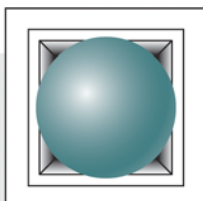


DOLESCENTS' EXPERIENCES AND VIEWS ON HEALTH CARE

Low-income adolescents are an underserved population with significant health needs. Although the design of new patient-centered models of primary care is receiving growing attention, the needs of vulnerable adolescents at risk of chronic conditions have not been addressed. This report provides the findings from a focus group study conducted with low-income adolescents in 4 cities -- Chicago, Los Angeles, Miami, and Washington, DC -- and shows the difficulties they face in obtaining needed care. They understand the many health needs of today's adolescents and offer suggestions for a health care setting that would provide greater access, deliver comprehensive teen-specific services, and help them to play a greater role in their own health care.

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HHealth care reform discussions have focused considerable attention on the design of improved models of primary care, but they have not addressed the unique health care needs of low-income and minority adolescents. This is due largely to the lack of relevant research. There are no large-scale studies showing the best ways to serve adolescents. In its recently released report, the Institute of Medicine concluded that there is a lack of evidence for effective models of adolescent health care and a need for further research.¹ This focus group study with adolescents offers additional information about health care for teens that can guide the direction of future studies.

Eliciting adolescents' own views can yield powerful information about their health care experiences and preferences. While adolescents are not usually asked directly about their health conditions or problems, a large body of national survey research with high school students has provided extensive data about their health risks and behaviors.²⁻⁴ Additional survey and focus group studies shed light on their health seeking behaviors, including their reliance on family and friends for certain types of health information⁵⁻⁹ and the importance they place on providers who are competent,¹⁰⁻¹³ assure confidentiality,¹⁴⁻¹⁸ show them respect,¹⁹⁻²⁴ are nonjudgmental,²⁵⁻²⁷ give them ample time to discuss concerns,^{28,29} and understand their cultural background.^{30,31} Others have shown that adolescents use various sites for care, depending on the nature of their problem,³² but also that they often lack information about where to go for needed services.^{33,34} Still others have shown that adolescents frequently are unable to have the kind of provider-patient relationship they want.³⁵⁻³⁷ This research, with only a few exceptions, is based on information from a single site, a small sample, or a particular adolescent subgroup, and it offers only limited insights into adolescent preferences about the design of health care services except that offices should be clean and comfortable,^{38,39} materials should be directed to adolescents,⁴⁰ waiting times should be short,^{41,42} and there should be opportunities for discussion groups.⁴³

This report presents findings from focus groups and supplemental questionnaires structured to learn about adolescents' perceptions of the health problems facing teens, their experiences receiving care, and their ideas about how best to structure care for the adolescent population. The study documents the perspectives of 204 young people ages 14 to 20 from disadvantaged neighborhoods in Los Angeles, Miami, Chicago, and Washington, DC. Twenty-six total focus groups organized by gender and age were held in these 4 cities, and nearly half of the participants were asked to fill out anonymous questionnaires after the group sessions. The groups were ethnically diverse and representative of the demographics of the respective cities'

low-income populations: almost two-thirds total were African American and one-third were Hispanic. After a lengthy discussion about health care problems and experiences, each focus group worked in teams of 3-4 to design the “ideal” health care setting for teens and present their ideas to the group. The National Alliance to Advance Adolescent Health worked with Philliber Research Associates and ICR to conduct the focus groups.

Recognition of Health Problems

Adolescents were astutely aware of the challenges they and their peers faced in their schools and neighborhoods. When they were asked about the most important problems, various health issues topped the list. Sexually transmitted diseases were mentioned by all focus groups and drugs and alcohol by all but one. Teen pregnancy, violence, negative peer pressure, and mental health issues were frequently cited as well. Answers also varied by gender: females were more likely to mention abuse and obesity and males more likely to discuss poverty, homelessness, or the economy -- all issues with direct or indirect health consequences. Also mentioned, especially among males, were concerns about dropping out of school and the costs of health care. Several adolescents commented that family problems were of concern as well.

In response to a question about what “health care” means, nearly all focus groups cited health insurance and half mentioned cost or affordability as an issue. The topic re-emerged twice more during discussion: when teens were asked about their experiences with the health care system and when they were asked if they sometimes did not get health care when they needed it.

“...a lot of teens decide to have unprotected sex...and then they think, “Oh, I don’t need to go get tested or anything”... HIV [or] AIDS is one of the biggest problems right now.”

– Female (14-16) Miami Group

“There’s some kids that get treated so bad that they think doing drugs is going to help them through it...”

– Male (17-20) Los Angeles Group

“A lot of teens – they’re depressed.”

