
Teen Perspectives on HIV and the Relevance of Hawaii's Health Providers

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Based on focus group interviews with adolescents from an urban Honolulu community, the present article describes how these adolescents view HIV, HIV-prevention and the role of health care providers in addressing HIV-related needs. Although medical providers are known to be knowledgeable experts in a variety of health care areas, other research points to an underutilization of this potential. While knowledgeable about HIV, many of the youth in this study continue to engage in risky behavior. Few perceive they have others they can meaningfully talk to about their HIV and other health concerns. Even when probed for, almost none of these teens saw health care providers as pertinent to HIV or their health beyond the traditional illness/prescription role. Suggestions for ways to get more involved in the prevention of HIV and, more generally, positive health development in teens are discussed.

Over the past decade there has been increasing evidence that Hawaii's adolescents may be at significant risk for Human Immunodeficiency Virus (HIV) infection. While there have been only 5 reported cases of AIDS among Hawaii's adolescents aged 13 to 19 years, representing less than 1 percent of total cases, 261 cases (14 percent of total) have been reported among young adults aged 20 to 29 years.¹ Because the delay period between HIV infection and a diagnosis of AIDS has a median range of eight to eleven years, many of those diagnosed with AIDS in their twenties were likely infected as teenagers. The seroprevalence rate of HIV among Hawaii's adolescents, another indicator of risk, is unknown. It has been estimated that perhaps 3000 to 5000 individuals of all ages in Hawaii may be HIV positive. Youth of color may be at special risk for HIV infection. While the majority of Hawaii's AIDS cases to date have occurred among Caucasians, the proportion of cases among Asian/Pacific Islanders has increased steadily, from 18 percent in 1989 to 25 percent in 1996.¹

Ninety-five percent of AIDS cases in Hawaii have resulted from sexual activity and/or injection drug use. Although seroprevalence

rates are uncertain, recent studies have documented the high rates of HIV-related risk behaviors among Hawaii's youths. A 1990 Hawaii Department of Health survey of Oahu 10th graders found that 43 percent were sexually active.² Of these only 39 percent had ever used any form of contraception (not necessarily condoms). In a 1994 Hawaii Department of Health survey of seventh through twelfth grade students on Oahu, Kauai, Maui and the Big Island, 20 percent of seventh and eighth graders and 45 percent of ninth through twelfth graders said they had had sexual intercourse.³ One quarter of both sexually active grade groups had had sex with four or more partners in their lifetime. Two thirds of the sexually active seventh and eighth graders reported that their first sexual intercourse had occurred before the age of 13. Less than half of sexually active students used any effective contraception the last time they had intercourse. Concerning substance use, the survey reported that the incidence of alcohol use in the previous month was 31 percent for the younger grade group and 49 percent for the older students. Marijuana use in the previous month was 16 percent and 29 percent respectively for each group. Ten percent of seventh and eighth graders and 17 percent of older students had used some other illegal drug in their lifetime. Injection drug use was not specifically surveyed.

Health providers traditionally have assumed the dual roles of treating illness and promoting health and well-being. In the latter role providers screen, educate and counsel their healthy patients not only to prevent illness but to assure that their patients may achieve their full potential for physical, psychological and social well-being. Several professional guidelines and standards of practice related to adolescent preventive health care have been established.^{4,5,6,7} Most of these specifically affirm the responsibility of health providers to discuss in a substantive way HIV and HIV-related risk behaviors with their adolescent patients. The American Medical Association's 1992 Guidelines for Adolescent Preventive Services (GAPS) is considered by many to be the current "gold standard" of adolescent preventive health care.⁸ GAPS recommends that health providers see their adolescent patients yearly between the ages of eleven and twenty-one years. At each visit there should be an age-appropriate discussion of a wide range of health issues, including substance use, psychosexual development and sexual behaviors including specific discussion of abstinence, HIV and safer sex. It also recommends that policies on the provision of confidential care to adolescents be established in all clinical settings. Professional organizations, such as the American Academy of Pediatrics, have also espoused the principal of every child and adolescent having a "medical home" where health care would be provided in an "accessible, continuous, comprehensive, family centered, coordinated and compassionate" manner.⁹ Medical student, resident physician and

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nursing training curricula at the University of Hawaii also emphasize the need for health providers to address the entire breadth of medical and psychosocial issues with adolescent patients on a regular basis.

