AIDS epidemic in Chile are modest. There is a fairly elaborate monitoring of seroprevalence in the blood supply (Lake et al. 1992), but there have been no seroprevalence studies of the homosexual and bisexual populations, as have taken place in Peru, Brazil, Mexico, Argentina, Colombia and elsewhere in Latin America (Quinn et al. 1990:713; Caceres et al. 1991). Chile did participate in the Global Programme on AIDS: Social and Behavioural Research Unit, specifically the Research Package: Knowledge, Attitudes, Beliefs, and Practices on AIDS (Phase I). The Chilean component of this study was a random sample of men and women aged 18 to 50 in Santiago and two urban seaport areas on the central coast. The sampling frame was based on households and as there was no sampling frame for homosexuals, the relevant modules from the WHO Programme were not employed. Most other KAP studies in Chile have emphasized queries regarding knowledge and attitudes over those pertaining to practices, and have involved populations defined by geography and vocation, whose links to the locus of AIDS and HIV infection in Chile range from potential (female prostitutes [Luckacs et al. 1990] to more probably rhetorical than real, students [Rugiero et al. 1990; Santa Mar'a, Daniel and Rojo 1990] and other young adults [Valenzuela et al. 1991]).

A critique of KAP-based inquiries

Manton and Singer (1989:178) are pessimistic

about the cost-effectiveness of investment in large nationally-representative surveys of seroprevalence, disease incidence and prevalence, and disease processes. This is because the disease mechanism is too complex, its population incidence too low, and the privacy and confidentiality issues too great to allow such surveys of infection to be successful.

Analogous criticisms pertain as well to KAP-style surveys. The one-shot survey process is not well suited to obtaining valid measures of intimate behaviour, all the more so when some forms of behaviour are normatively sanctioned.

At first blush this would appear to imply that such surveys are underreporting behaviours relevant to the study of the spread of HIV. For example, the WHO KAP study covering Santiago (Pereda and Cifuentes 1991) sought to get around the unease associated with certain questions by conjuring a 'mirror sample'. Respondents were asked to think of a friend of their same age and sex, at random, without any overt cue from the interviewer as to why they were supposed to be thinking of this individual. Respondents were then asked a battery of questions about this 'friend' whether they have two or more regular partners, have had sex with occasional partners, have had anal sex, oral sex, or sex with someone of the same sex. Not surprisingly, reports about 'friends' exceed those in response to similar questions about the respondents themselves, for both sexes and young and middle-aged adults alike. The investigators do not leap to the conclusion that the 'friends' reports provide a criterion for assessing the validity of self-reports. They acknowledge that after so many questions about AIDS in the survey instrument up to the point of the 'friends' questions, respondents may have been led semi-consciously to select a friend whom they thought might have more of these risk activities. It is perhaps revealing that in the one area where respondents might be prone to over-report their own behaviour, the reports by young men of the number of female partners, regular and occasional, the survey respondents still put their 'friends' way ahead of themselves.

If, however, the emphasis is on relevant behaviours, then there is almost certainly overreporting of associated risk, owing to no fault of the respondents, but rather to a failure of investigators to think hard about the relationship between the behaviours they are measuring and the disease phenomenon they are studying. The last several years of AIDS research have seen much self-congratulation attendant on the shift in focus from 'risk groups' to 'risky actions' (or behaviours) (for example, Schopper 1990:1266) and there is certainly much to be said for ceasing to contribute to stereotyping and stigmatization – of homosexuals, of African-Americans, of Haitians, and so on – which was all too prevalent before the AIDS epidemic. In Chile, the national AIDS commission has advocated the abandonment of '*grupos de riesgo*' in favour of efforts directed at '*las prácticas de riesgo*', primarily with reference to the unfairness of the former term (CONASIDA 1990:129).

Whether the shift to a focus on risk behaviours has had a concomitant scientific payoff is less clear. Perusal of, for example, Track D (Social and Behavioral Science) of the Seventh International Conference on AIDS (Istituto Superiore di Sanit^e 1991) suggests that there is now a veritable cottage industry that competes in the use of general population surveys to document ever larger numbers of individuals 'at risk' of HIV infection. Such efforts have the best of intentions: there are individuals all over the world, in all walks of life, who are HIV infected; and in virtually all cases it is possible to identify some past behaviour directly implicated in transmission of the virus. Conversely, it is possible to specify a set of behaviours (such as abstinence or monogamy plus condom use) that would all but guarantee for any individual the impossibility of HIV infection. The fallacy, however, is the leap from the necessity of certain behaviours, with respect to HIV infection, to their sufficiency. Particular behaviours may have little to do with the presence of the virus.