– Female (17-20) Chicago Group

Where Teens Get Their Care

Adolescents in our focus groups received routine and sick care from a variety of sources, including doctors’ offices, community health clinics, and emergency rooms. A questionnaire at the end of each focus group session showed that slightly over a quarter reported using an emergency room when they were sick. Sometimes, when they did not have the time or money to seek care, teenagers mentioned “fighting” colds or going to CVS to treat the flu. They also mentioned sometimes using mental health clinics, substance abuse programs, and family planning clinics.

"They go to clinics, most of my friends do... they know if they go to their doctors, then it will come up on the health insurance bill..."

– Female (14-16) Washington, DC Group

"When I was younger... I went to the doctor because I was fighting, and... I busted my hand up... I was lucky to have it covered. Now when I got older... [they] weren't able to cover it anymore."

– Male (17-20) Washington, DC Group

Many teens who received sick care from their doctors' office did not receive other forms of care there. According to information from the questionnaires administered after the focus group sessions, among adolescents who reported that people their age went to the doctor's office when they were sick, 83% did not report it as the usual site for drug or alcohol abuse problems, 62% did not report this as the usual site for care for mental health problems, 60% did not report it as the usual site to receive health education, and 55% not did report it as the usual site for sexual health issues.

Lack of knowledge about where to go for services presented another obstacle. Questionnaire results showed that roughly half knew to use mental health clinics for mental health care problems, but about a quarter did not know of a specific place or where to go for these services. Similarly, just over two-thirds recognized the need to find a substance abuse program for drug and alcohol problems, but one-fifth did not know where to go. Only 6% of teens, however, did not know of a place to go for sexual health services.

What else is preventing these young people from seeking more treatment for their health problems? Not having health insurance was identified as a major impediment, especially among older adolescents, as well as high copayments for covered services. In addition, adolescents noted that there was a lack of teen-specific information and resources and that they often have inadequate knowledge about where to go for needed services. Younger adolescents, in particular, claimed that many of their peers were uninformed about health risks, felt uncomfortable talking about their problems, or were afraid to find out if something were really wrong with them.

Experiences with Health Care

When the focus groups were asked about their experiences with health care, their answers were overwhelmingly negative. Teens most often cited two factors that affected their experiences within the health care system: long wait times and providers being too busy. A majority of the focus groups mentioned long waits in doctor's offices and in emergency rooms. They also recounted excessive wait times and difficulties in scheduling appointments.

TABLE 1: Questionnaire Responses: Where Teens Get Their Care (n=96)

| Sources of Care* | Checkups or Preventive Care | Sick Care | Mental Health Care |
|----------------------|-----------------------------|-----------|--------------------|
| Doctor's office | 70% | 60% | 27% |
| Community clinic | 54 | 38 | 24 |
| Hospital clinic | 40 | 51 | 19 |
| School nurse | 12 | 17 | 6 |
| Mental health clinic | NA | NA | 52 |
| Emergency room | NA | 27 | NI |
| Don't know/no place | 7 | 7 | 28 |

*Respondents could identify more than one source of care.

NA = Not applicable

NI = No information

Young people were most vociferous about inadequate attention and being rushed at the hands of busy health care providers. The wait to see the doctor was usually long, but the time spent with the doctor was short. They claimed that if the doctor spent more time with them, he or she could better assess what was wrong and provide better care. If the doctor just trusted the “symptoms” they mentioned without questioning and examining them, they said that it was possible to miss important information. Teens also reported that they sometimes forgot to bring up concerns because they felt hurried or the doctor did not have enough time to give a thorough explanation.

Questionnaire results showed that only 14% of focus group participants felt that their health care provider spent enough time with them “all of the time.” A roughly equal percentage (16%) felt that their health care provider “never” spent enough time with them. Approximately a quarter (27%) of teens were satisfied with provider time “most of the time.”

The few positive experiences mentioned by focus groups involved the adolescents’ closeness with doctors or counselors. Some teens felt relaxed with their health care providers and trusted them. They mentioned that they felt comfortable going to their pediatricians’ offices because they knew them well there.

“I feel like they’re trying to rush you out when you go. They have a schedule and they just attend to you and then just move you right out to the next person. They don’t let you get a chance to ask so many questions.”

– Female (14-16) Chicago Group

“You know I’m here to talk [to the doctor] about my health problems... So it’s just too much for him to have different people in different rooms and for him to go in his office and sign papers and have me sitting there for 45 minutes... that’s just too much.”

– Female (17-20) Los Angeles Group

Parental Involvement

Adolescents voiced mixed opinions about their comfort with having parents involved in their care. They said their parents usually went with them for routine check-ups and physicals. For younger teenagers of both genders, many of the parents entered the doctor's office with the teen. If adolescents were sick or had to go to the emergency room, parents were usually present, regardless of the teen's age. Younger and older teens expressed the desire to have parental involvement for serious health issues, such as HIV, AIDS, or pregnancy.

