Organizational Response to Adolescent HIV Risk

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Using semi-structured interviews, the present study examined organizational responses to adolescent HIV risk in an urban Honolulu community. All 23 health, social service, and educational organizations studied have been impacted by HIV. However, the overall organizational response has been compartmentalized and limited. Recommendations concerning improved organizational responses are provided.

Introduction

The response of public and private health, educational, and social service organizations toward adolescent HIV infection and its prevention has been slow for several reasons.

First, the small number of actual AIDS cases among teenagers (less than 1% of the total AIDS population nationwide as well as in Hawaii) has obscured the true infection rate and thus diminished a sense of urgency. However, with an average latency period of 10 years from infection to illness manifestation, AIDS data on adolescents can be collected only from adults in their 20s. This group constitutes a rapidly rising 19% of the total AIDS population and about 16% of its members are women.[1]

Second, the Centers for Disease Control has collected separate data on adolescent AIDS only for the last 5 years. Teens are the least researched group within the HIV population, and information on the course of illness, response to medication, and service utilization is much less well known than for the adult or pediatric age groups.

Third, affected teens are the age group most difficult to reach. Disenfranchised, ethnic minority, and gay youths are overrepresented in the HIV-infection spectrum, but health services are even less available to *marginalized* than to mainstream youths. Constraints on agencies related to consent and confidentiality policies and confusion as to whether confidentiality policies for sexually transmitted diseases (STDs) apply to HIV further complicate service delivery.

Fourth, unrelenting controversy about the content and methods of AIDS education has hampered the development of effective prevention strategies directed toward young people.

Finally, evidence suggests that physician-adolescent contacts are too short or infrequent and lack routine sexuality and drug-use history-taking and counseling to allow for a meaningful role in adolescents' lives related to HIV prevention.[2-4] Furthermore, a 1991 sample survey of Oahu tenth graders found that half reported having no personal physician.[5]

Only scant information is available in the U.S. and in Hawaii on the scope and quality of HIV services developed by new or existing community organizations in regard to adolescent AIDS. The extent to which HIV programs reach and influence youths is unclear.

As part of a larger NIMH-funded study on social networks of young ethnic-minority adolescents (ages 12 to 15) living in high-risk settings in Puerto Rico, Atlanta, Seattle, and Honolulu, the Hawaii research team conducted an exploratory survey of the organization of HIV services provided to Kalihi-Palama youths. The type and quality of responses to HIV by health and other community service organizations and their inter-organizational environment were assessed. We focused on 12 to 15 year-olds because this group has been studied the least and yet represents the age at which the incidence of unprotected sexual behavior and substance abuse remains fairly low, while by ages 16 to 18 most of these youths will be engaging in high-risk behavior, and interventions may be too late.

Methods

Through an open-ended interview and a review of organizational documents, one or more key informants from 23 agencies provided information about their general mission, goals, and services; provision of HIV-specific services; the institution's formal and informal conceptualization of HIV infection risk for 12 to 15 year-old youths; and the staff's perception of the effectiveness of their programs. All agencies resided in or served youths for a specific urban Honolulu neighborhood, Kalihi-Palama.

Organizations were selected by using a mix of an a priori fixed list and snowballing approach, where interviewees could suggest other organizations for additional interviews. Agencies included health clinics, social service agencies with youth programs, agencies with services for specific ethnic groups, HIV-specific agencies, and private and public schools.

All interviews were conducted between January 1992 and December 1993. Oral and written materials were reviewed and summarized. Data analysis included qualitative and quantitative approaches. The qualitative analysis focused on organizational responses to HIV, organizational perceptions of HIV risk in the target population, and organizational perceptions of effectiveness of HIV services.

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The quantitative analysis identified organizational characteristics of overall responsiveness to HIV services to young teens. Here, 2 judges read the interview materials and independently rated each agency along a number of dimensions. The major dependent variable consisted of a 6-point scale describing the agency's overall response to HIV services for young teenagers, ranging from no response (1) to direct, proactive, and effective response (6).