Forms of sexual activity

Men and women are queried regarding forms of sexual intercourse, specifically anal intercourse. Let us set aside here the distinction for males between insertive and receptive anal intercourse with another male, not because it is not useful information, but because the rate of reported homosexuality is low in general population surveys. Anal intercourse is a classic 'risky behaviour' in surveys of heterosexuals, owing to certain physiological and epidemiological evidence that being the receptive partner raises the

relative risk of infection. Relative to what? Relative, typically, to vaginal intercourse. But the data underlying such studies of relative-risk condition on the presence of HIV infection in the insertive partner, either explicitly, in the case of HIV-discordant couples, or implicitly, as in studies of female prostitutes for whom, in certain settings, sustained exposure to HIV is not improbable. In low-seroprevalence populations, this relative risk has little meaning. It is easy to imagine other information that, when linked to reported forms of sexual activity, makes the relative risk of anal versus vaginal sex irrelevant. What is the risk of anal intercourse with a single partner versus vaginal intercourse with a very large number of partners versus vaginal intercourse with a single partner with a history of injectable drug use? Giesecke et al. (1992:101–102) make the same point, as do Hearst and Hulley (1988), who consider the issue from the standpoint of what doctors should advise patients.

Often the situation is worse, since the risks are conflated with one another in ways that do not make sense even conditioning on the presence of HIV in one partner. Bernal, Bonacic et al. (1989) offer an omnibus KAP questionnaire that contains a battery of items on personal conduct, beginning with smoking, alcohol consumption and use of marijuana, moving through such diverse topics as the viewing of pornographic movies and receipt of blood transfusion, and eventually reaching (*seriatim*) group sex, anal sex, and oral sex. Anal sex and oral sex are combined together in a later article in which survey data are presented, for a sample of Chilean teachers and students (Bernal, Lukács et al. 1989). Here the researchers' conceptualization of risk factors appears to derive more from a generalized notion of 'deviance' than from anything we know about the epidemiology of HIV since, as sex goes, oral sex is a comparatively innocuous means of transmission; and there are no reports of HIV transmission directly related to the viewing of pornographic videos.

Numbers of sexual partners

Advocates of the study of risk behaviours are not unaware of the contingent issues raised above, although they tend to address them by adding risks rather than conjoining them. Thus 'multiple partners' is a common component of 'risk-assessment' scales. But a focus on this particular 'risky action' often reflects a confusion between the prevalence of branching conditions required to sustain an epidemic in a population or subpopulation and the risks to an individual of alternative forms of sexual behaviour. We first consider the latter.

Eisenberg (1989) derives the relative probability of HIV infection under simple conditions: There are n sexual contacts with m partners, 1^2m^2n , and the HIV status of contacts may or may not be known. Risk of HIV infection, in increasing order, is as follows:

- A. a monogamous relationship with a non-infected partner ($m=1$);
- B. a monogamous relationship with a randomly selected partner ($m=1$);
- C. m randomly selected partners ($1 < m < n$);
- D. n randomly selected partners ($m=n$);
- E. a monogamous relationship with an infected partner ($m=1$).

This ordering exercise is useful because it reminds us that the main dimension underlying variation in risk is not monogamy versus multiple partners, but rather the HIV status of partners. The interest in labelling 'multiple partners' a 'risk behaviour' appears to reside in the much lower risk associated with type A behaviour than types C and D. However, undifferentiated inquiry into number of partners is more akin to comparing the risks of type B with types C and D. For infection rates per sexual contact with an infected individual of 1 per 1,000, the difference between one contact with each of n randomly selected individuals (type D), and n contacts with one randomly selected individual (type B), is

vanishingly small, even with prevalence rates as high as 0.5, at least until $n=200$ (and relative risk remains less than two even at $n=1000$). Moreover, and especially in low-seroprevalence populations, having multiple partners (type C and D behaviour) is far less risky than a monogamous relationship with an infected partner (type E). The apparent triteness of this last observation is reduced when we drop the assumption that a partner's HIV status is either known or positive with probability equal to the average level of seroprevalence in the population under study. More probably, there are observable characteristics of partners that condition the probability of HIV infection to the point where multiple partners chosen from one subgroup are less risky than a single partner chosen from another group.