Despite the recognition that health providers have a responsibility to join in efforts to prevent adolescent HIV risk behaviors, there is considerable evidence that they may not be fulfilling this role. Survey research has shown that many physicians, for example, do not routinely take a sexual history of their adolescent patients or provide counselling about HIV, sexuality or a variety of other HIV risk behaviors.^{10,11} Marks et al reported in 1990 that only one in ten pediatricians regularly saw teens for sexuality-related concerns or substance use.¹² Fewer than half provided anticipatory guidance related to sexuality. Bradford and Lyon's study of Pittsburgh pediatricians showed that only 35 percent provided AIDS counselling to adolescent patients and a minority provided any gynecologic (29%), family planning (20%), drug and alcohol (27%) or depression (33%) counselling.¹³ Only 32 percent acknowledged "always" or "frequently" discussing AIDS with their teen patients.

A survey of Washington, D.C. physicians found that sexual histories were taken in only 60 percent of new teen patient visits and less than half of continuing patient visits.¹⁴ Blum et al in 1995 reported on a chart review survey of adolescent patients in four settings—private pediatric practice, family practice, a school based clinic and a community teen clinic.¹⁵ Less than 45 percent of charts in each setting reflected any screening in the areas of emotional health, sexuality or substance use. The highest rates of documented screening were in the teen and school based clinics. The lowest rate of screening was in pediatricians' offices. In contrast, physical health screening was documented in more than 95 percent of all clinics' charts. Nussbaum et al demonstrated that physicians' gender may influence the willingness to discuss sexuality with teen patients.¹⁶ They found that 88% of female pediatricians but only 39% of male pediatricians routinely took sexual histories of fourteen to fifteen year old girls. A significant differential appeared even among sixteen to seventeen year old girls, with overall only 69% of pediatricians willing to discuss sexuality.

Survey research indicates that many physicians feel untrained and uncomfortable in discussing HIV-related issues with adolescents.¹⁷ In 1978 The American Academy of Pediatrics Task Force on Pediatric Education cited knowledge and skills in adolescent medicine as among the major deficits in pediatric practice.¹⁸ Blum and Bearinger in 1990 reported that nearly half of physicians in a national survey (including pediatricians, family practitioners and internists) felt insufficient training was a significant barrier to working with adolescents.¹⁹ Among areas of perceived inadequate training were alcohol/drug abuse (39%), homosexuality (54%), STDs (16%), family planning (22%) and delinquency (55%). Seventy-four percent of physicians acknowledged that adolescents were their least-preferred age group. Only 32 percent were interested in improving their perceived deficits in working with teens. Levenson et al in 1986 found that only 13 percent of pediatricians felt they were adolescents' preferred source for health information, with only 3 percent ranking themselves as the most frequently used source.²⁰ In the study by Marks et al, most pediatricians said that adolescents rarely came to them for mental health or sexuality issues.¹² Reports indicate that pediatricians feel less competent in sexuality-related care than other primary care specialists.^{21,22,23} Bradford's survey of Pittsburgh pediatricians found low levels of comfort in addressing various adolescent health issues related to HIV, with only about half of physicians comfortable in discussing sexuality, HIV or STDs.¹³

Several surveys have shown that adolescents see physicians as one of the most authoritative sources of health-related information.^{24,25} Furthermore, teens list sexuality, substance use and HIV as among the subjects they are most interested in discussing with physicians.^{20,26} Other adolescent surveys, however, tend to confirm the picture of physicians unable or unwilling to discuss HIV and associated risk behaviors. A study by Hingson found that although 80 percent of the teen respondents had seen a physician in the past year only 13 percent had been counselled about AIDS.²⁷ In fact in several surveys, adolescents ranked physicians last as an actual source of information about HIV or sexuality.^{28,29} Joffe et al reported in 1988 that three-fourths of college freshmen had received no counselling on eleven of fifteen topics they were most interested in discussing with a physician, including STDs, contraception, alcohol/drug use or depression.³⁰ Overall, internists were more likely to provide counselling than pediatricians or family/general practitioners. A survey of Boston 9th and 12th graders by Rawitscher et al, found that a majority of students wanted information about HIV, STDs, sex and condoms.³¹ They would like a physician to discuss with them their personal experiences related to these same issues, but most would be uncomfortable initiating a discussion of these on their own. Only 37 percent of the 12th graders had ever discussed sex and 28 percent had ever discussed HIV/AIDS with a physician.