Results

Data from 23 agencies were available for analysis: 5 agencies primarily engaged in health care delivery, 14 social service agencies, 3 HIV-related school education programs, and 1 agency providing primarily HIV education and HIV-specific support services. Except for the latter, all agencies had been established prior to the AIDS epidemic. All had added or incorporated some form of HIV services into existing programs without changing or adjusting their general program mission or overall goals, except when funding demanded some specific HIV intervention. For example, an ethnically focused service agency provided HIV brochures in native languages to immigrants. Staff training in HIV issues was provided generally through sporadic in-service lectures, but rarely was extra staff hired to organize or coordinate HIV-related programs. Instead, staff was diverted from other ongoing programs. The intensity of agency involvement, in the absence of written curricula or program guidelines, largely depended on the designated staff members' own initiative.

The dilution of personnel resources without clearly defined goals often led to conflicting priorities within agencies and contributed to a lack of staff confidence in their own expertise. Furthermore, in the absence of clear policy statements and guidelines in many organizations, everyday staff provided HIV education and service at their personal discretion.

Many staff members from social service agencies voiced discomfort in discussing sexual issues with teens. For many, sex and HIV education were considered "health issues" that could be handled better elsewhere—for example, in schools where teaching HIV-related subjects is mandatory, or in health care settings. Sometimes, cultural sensitivities and embarrassment played a role in avoiding sexual topics considered deeply private, particularly among Asian/Pacific Islanders.

With the exception of public school programs and one health agency, all organizations were privately funded or volunteer based. The majority had public fund support for other components of their programs. We found that the type of funding had little influence on the creation of HIV-related services unless a specific mandate was given. This was a rare occurrence.

All agencies recognized a need for HIV prevention services. Community youths were perceived to be at risk for infection primarily through sexual behavior; injection drug use was uniformly considered rare and not of great significance. Compared with other compelling social, educational, and psychological needs, however, HIV risk *in itself* was not seen as a high priority, but "just one of many problems."

Table 1.—HIV Responsiveness Scores as a Function of Agency Type

Agency Type	n	Mean	Standard Deviation
Health	5	4.20_b	.45
Social Services	14	2.25_a	1.25
School	3	3.83_{ab}	.76

Note.—Means with different subscripts are significantly different, $p < .05$ with Bonferroni correction. Higher scores indicate greater responsiveness.

Overall responsiveness of programs to the HIV challenge was independently assessed by 2 raters. Interrater reliability was .78. When scores disagreed, the arithmetic mean between the 2 ratings was taken. These average responsiveness ratings were then subjected to a one-way analysis of variance comparing health, social service, and education agencies (scores from the one HIV organization were eliminated for this analysis). A significant overall effect, $F(2,19) = 7.22$, $p < .01$, and subsequent least significant difference tests (with Bonferroni correction) indicated that the community health clinics were rated higher than the social service agencies in the vigor of their response to HIV (Table 1). However, these health clinics functioned primarily in a tertiary prevention mode with limited outreach efforts. Aside from providing medical services, many health clinics offered information, protective devices (eg, condoms), and HIV testing and counseling to their adolescent patients on request. The total number of teens reached was low, both because of the individualized nature of the service and the fact that few teens, especially 12 to 15 year olds, use health services or initiate requests for HIV information or services on their own.

HIV-related programs by youth social service agencies or schools often were restricted to providing basic HIV/AIDS information by handing out brochures, giving sporadic talks, or answering specific questions when teens asked—a rather infrequent event. While protection through condoms was usually discussed, only a few agencies made them available to sexually active teens. HIV prevention programs specifically directed toward young teens were not available except in school educational programs, and services for gay youths were nonexistent.[6]

No agency in the survey had a formal protocol for evaluating the effectiveness of its HIV-related interventions. Informal assessments were restricted to subjective impressions by staff with a general consensus that improved knowledge about HIV seemed unlikely to change teen behavior. The adolescents' own perceptions about the usefulness of HIV-related services was unknown. Generally, well-established interagency relationships did not seem to extend to HIV services.