Returning to an epidemiological perspective, I acknowledge the potential utility of data on multiple partnerships since, *ceteris paribus*, the more branches from a given node, the greater the speed and penetration of the virus within the population defined by the network. Certainly there is a strong empirical correspondence between mean partner frequency and the velocity of the spread of HIV infection, for example, among urban male homosexuals in the United States.⁴ The problem is that populations, or subpopulations, as defined by behavioural networks are not necessarily isomorphic with frame populations for sample surveys and, even where they are, the individuated nature of a sample survey militates against an epidemiologically sophisticated understanding of the meaning of multiple partnerships. The importance of 'weak ties' – relationships between one's partner or partners and their partners to whom one is otherwise unlinked – for propagating the diffusion of anything from ideas to disease is well-apprehended in sociology (for example, Granovetter 1973) and social epidemiology (for example, Hunt 1973). Thus Wallace (1991) argues that social and geographic dislocation create the sort of weak ties necessary for the continued spread of HIV infection, but that information about reducing risk behaviours, and validation for same, appears to require the reinforcement mechanisms typical of integrated, 'strong-tie' networks. But network data are difficult to come by in KAP-style surveys, where even well thought-out questions on partners do not provide the information necessary for evaluating the extent of overlap in networks implied by the number of reported partners; see, for example, Section D of the proposed, but never implemented, US National Survey of Health and Sexual Behavior.

Consider, therefore, a proposal by Burt (1991), that network data collected in the US General Social Survey 'could be used to model the diffusion of AIDS through the population' (p. 27). He observes that data on 'heterosexual contacts' show great variability by age:

The implication of these results for AIDS diffusion is that contact processes are much more important than would otherwise have been thought. Diffusion through the marriage network is primarily an aging process, enhanced by contact. People move from status to status as they grow older, carrying the infection with them. This process is augmented by the concentrated ties each status has with the prior status, however, the homogeneity of the step-ladder structure across all age statuses means that the primary motor for diffusion is aging. Diffusion through heterosexual ties outside the family is quite different, and much more dependent on contact because females in status V [37-46 year-olds] are a bridge population to older people. Eliminate transmission from status V females to status V and

⁴ This empirical correspondence derives from a theoretical result – that the rate of disease reproduction is a function of the average number of partners per new partnership. This average is a function of the mean and variance for the distribution of new partners per unit of time in a population (that is, mean coefficient of variation) (May and Anderson 1987); across a wide range of studies and populations, the means and variances of these distributions are linearly related on a log-log scale (Anderson and May 1988:516).

VI [47-52 year-old] males and diffusion will be limited to aging processes, thus sparing the current older population from the infection (Burt 1991:31).

But the data on 'heterosexual contacts' are for networks based on reports of persons with whom the respondent has 'important discussion relations', not necessarily *sexual* relations! Burt (1991) argues that:

In the absence of network data on actual sexual contact, [data on important discussion relations beyond the family] indicate opportunities for sexual contact – under the presumption that sexual relations develop from the same factors that make people attractive to one another for important personal discussion. (Burt 1991:27).

Even if this presumption is correct, there is still the problem that we have no evidence that the affiliative behaviour of the population studied corresponds to that of the population that is HIV-infected. Burt (1991) offers a useful idea about the network basis of a demography of ageing without beginning to provide the rich understanding of the epidemiology of AIDS in an actual population such as appears, for example, in the contact-tracing studies of Wykoff et al. (1988, 1991) in rural South Carolina.

Most KAP-style operational constructions of risk behaviours posit an epidemiology of AIDS based on weak or irrelevant correlations. An irony is that a correlational science of AIDS runs the risk of a return to a focus on risk groups, since it is not hard to pick out sets of ascriptive social characteristics, such as race, with reduced-form relationships to HIV infection that are stronger than the relationships between risk behaviours and infections, at least as measured in low-seroprevalence populations. Nor is it clear that, were these risk behaviours reconceptualized as proximate determinants (that is, intervening variables, as in the fertility literature [Bongaarts and Potter 1983]) adjusting for differences in their distribution across groups would be sufficient to 'account for' group differences in HIV infection and AIDS. The reason is that HIV is not spontaneously generated by risk behaviours; rather, the HIV epidemic occurs when and where uninfected people have sexual contact with infected people. This occurs not at random, but at the intersection of social and geographic sites in which the confluence of group linkages and behaviours is propitious:

Research on factors influencing transmission of HIV infection has tended to ignore questions of context, yet each individual contracting the disease is deeply enmeshed in constraints defined by socioeconomic, geographic, historical and other contexts. These constraints may profoundly influence, or even determine, behavior patterns associated with the risk of acquiring disease, and can determine as well the magnitude of that risk for a given population (Wallace 1991:847).