"My mom's going to already know... She's hip to you, you know. Can't hide too much from her. She'll be looking in your eyes."

– Male (17-20) Washington, DC Group

However, reproductive health and substance abuse issues brought a different attitude among teens. The majority of adolescents, regardless of gender or age, did not want their parents to know about receiving birth control, STD or pregnancy testing, or if they abused drugs or alcohol. Some teens mentioned that they visited certain sites, such as free clinics or Planned Parenthood, so their parents would not know. They appreciated the clinics' confidentiality: the sites would not call their parents and their visits would not show up on their health insurance bills.

"...the doctors are not going to change the way my mother feels or my father feels about what I did. So him or her telling them what I did is not going to make any difference. Either way I did it. So that's how they're going to look at it..."

– Female (14-16) Washington, DC Group

"I'd let the doctor [tell them]. Because, if my mom and dad are getting a professional point of view it'll be a lot easier and the doctor could probably break it down and explain it to them better than me trying to explain it to them..."

– Female (17-20) Washington, DC Group

Most focus groups varied in their answers about health care providers' communication with parents: some thought it would be easier and more efficient having a professional directly explain an issue to their parents, while others wanted the professional to talk to teens alone and recommend how to explain the situation to parents. Some thought that the provider, parents, and teen should all discuss the issue together. Many said their preferences depended on the nature and severity of the problem; adolescents tended to favor privacy for reproductive issues and STD testing but wanted their parents to be directly involved in more serious health issues.

Questionnaire results showed that only 22% of young people wanted their parents or guardians involved their health care "all the time." A roughly equal proportion (one-third) of teens preferred parental involvement "most of the

time” or “some of the time.” Nineteen percent “never” wanted their health care provider to communicate with their parent or guardian about their health. The majority of teens (64%) preferred communication with guardians “some of the time” or “most of the time.”

The Ideal Health Care Experience

Each focus group was divided into teams of 3-4 individuals to discuss aspects of an ideal health care site: where it would be located, what it would look like, who would work there, and what services would be provided. Each team then presented their ideas to the larger focus group.

With respect to location, accessibility was mentioned by all focus groups as a key factor. They supported a site in a main area of town, perhaps near a shopping center, that everyone could reach. Some also gave suggestions of having several sites, one in each ward or neighborhood. The general theme was that it should not be a hassle to get there. All but one of the groups agreed that a health care site should have all services in one place. According to results from the questionnaire completed after the focus group, 91% of adolescents felt that an easily accessible site was “important” or “very important.” To achieve this, teens suggested during the focus group sessions that such a site be on a public transportation route or close to their schools or homes -- ideas that were deemed “important” or “very important” by 92%, 71%, and 76% in the questionnaire, respectively.

Young people also mentioned that they wanted the site to accept both appointments and walk-ins; questionnaire data showed that 82% found the latter to be “important” or “very important.” Most focus groups mentioned that the health care site should be open 24 hours, be affordable, and have fast service. The questionnaires revealed that these ideas were favored by 92%, 90%, and 88% of adolescents, respectively.

Adolescents described the aesthetics of an inviting atmosphere during the focus group, which was “important” or “very important” to 82% of them. They preferred a clean, modern, attractive bright look in a safe neighborhood so they would not feel intimidated. They also expressed a desire for equipment to use while waiting, such as televisions, internet access, games, music, refreshments, posters, and a “chill” room. Questionnaire data showed that nearly two-thirds of them favored an atmosphere with just people their age.

TABLE 2: Characteristics of Ideal Health Care Site for Teens

| Groups' Descriptions | Number of Focus Groups Mentioning (n=16) |
|---------------------------------------|--|
| Easily accessible | 16 |
| Inviting | 16 |
| Caring and interested staff | 16 |
| Knowledgeable and experienced staff | 16 |
| All services in one place | 15 |
| Close to schools | 15 |
| Easy to relate to staff | 14 |
| Takes appointments and walk-ins | 14 |
| Affordable | 13 |
| Fast service | 13 |
| Open 24 hours | 13 |
| Young staff | 10 |
| Confidential | 9 |
| Transportation provided | 8 |
| Parental involvement encouraged | 7 |
| Staff from diverse ethnic backgrounds | 7 |
| 24-hour hotline | 2 |
| Services separated by gender | 2 |

All focus groups felt that being knowledgeable and caring were important characteristics for staff working at this health care site. Adolescents wanted people who were smart and experienced to diagnose their problems. They desired well-informed staff to answer whatever questions they may have. Young people also described staff that was caring, with a good attitude. They wanted to feel as though they were being cared for genuinely. “Friendliness” was mentioned often in group sessions, and according to questionnaire data, 93% and 87% of teens felt it was “important” or “very important” for doctors and staff, respectively.