When queried about perceived barriers to working with adolescents, physicians cite lack of training, time constraints, inadequate reimbursement, physician image, physician discomfort, office setting, confidentiality concerns, and a generally alienating system of care.^{12,15,20,32,33} There are clearly other barriers to the provision of quality health care to adolescents. While most surveys suggest that over half of teens see a physician at least once a year,^{34,35} many of these contacts may be for acute illness or sports physicals and may not include discussions of adolescent risk behaviors.^{23,36} In a national survey of office visits by adolescents it was found that the mean duration of visit for adolescent patients was fourteen minutes.³⁷ Marks et al reported in their survey of suburban New York pediatricians that an average of twenty-eight patients were seen in a seven hour clinic day.¹² The average office visit lasted fifteen minutes and only a small minority of physicians scheduled longer visits for new or returning adolescent patients.

Because there is evidence that the risk for HIV infection among Hawaii's adolescents is real and because research in other communities suggests that health providers may not always be meeting adolescents' needs in the area of HIV prevention, it is important to obtain a better understanding of adolescents' perspectives on HIV and the relevance of Hawaii's health care providers. A previous study conducted by the authors attempted to evaluate the responsiveness of health clinics, social service agencies and schools to the challenge of HIV-prevention among Kalihi-Palama youths.³⁸ In general, health clinics appeared most responsive, although often in a tertiary prevention mode, with little outreach and relatively few teens contacts. The present study looks at the other side of the coin. In order to allow adolescents a relatively unstructured opportunity to express their perceptions related to HIV-related issues, a qualitative study design was developed. Through a series of focus groups, adolescents were asked to describe the meaning of HIV in their lives. Through succeeding focus groups, patterns of teen experience and perceptions became apparent. These patterns related to adolescents' HIV-related knowledge, behaviors, perceptions of risk, perceptions of HIV-prevention messages, and the role and relevance of health providers in their lives. Based on these findings, recommendations are presented that may enhance the role of health care providers in the prevention of HIV infection among Hawaii's adolescents.

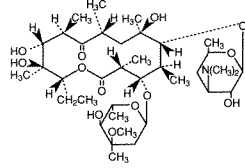
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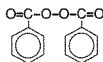
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Methods

A total of 125 Kalihi-Palama youth (66 females and 59 males) between the ages of 12 and 19 participated in focus group interviews over the course of six months. Participants were recruited through word-of-mouth and flyers distributed by health, social and educational providers in the neighborhood. Nineteen separate same or mixed gender groups were conducted. Group size ranged from 2 to 15 and most participants within each focus group were known to each other prior to participation. Most youths were of Asian, Pacific Islander, or "cosmopolitan" background.

Using a modified Grounded Theory approach³⁹ topic order and content across focus groups continually evolved over the course of the study. All group discussions were recorded and transcribed verbatim. Findings for each group were examined and further clarified in one or more subsequent groups. As new ideas and insights emerged, they were pursued in subsequent groups. Group facilitators used probes for clarification, validation of what was being said, and encouragement for active participation. Final transcripts were coded using The Ethnograph V4.0,⁴⁰ a computer-based qualitative text management program, which allowed for further data analysis and provides a stored record of all discussions, coded by content topic.*

Results

One of the most striking findings of this study was the participants' eagerness to discuss HIV within the broader context of their lives. They expressed a clear preference for a group setting in which they were not lectured at or judged, but had complete freedom to express and explain their feelings, perceptions and experience. As one teen noted, "At school, they lecture. They just talk. They no like let us talk. And it gets boring, yeah?, after a while. But like you guys asking us, and it's fun communicating." It was in the context of these open discussions that the teenagers taught us about the meaning of HIV in their lives, and the perceived relevance of health providers.

Adolescent Experience of HIV

In a previous article, the authors discuss in greater detail adolescents' construction of HIV and HIV-prevention.⁴¹ To summarize, the teen participants generally view HIV in negative terms with a range of emotional responses—fear, anger, and sadness—often connected to the expectation of social ostracism or death. Despite the strong emotional response, there was an admission that HIV was seldom discussed with family or friends, except perhaps in a bantering manner. It also was agreed that the risk of HIV was generally not on the minds of participants in the minutes preceding risky behaviors (usually unprotected sex) though occasionally it might be after the act was completed. The possibility of pregnancy appeared to be more consciously considered than HIV in these situations. In general, any post-coital concerns about HIV were short-lived.