Well designed surveys, with well specified measures across relevant populations, have their purposes: sexual-behaviour surveys of general populations for example may provide estimates of parameters required for epidemiological models of HIV infection (Michael et al. 1988). According to Anderson and May (1988:517), '[t]he most important factors in survey work are assessment of changes through time and at different spatial locations'. They note that studies of sexual activity among male homosexuals have focused on the average number of sexual partners, as distinct from the (sub)population data most necessary, namely, the distribution of new partners per unit of time (May and Anderson 1987:138-139); and describe the 'urgent need' for interview studies to gather data on rates of partner change in different communities, stratified by age and social status (May and Anderson 1987:141). Stigum et al. (1991) conducted a very large, population-based sample to model the spread of HIV infection within the Norwegian heterosexual population. Their empirical data on number of

contacts and frequency of intercourse led them to conclude that an HIV epidemic cannot be internally sustained in Norway. This conclusion is sensitive to the population's distribution of sexual behaviours, and might not have been reached were these parameters estimated with less representative data.⁵

Alternative methods of inquiry

Comments on the disutility of a standard form of social-science inquiry are themselves of limited utility in the absence of preferred alternatives. A noted statistician, pressed for advice on the conduct of social science, offered as exemplar the 'shoe leather epidemiology' characteristic of Snow's (1965 [1855]) research into the aetiology of cholera (Freedman 1991). Social scientists interested in the epidemiology of AIDS could find worse exemplars. To obtain a better understanding of the AIDS epidemic in Chile, as well as opportunities for intervention, we have been led to study the social context of AIDS in Chile, primarily through attention to people with AIDS and to the medical system that locates and deals with people with AIDS and the asymptomatic HIV-infected. Two initial studies which are described in more detail in Smith et al. (1992) and Lake et al. (1992) are summarized below.

In-depth interviews of persons with AIDS

These were undertaken to serve as a validity check on the presumed character of the epidemic as constructed from mandatory case-reporting data, and to ascertain the feasibility of various interventions. The limitations of AIDS case reporting as a method of HIV surveillance are well known (for example, Dondero, Pappaioanou and Curran 1988:214). Nonetheless, we found that these in-depth interviews were useful for addressing the following issues:

1. *Avenues of infection to the female population.* Few women in Chile have AIDS or are known to be HIV-infected, but there is widespread concern that a predominantly heterosexual epidemic is imminent (see, for example, Rodriguez 1991). Some of this thinking undoubtedly derives from the accumulation of undifferentiated evidence regarding the prevalence of 'risk behaviours', but it also has to do with the large proportion of AIDS cases classified as other than homosexual by the Ministry of Health. We were interested in probing the validity of risk-factor classifications obtained via the mandatory reporting form.
2. *Locus of infection and sexual networks.* Again, neither official reporting systems nor KAP-style surveys say much about the connectedness of persons with AIDS. We were interested in obtaining information about the nature of past sexual behaviour, likely sources of infection, and social and sexual networks.
3. *Ability to identify partners and willingness to notify them.* Studies of contact tracing and partner notification in the US have revealed that many individuals have no idea that they have been exposed to HIV (see, for example, Wykoff et al. 1988, 1991). The same probably holds true in Chile, but it is difficult to be sure because organized tracing and notification of contacts is rare. This is due in part to a belief that HIV-infected individuals cannot identify past partners or, if they can, do not want them notified. We were interested in examining the accuracy of this belief.

⁵ However, the dynamics of infection *within* national subpopulations are not independent of the dynamics of HIV transmission *between* subpopulations, and more elaborate multistate models (for example, Van Druten et al. 1990) involve parameters for which empirical estimates are difficult to obtain.

We began with a closed-ended interview similar in form and execution to that of a questionnaire that might be used in a general sample survey. Although this format elicited responses, it was not a congenial form for the discussion of sensitive topics. We then moved to an open-ended, focused interview. This format improved the richness of the responses, particularly with regard to the contextual embeddedness of the subjects, but it was not an ideal format for collecting the kind of systematic information necessary for partner notification. We eventually settled on a focused, probing interview modelled on that typical of a medical or nursing history. The discussion of intimate behaviour in a medical context is apparently less intrusive and threatening to respondents, and thus proved more effective in eliciting information of importance, particularly about sexual partners.

Between July 1991 and January 1992, in-depth interviews were conducted with a convenience sample of 44 AIDS patients by two nurse co-investigators. The patient sample included individuals at different stages of HIV-related illness, recruited primarily from a large AIDS-care clinic in the Central District of Santiago. These 44 patients constituted almost one-fifth of the total number of people alive with AIDS in Santiago at the time the interviews were undertaken.

We found that classification of subjects based on reported sexual behaviour rather than on personal identity yielded fewer bisexuals and more homosexuals. Detailed probing of social and sexual networks suggested that a substantial fraction of these individuals are in overlapping networks. That is, these subjects frequent the same discos, bars, theatres, and saunas in both Santiago and in the seaside communities of Valparaíso and Viña del Mar. The two interviewed male prostitutes work on the same streets reported to be 'hang-outs' by several of the interviewed male homosexuals. In contrast, the only locational information on the mandatory reporting form is the commune of residence, which is a locale of several hundred thousand people.