Discussion

The results of this survey indicated a poorly integrated, fragmented, and insufficient response to HIV by community organizations designated to service youths in this urban community. Most interventions consisted of attempts at education through occasional lectures or handouts of printed brochures. Social skills training to negotiate safer sex practices or teaching the use of and providing access to protective devices (condoms) was rare. With the exception of the school programs, the number of adolescents reached was small, and they were usually served for reasons other than HIV prevention.

While research on organizational responses to the AIDS epidemic has been scarce, it describes a limited, inconsistent reaction by the majority of agencies throughout the U.S.[7-8] Our data reflect a similar picture in our target community. At the time of our study, agencies that attempted to incorporate HIV ser-

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vices into existing programs lacked clearly defined goals related to this effort. Funding was either absent or had to be diverted from other programs. HIV services were given low priority in view of other pressing service needs. Inconsistent staff training and discomfort with the subject matter also hampered the development of effective, consistent HIV interventions. These agencies deferred most often to mandated HIV education in schools, which teaches knowledge about HIV. It is well established, however, that knowledge alone does not change high-risk behavior.[9]

The results of this study suggest that in order for HIV/AIDS-related programs to be successful, several minimal conditions need to be fulfilled (Table 2). They include well-defined AIDS/HIV-specific organizational goals and policies, designated funding, selection of experienced and culturally sensitive key personnel, incorporation of community involvement and natural social networks, and thoughtful evaluation. In many communities, these conditions have been met better by new, small community-based organizations formed directly as a result of the HIV/AIDS crisis.[10] Such an approach would allow a specific focus on HIV programs without competition for financial and staff resources from other programs within the same institution. Unfortunately, at the time of our survey the only HIV-focused agency did not effectively reach a large number of young teenagers. A separate organization with a focus on HIV prevention in adolescents and a combined health and psychosocial approach is needed.

Table 2.—Conditions for Successful HIV/AIDS Programs

1. A clear mission and legitimate, well-defined AIDS/HIV-specific organizational goals.
2. Funding targeted at these specific goals.
3. Selection of experienced key personnel.
4. Adequate risk perception of target population by staff.
5. Cultural sensitivity to population served.
6. Community involvement and support.
7. Recognition and utilization of naturally occurring social networks of youth.
8. Effective evaluation.

The results of this study also suggest that while those health agencies surveyed appeared more proactive in their HIV activities, they reached relatively few younger adolescents. This study did not compare Hawaii's physicians' similarities to Mainland physicians, where it has been noted consistently in studies that due to time constraints, lack of comfort and lack of training, sexuality, and drug abuse are not discussed with most adolescent patients. Concerns about underutilization of physician services have fostered the local movement to develop school-based health centers in Hawaii. Physicians, who generally are respected as authorities in health-behaviors of adolescents, can increase their influence in several ways. In clinical care they can follow the "Guidelines for Adolescent Preventive Services" (GAPS) of the American Medical Association. They will need to routinely and confidentially discuss sexual activity, drug abuse, and other risk behaviors with all adolescent patients. Physicians who serve as consultants or on boards of directors of youth agencies can help assure that proactive HIV/AIDS prevention programs are developed. They can lobby legislators for funds to support such programs. Finally, they can participate in the development of a statewide collaborative network of adolescent-focused HIV prevention services that would include private and public health and social service agencies, schools, churches, the business community, and public officials. Anticipatory guidance related to STDs, safer sex practices, pregnancy and contraception should be provided by all youth agencies before, not after, a teenager becomes sexually active.

Very little research has been done on the importance of community organizations in the social networks of adolescents and how these organizations actually influence teen behavior. Initial findings soberingly suggest that young teens more often follow the beliefs and behavioral choices of often misinformed peers and parents rather than those of teachers or community agencies who frequently lack credibility or access.[12] More extensive social network analyses of adolescents may provide important information to community agencies on how to develop HIV-intervention programs that are not only accessible but also utilized by teens or by those persons who have the greatest likelihood to influence teen behavior. We plan to continue such research.

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