Knowledge and Perceptions of Risk

In general, the teen participants showed good knowledge of HIV, its effects on the immune system, associated risk behaviors and safer sex practices. When misconceptions were expressed, the groups were often self-correcting as other participants provided more accurate information. Misconceptions were usually

*A more detailed description of participants, participant recruitment, and focus group procedures is provided in Mueller et al., 1996.⁴¹

in the direction of overestimating risk (for example, transmission by mosquitoes) rather than denying the danger of known risk behaviors. Perhaps related to this was the participants' marked overestimation of HIV prevalence among their teen peers with estimates ranging from 25 to 75 percent of Hawaii's adolescents being HIV-positive. However, only one teen acknowledged knowing personally another teen who was HIV positive.

HIV Risk Behavior

Despite good knowledge of HIV and personal perceptions of risk, about half of the teen participants acknowledged being sexually active. Very few reported using condoms consistently; in fact, most did not use condoms at all. Both boys and girls generally believed that responsibility for deciding to have sex or use condoms lay equally with both partners. Many reasons were presented to explain the onset of sexual activity (eg., peer pressure; "fun") and the failure to use condoms (eg., "no like"; boring; "don't think, no like stop"). None of the participants openly reported either homosexual or bisexual behaviors. Repeatedly, the teens spoke of sex taking place in the context of concurrent alcohol and drug use. Several groups described "house parties", "hotel parties" and "beach parties", where youths of a variety of ages come together unchaperoned to partake in an abundant availability of drugs and sex.

While drug use was acknowledged by most of the teen participants, none spoke of personal use of injection drugs, including steroids. However, many of the teens had self- and friend-applied tattoos, which often involves the sharing of needles.

Perception of HIV Messages and Messengers

Schools, television, radio and newspapers were cited most often as providing information about HIV. Teen-focused media messages were felt to be no more effective than school health class curricula in providing information or changing behaviors related to HIV. In fact, the teens appeared skeptical that any of these isolated attempts to influence behavior would be successful. When asked how HIV messages could be made more effective, the teens appeared to take upon themselves the responsibility for change, or lack of it. As one boy put it, "It's up to you. You make your choices. If you take the wrong, it's your fault....Right now we're walking a line between choices; and if you take the wrong path, then it's up to us....to walk out there and walk the right path."

Those "messengers" viewed most positively were the counselors, teachers, and others who took the time to talk with the teens about their lives without lecturing or judgement. These relationships allowed the teens to be more open and honest in discussing their risk behaviors and concerns.

Perceptions of Health Care Providers

How do teens see health care providers in relation to their general health and risk for HIV? The participants in this study gave the distinct impression that health providers are relatively peripheral figures in their lives. There was little indication that they are seen as significant sources of HIV information or have any special relevance to whether or not a youth might decide to engage in HIV risk behaviors. Among 125 youths in 19 groups, only two mentioned health providers or clinics as somewhere they would go to ask about HIV if they had concerns about it. Only one teen indicated that she had gone to a clinic where there had been a discussion of HIV and safer sex and a provision of condoms.

In almost every group in which health providers were mentioned, the discussion was brief and in terms that portrayed providers as primarily technicians—people one might go to for the human equivalent of an auto tune-up or safety check. Even with strong

prompting, teens gave little indication that they would consider going to health providers for health information or a discussion of personal problems or concerns that were not directly medical in nature. Health providers and clinics, as described by these teens, are places one would go to get a physical exam or "check-up", a blood test for HIV, an STD check, a pregnancy test or for medicine to treat an illness. One teen, when asked if a health provider had ever talked to him about violence, drugs, sex or HIV, answered, "No. They no say about HIV. No talk about gangs, nothing. They are just there for give me medicine." Another teen in the same group responded, "Should get more doctors talk to you one on one, talk to you about AIDS and all that stuff...cause every time you check-up for one appointment, they would be someone telling you about not doing this, not doing that, right? And you will always have 'em in your head, about that thing...."

Teens come into contact with health providers in a number of settings including at school, in clinics and through the media. However, most references to health providers in this study were related to going to a provider, usually for the treatment of some medical problem. Interestingly, this was often put in terms of going to a building or place—"Kapiolani", "Kaiser", "KKV", "Kalihi-Palama", or "clinic"—rather than to a specific individual or type of provider (eg, doctor or nurse). A number of participants could not recall where they went for care, giving vague approximations such as "down by Liliha." School nurses were not mentioned in any of the focus groups.