No patient refused to be interviewed. Most were still sexually active. Many reported a pattern of sexual behaviour that included a stable partner as well as casual partners. Most respondents could recall their sexual contacts over a two-year period. The vast majority of respondents believed that both their stable and casual sexual partners should be informed about their potential exposure to HIV. Two-thirds reported that they could locate all stable sexual partners over the most recent two-year period, and many had information on casual partners that would presumably facilitate their contact by health officials. There were two modest paradoxes. First, most infected patients interviewed claimed to be in favour of notifying partners, but generally preferred to notify their stable partners themselves; notwithstanding the fact they had heretofore failed to do so. Secondly, the infected individuals whom we interviewed had good knowledge about AIDS and its transmission but few reported consistently using condoms or other safer sex practices.

A systematic survey of HIV-testing sites

A desire to widen the frame from within which HIV-positive individuals could be sampled led us to consider alternative sources from which infected individuals could be identified. All HIV-positive tests (typically, ELISA) are confirmed at the Public Health Institute (ISP) in Santiago. Theoretically, the ISP should have a complete record of all HIV-positive persons and could thus provide a useful sampling frame for further study of HIV-positive individuals.

The blood samples that are re-tested at ISP derive from a large network of hospitals, clinics, laboratories, and blood banks (Sánchez et al. 1991). In Chile, blood-bank donations are obtained from the family, friends or co-workers of hospitalized patients, rather than by solicitation of the general population, as in the United States. For example, at one hospital each patient admitted to a hospital must provide two blood donors. Blood banks are exclusively located in hospitals and do not solicit donations from the public at large. In addition, many hospitals routinely screen all surgical and

obstetrical patients for HIV. This system is thus responsible for a surprisingly high level of blood testing for HIV infection.

The utility of blood-screening programs for estimating the seroprevalence of a population depends crucially on a typically unmeasured factor, the propensity of individuals to select themselves into testing programs or situations in which they are subject to testing (for example, Manton and Singer 1989). In addition, the biases attendant on self-selection may work in either direction: some HIV-positive individuals will be more likely to seek counselling and diagnosis of symptoms; others will be more likely to decline to volunteer for studies or submit to screening (Dondero, Pappaioanou and Curran 1988). We were thus led to consider the extent to which 'side information' gathered from the component sites underlying the ISP data might inform us about coverage, selectivity, and so forth.

The extent of our survey of testing sites and screening procedures is detailed in Lake et al. (1992). We are led to conclude that variability across sites in rates of seropositivity are chiefly a function of *observable* differences in who is being tested and why (that is, at whose behest: it appears that a substantial volume of HIV testing is conducted for the sake of providers and not patients). Variation in seropositivity between testing sites in different locales is comparatively low, especially when contrasted to variation within sites (that is, tests of blood bank donors as contrasted with tests for hospitalized patients and others for whom the hospital staff believed a test to be indicated).⁶ Comparatively high rates are found in unsurprising places: an AIDS clinic, STD clinics, and a penitentiary, where testing is consequent on suspected homosexual activity.

Variation in screening protocols and content allows entry of some 'high risk' individuals into the donor pool. Screening is not standard across sites, nor is it primarily intended to identify and exclude donors at high risk of HIV infection. There is both interview and anecdotal evidence that some individuals use blood banks as HIV-test sites, since tests through blood banks are free. Given what we have observed about blood-bank screening and the proportion of positive results, we suspect that seroprevalence rates based on blood donations, low as they are, probably overestimate the 'general population' prevalence (compare Bernal 1990:143; S nchez et al. 1991:1277).

Conclusion

I have argued that unfocused inquiry into diffuse behaviours in undifferentiated populations is not a productive line of research in the epidemiology of AIDS and HIV infection, particularly in low-seroprevalence populations and especially when the point is to design some form of intervention that might actually avert further infection. Such inquiry, which aggregates individual behaviours of dubious relevance, has promoted prescriptions for mass behaviour modification at the expense of traditional methods of control of sexually-transmitted diseases, such as contact tracing and partner notification, with their focus on actual social and sexual networks and the true aetiology of viral contagion.

Undifferentiated extrapolation of the early stages of the AIDS epidemic in Chile led to predictions that the Chilean epidemic lagged behind that of Brazil, Canada, Africa, and the United States by somewhere between two and five years (Bernal 1989a,b). This does not appear to be coming to pass, a point in support of May and Anderson's (1987:140-141) 'distrust' of extrapolations not 'based on the underlying epidemiological phenomena'. But the number of new cases is increasing annually in Chile

⁶ The distinction between blood donors – individuals giving blood to clinic blood banks – and all blood samples subject to testing for the presence of HIV (as confirmed by ISP) is not always clear. For example Bernal's (1990b:142–143) discussion of the reason for a 300 per cent rise over a two-year period in the seroprevalence rate among blood donors makes reference to a reporting lag that is especially pronounced in the private sector – for example, among private-clinic patients admitted for some other condition such as hepatitis.

and surely will continue to do so: witness the large proportion of individuals with AIDS who remain sexually active. Any reasonable intervention program should be targeted at these individuals and their partners (for example, Francis et al. 1989; Francis 1992), since diffuse education campaigns targeted at either mass publics or classes of risky actions (see Schopper 1990) would, even if they 'worked', have little impact on the spread of a virus whose existence appears to remain fairly circumscribed in the Chilean population. The substantial amount of blood testing that already occurs in the Chilean health system constitutes a fairly good *de facto* surveillance system, especially when interpreted in light of selection factors leading to testing; and will pick up new cases to be counselled, in a context where counselling and referral is not too difficult to implement.

I should acknowledge certain risks attendant on my scepticism of research targeted primarily at 'risk behaviours' since the risky-behaviour rubric arose out of certain problems with the 'risk-group' framework that it supplanted. Focus on risk groups may, first, unjustly stigmatize or blame certain groups; secondly, contribute to a lack of unity against the virus, and hence undercut funding and ameliorative legislation; and thirdly, create a false sense of security for individuals not in these risk groups (Wilmoth 1992). The first two points pertain more to politics and moral philosophy than to social science and epidemiology. In any event, I am not advocating a return to risk groups as an analytic framework so much as I am urging that an interest in risk behaviours not distract from research aimed at the social and geographic communities where the virus is differentially prevalent, and that interventions be developed and evaluated with reference to these communities. As for the third point, it is true that observations about the relative risks of behaviours within different social contexts may be of little import to individuals whose primary concern is searching for behaviours sufficient to avoid infection, regardless of their own group membership (compare Hearst and Hulley 1988; Wilmoth 1992). This should highlight the fact that the epidemiology of a disease in a population and the perspective on that disease by an individual may not concur,⁷ a point apparently missed in many prescriptive treatments of the epidemic.

References

- Anderson, R.M. and R.M. May. 1988. Epidemiological parameters of HIV transmission. *Nature* 333:514-519.
- Bernal, B., J., B. Campos, T. Walter, E. Orrego and H.S. Lacassie. 1988. Mesa redonda: SIDA en obstetricia, ginecología y perinatología. *Revista Chilena de Obstetricia Ginecología* 53,5:255-260.
- Bernal, J., H. Bonacic, I. Lukács and A. Malbran. 1989. Cuestionario de conocimientos y actitudes sobre el SIDA. *Revista Chilena de Enfermedades Transmitidas Sexualmente* 4:85-92.
- Bernal, J.N. 1989a. SIDA en Imágenes I - 1989. *Revista Chilena de Enfermedades Transmitidas Sexualmente* 4:20-23.
- Bernal, J.N. 1989b. SIDA al día: Chile Marzo 1989. *Revista Chilena de Enfermedades Transmitidas Sexualmente* 4:24-25.
- Bernal, J.N. 1990. SIDA al día: Chile, Diciembre 1990. *Revista Chilena de Enfermedades Transmitidas Sexualmente* 5:142-144.
- Bernal, J.N., I. Lukács and H. Bonacic. 1989. Conocimientos y actitudes sobre el SIDA en la población Chilena. *Revista Chilena de Enfermedades Transmitidas Sexualmente* 4:120-129.

⁷ For example, equivalent rates of HIV prevalence for males and females in a heterosexual population (with heterosexual transmission alone) need not imply equivalent chances of male-to-female as female-to-male transmission. The latter may exceed the former by a substantial amount, if the variance in the distribution of new contacts is greater among women (for example, female prostitution) than among men (May and Anderson 1987:142).