Discussion

Local adolescent behavioral surveys and Hawaii age-specific HIV/AIDS data indicate that Hawaii's adolescents are at real risk for HIV infection. A large percentage of Hawaii's teens are sexually active and as the teen participants in this study indicated, alcohol and drugs often serve as social "lubricants" that facilitate the onset of sexual activity. While health care providers are logical players in the effort to prevent HIV infection among teens, research in other communities suggests they may not be fulfilling this role. With insufficient training or interest, and an average office visit of 14 minutes, it is difficult to address issues such as home life, school performance, extracurricular activities, drugs, sex and depression in a meaningful way. The teen participants in this study, like those in other communities, generally perceive Hawaii's health care providers as distant figures, technicians whose function is to diagnose illness and provide medicine.

A caveat or two are in order. It would be unfair to suggest that all health care providers fit this perception. Many providers undoubtedly do an exemplary job of promoting teen health and others do the best they can do within imperfect settings and systems of health care delivery. Furthermore, the teen participants of this study are representative only of themselves and not of all Hawaii's teens or even of all teens in Kalihi-Palama. In a group setting it was not always possible to explore the nuances of teens' perceptions related to health providers. The picture they painted was therefore necessarily done in broad strokes. Nevertheless, these youths came from diverse backgrounds and spoke openly about their lives. Their observations are instructive and can help health care providers reflect on their work with teens and consider opportunities to increase their relevance in the fight against HIV.

How might health care providers become more relevant to their teen patients/clients? Changes might occur both in the context of present practice settings and at a systemic level. In a health provider's office or clinic setting, there could be a shift from the "medical home" model, viewed narrowly by teens in this study, to a "health home" model. In a "health home" a teenager would not only get

“check-ups”, immunizations or blood tests but would on a yearly basis sit down with a health provider to talk about both medical and psychosocial health issues (as recommended by GAPS). These meetings would be confidential two-way discussions and would help increase trust and openness between both teen and provider. This study and many others confirm the generally high level of HIV knowledge among teens. This suggests that providers should avoid knowledge-only based discussions and spend more time discussing in depth teens’ behaviors, perceptions and concerns in the broader context of their lives. Such visits would provide a lifelong model for the teen demonstrating the breadth of health issues a provider should be able to address. Such visits will necessarily be longer than

traditional visits. For example, some providers schedule 45 minutes for all new teen patients and 30 minutes for continuing patients who have not been seen recently.

Providers in group practice, community health centers and other settings might explore the usefulness of reaching teens through a group discussion format. One of the most significant findings of this study is the ability of teens to engage in open and lively discussions of their lives. The authors found that the groups were most responsive when they were made up of peer friendship groups, and were facilitated in a flexible, nonlecturing, nonjudgemental style. Refreshments also seem to help. Such groups may be a more efficient and meaningful way of reaching larger numbers of teens and helping them see health providers in a new light.

Systemically, there are other actions that could help improve the relevance of health care providers in promoting adolescent health. Curricula in adolescent health, both for health providers in training as well as for those already in the community, must go beyond simply the development of adolescent health screening and counseling skills. These skills, while essential, will not be implemented without an honest discussion of the practical aspects of how to employ them in the context of busy and cost-conscious health care settings. Secondly, managed care systems could work together with health providers to develop local “gold standards” for adolescent “well-teen” and acute care visits. Through periodic and thorough quality assurance chart reviews, managed care programs can assure that their clients/patients are receiving the quality care they deserve from networks of providers. Additionally, consumers (in this case teens and their parents) need to be educated about what kind of services their health providers should be offering. In relation to adolescent health this means the provision of confidential and comprehensive care through yearly visits that cover both medical and psychosocial concerns. A 14 minute visit should lead consumers to shop elsewhere.

There are also opportunities for providers to go beyond the walls of their offices to reach teens in other settings. Many have done so already through advocacy activities, developing community health screening programs, volunteering as sports team health providers, or as speakers in school health classes. Another community involvement could be through taking part in the expansion of Hawaii’s school-based and school-linked health centers. In the past, some providers have opposed such centers because they were seen as interfering with the “medical home”. This study has shown us that in this respect, many teens are “homeless”. Physicians and other health care providers can take a lead in resurrecting the concept of comprehensive school health centers and create a true “health home” model for adolescents in partnership with other community health care providers.

Given the present system of health care deliv-

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ery, health care providers may never be the primary players in the promotion of adolescent health. The responsibility for assuring teen health is shared with teachers, counselors, social workers, clergy, government officials, the media, families and teens themselves. Nevertheless, the participation of health care providers is essential, because of their special expertise, respected position in the community and their true concern for the health of young people.

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