- Bernal, J.N., I. Lukács, H.M. Bonacic, M. Riedemann and M. Figueroa. 1989. Conocimientos y actitudes sobre el SIDA en un grupo de educadores y educandos. *Revista Chilena de Enfermedades Transmitidas Sexualmente* 4:9-15.
- Bongaarts, J. and R.G. Potter. 1983. *Fertility, Biology, and Behavior: an Analysis of the Proximate Determinants*. New York: Academic Press.
- Burt, R.S. 1991. Measuring age as a structural concept. *Social Networks* 13:1-34.
- Cárceles P., C., E. Gotuzzo, S. Wignall and M. Campos. 1991. *Bulletin of PAHO* 25:306-319.
- Carrier, J.M. 1989. Sexual behavior and spread of AIDS in Mexico. *Medical Anthropology* 10:129-142.
- CONASIDA (Republica de Chile Ministerio de Salud Comision Nacional de SIDA). 1990. Programa de Mediano Plazo para la prevencion y control del SIDA. *Revista Chilena de Enfermedades Transmitidas Sexualmente* 5:127-136.
- Davis, K. and J. Blake. 1956. Social structure and fertility: an analytic framework. *Economic Development and Cultural Change* 4:211-235.
- Dondero, T.J. Jr., M. Pappaioanou and J.W. Curran. 1988. Monitoring the levels and trends of HIV infection: the public health service's HIV surveillance program. *Public Health Reports* 103:213-220.
- Eisenberg, B. 1989. The number of partners and the probability of HIV infection. *Statistics in Medicine* 8:83-92.
- Francis, D.P. 1992. Toward a comprehensive HIV prevention program for the CDC and the nation. *Journal of the American Medical Association* 268:1444-1447.
- Francis, D.P., R.E. Anderson, M.E. Gorman, M. Fensterseib, N.S. Padian, K.W. Kizer and M.A. Conant. 1989. Targeting AIDS prevention and treatment toward HIV-1-infected persons. *Journal of the American Medical Association* 262:2572-2576.
- Freedman, D.A. 1991. Statistical models and shoe leather. Pp. 291-313 in *Sociological Methodology 1991*, ed. P.V. Marsden. Oxford: Basil Blackwell.
- Giesecke, J., K. Ramstedt, F. Granath, T. Ripa, G. Riedel and M. Westrell. 1992. Partner notification as a tool for research in HIV epidemiology: behaviour change, transmission risk and incidence trends. *AIDS* 6:101-107.
- Global Programme on AIDS. 1989. Steering Committee on Behavioural Research - report of the first meeting. World Health Organization GPA/DIR/89.7.
- Global Programme on AIDS. 1990. Steering Committee on Behavioural and Health Promotion Research - report of the second meeting. World Health Organization GPA/DIR/90.3.
- Granovetter, M.S. 1973. The strength of weak ties. *American Journal of Sociology* 78:1360-1380.
- Hearst, N. and S.B. Hulley. 1988. Preventing the heterosexual spread of AIDS: are we giving our patients the best advice? *Journal of the American Medical Association* 259:2428-2432.
- Hermalin, A.I., B. Entwisle and L.G. Myers. 1985. Some lessons from the attempt to retrieve early KAP and fertility surveys. *Population Index* 51:194-208.
- Hunt, L.G. 1973. *Heroin Epidemics: a Quantitative Study of Current Empirical Data*. Washington DC: Drug Abuse Council.
- Instituto Superiore Di Sanit . 1991. VII International Conference on AIDS. Florence 16-21 June 1991. Abstract Books Volumes I and II.
- Lake E.T., H.L. Smith, N. Peragallo, X. Ferrer S-G. and L. Aiken. 1992. *Test Selection as a Critical Factor in Estimating HIV Seroprevalence from Existing Surveillance Mechanisms: Findings from Santiago, Chile*. Philadelphia, PA: University of Pennsylvania, Center for Health Services and Policy Research, School of Nursing.
- Lukács A., I., M.L. Langerfeldt U., A. Malebr n R., L. S nchez and J. Bernal. 1990. Conocimiento sobre enfermedades de transmision sexual de prostitutas femeninas. *Revista Chilena de Enfermedades Transmitidas Sexualmente* 5:61-68.

- Manton, K.G. and B. Singer. 1989. Forecasting the impact of the AIDS epidemic on elderly populations. Pp. 169-191 in *AIDS in an Aging Society: What We Need to Know*, eds. M. White Riley, M.G. Ory and D. Zablotsky. New York: Springer Publishing Company.
- May, R.M. and R.M. Anderson. 1987. Transmission dynamics of HIV infection. *Nature* 326:137-142.
- McNally, J.W. and W.D. Mosher. 1991. AIDS-related knowledge and behavior among women 15-44 years of age: United States, 1988. *Advance Data from Vital and Health Statistics of the National Center for Health Statistics*, Number 200, May 14.
- Michael, R.T., E.O. Laumann, J.H. Gagnon and T.W. Smith. 1988. Number of sex partners and potential risk of sexual exposure to Human Immunodeficiency Virus. *Morbidity and Mortality Weekly Report* 37:565-568.
- Pereda, C. and M. Cifuentes. 1991. Preliminary Results: *Combined Study on Partners Relations and Risks of HIV Infection/Knowledge, Attitudes, Beliefs and Practices on AIDS, in Chile's Capital City and Two City Ports 1990*. Santiago: World Health Organization, Global Programme on Aids, University of Chile.
- Population Council Inc. 1967. *Selected Questionnaires on Knowledge, Attitudes and Practice of Family Planning*, Volumes 1 and 2. New York: The Population Council Inc.
- Quinn, T.C., J.P. Narain and F.R.K. Zacarias. 1990. AIDS in the Americas: a public health priority for the region. *AIDS* 4:709-724.
- Rindfuss, R.R. and S.P. Morgan. 1983. Marriage, sex, and the first birth interval: the quiet revolution in Asia. *Population and Development Review* 9:259-278.
- Rodriguez V., M. 1991. Afectadísimo por el SIDA. *APSI* 406:16-19.
- Rugiero P., E., C. Bruna M., E. Avil'zs C., M. Montenegro C. and J. Bernal B. 1990. Conocimientos y actitudes sobre sexualidad y SIDA en adolescentes de Penalolén. *Revista Chilena de Enfermedades Transmitidas Sexualmente* 5:137-141.
- Ryder, N.B. 1973. A critique of the National Fertility Study. *Demography* 10:495-506.
- S'ınchez H., G., L. Vera D., G. Soto L., J. Mora R. and E. Ramirez V. 1991. Infección por VIH, diagnóstico en la Red Nacional de laboratorios de Chile. *Revista Médica de Chile* 119:1277-1283.
- Santa Mar'a M., L., M. Daniel M. and A.P. Rojo B. 1990. Conocimientos y actitudes sobre el SIDA, en el Ambito Educacional Medio y Superior Iquiqueño. *Revista Chilena de Enfermedades Transmitidas Sexualmente* 5:96-102.
- Schopper, D. 1990. Research on AIDS interventions in developing countries: state of the art. *Social Science and Medicine* 30:1265-1272.
- Smith, H.L., N. Peragallo, S-G. Ferrer, X. Ferrer, E.T. Lake and L. Aiken. 1992. AIDS prevention research: population-based and epidemiological perspectives, as applied to the AIDS epidemic in Chile. Paper presented at the 1992 Annual Meeting of the Population Association of America, Denver, Colorado.
- Snow, J. 1965 [1855]. *On the Mode of Communication of Cholera*. Reprint edition. New York: Hafner.
- Stigum, H., J.K. Grønnesby, P. Magnus, J.M. Sundet and L.S. Bakketeig. 1991. The potential for spread of HIV in the heterosexual population in Norway: a model study. *Statistics in Medicine* 10:1003-1023.
- Turner, C.F., H.G. Miller and L.E. Moses, eds. 1989. *AIDS: Sexual Behavior and Intravenous Drug Use*. Washington, DC: National Academy Press.
- Valenzuela, G., M. Solange, J.M. Herold, L. Morris and I. L—pez B. 1991. Survey of reproductive health in young adults, greater Santiago, 1988. *Bulletin of PAHO* 25:293-305.
- Van Druten, J.A., A.G.M. Reintjes, J.C. Jager, S.H. Heisterkamp, M.J.J.C. Poos, R.A. Coutinho, M.G.W. Dijkgraaf and E.J. Ruitenber. 1990. HIV infection dynamics and intervention experiments in linked risk groups. *Statistics in Medicine* 9:721-736.
- Wallace, R. 1991. Traveling waves of HIV infection on a low dimensional 'socio-geographic' network. *Social Science and Medicine* 32:847-852.

- Wilmoth J. 1992. AIDS in the Americas. Discussion of paper presented at the 1992 Annual Meeting of the Population Association of America, Denver, Colorado.
- Wykoff, R.F., C.W. Heath Jr., S.L. Hollis, S.T. Leonard, C.B. Quiller, J.L. Jones, M. Artzrouni and R.L. Parker. 1988. Contact tracing to identify Human Immunodeficiency Virus infection in a rural community. *Journal of the American Medical Association* 259:3563-3566.
- Wykoff, R.F., J.L. Jones, S.T. Longshore, S.L. Hollis, C.B. Quiller, H. Dowda and W.B. Gamble. 1991. Notification of the sex and needle-sharing partners of individuals with the Human Immunodeficiency Virus in rural South Carolina: 30-month experience. *Sexually Transmitted Diseases* 18:217-222.
- Yoder, P.S., R. Drew and Z. Zhong. 1989. Knowledge and practices related to diarrheal disorders, oral rehydration therapy, and vaccinations in Lubumbashi, Zaire. Working Paper No. 119. Philadelphia, PA: Center for International Health and Development Communication, University of Pennsylvania.