Most of the focus groups agreed that they wanted staff that would be able to relate to and understand them without judging them. For this reason, many of the groups mentioned having young doctors. Adolescents also felt very strongly about the need for both male and female doctors, and some wanted to be able to choose the gender of their doctors. They voiced a definite need for counselors, therapists, and social workers to help with mental health and behavioral issues.

Services at an Ideal Health Care Site

Within their teams, adolescents were nearly unanimous that the ideal health care center should have services for sexual health (including STD and pregnancy testing and free birth control) and mental health: all focus groups except one included these services in their descriptions of the site. The most common mental health service requests included counseling and therapy. Most of the focus groups felt that routine care such as physicals and check-ups were necessary, as well as substance abuse programs and health and wellness services.

Additionally, they preferred having pharmacy and lab services onsite so they could fill prescriptions or get blood and urine work done immediately rather than having to do it after their visits and not following through. For health and wellness, young people wanted nutritional counseling and fitness classes.

Most focus groups agreed that services should be located in the same place, though a few teens voiced worries about it. Questionnaire data collected after the focus groups showed 80% of adolescents either “agreed” or “strongly agreed” that going to the same place for all health care was a good way to get health care needs met, but 38% of adolescents either “agreed” or “strongly agreed” that going to different places to get all health care was a good way to get health care needs met. The concerns of those who worried about one-stop health care largely centered on confidentiality and crowding issues.

TABLE 3: Types of Services Provided at Ideal Health Care Site for Teens

| Groups' Descriptions | Number of Focus Groups Mentioning (n=16) |
|---|--|
| Sexual health care and family planning services | 15 |
| Mental health care | 15 |
| Physical exams and check ups | 12 |
| Substance abuse programs | 11 |
| Pharmacy and lab services | 10 |
| Health information and education | 8 |
| Health education by peers | 7 |
| Dental or vision care | 5 |
| Social services | 5 |
| Physical or massage therapy | 3 |
| Sports medicine | 3 |
| Domestic abuse or gang violence programs | 1 |

How to Bring Teens In and Keep Them Coming Back

“It makes you want to be careful, like, make better decisions.”

– Female (14-16) Washington, DC Group

“People would probably be more educated in, like if they have a center like that, people would learn how to eat better. I think obesity would go down.”

– Male (17-20) Los Angeles Group

Young people gave suggestions about what would encourage them to come into a center like this and keep returning. The most popular response was public relations and outreach. Most of the groups thought holding an event or advertising would help spread the word about the center. Ideas included teens doing community outreach, having a health fair, putting up posters, and advertising on the television, radio, and the internet. They also mentioned that the environment of the center itself and the services offered would attract young

people. Adolescents in the community would know there is a high likelihood that they would receive good service.

These young people expressed a commitment to changing their health if a center like this existed. The vast majority of groups thought that if their ideal health site existed, they would be very likely to use it. Also, they claimed they would then work harder to improve their health.

"...if you have something geared towards our age, I'd be more likely to go there."

– Male (17-20) Miami Group

"...if you receive good treatment you're going to keep coming back."

– Male (17-20) Miami Group

Conclusion

As the nation focuses on reforming health care, special attention should be given to health care for adolescents. Young people across the country are aware that sexual diseases, drugs and alcohol, teen pregnancy, violence, peer pressure, and mental health issues are problems for their age group. However, due to factors such as inadequate knowledge, lack of insurance, or negative health care experiences, many of them are not seeking or receiving the care they need.

The voices of these adolescents can help provide direction for future thinking about a new model of care for this age group. Regardless of ethnicity or location, disadvantaged adolescents voiced similar concerns about the quality of health care they received and how they thought care could be improved. To meet their needs, they recommend a health care site that is accessible and inviting, with knowledgeable and caring staff in an environment of trust and comfort. Most of them want comprehensive services in such a center, including services for sexual health, mental health, and wellness. The young people in these focus groups believe such a center would be widely used and that the environment and services of such a center would be the deciding factors in its success.

Methodology

This report presents the findings from a focus group study undertaken by The National Alliance to Advance Adolescent Health. A total of 204 adolescents from Chicago, Miami, Los Angeles, and Washington, DC participated in a total of 26 focus groups, which were conducted from the spring of 2008 to the spring of 2009. To obtain supplemental information for the study, an anonymous questionnaire was administered to 96 focus groups participants from 14 of the groups after the focus group sessions were completed. The focus groups were conducted by Philliber Research Associates and ICR.

Staff at local youth-serving organizations in each of the 4 cities recruited adolescents from disadvantaged neighborhoods to participate in the study. The groups were chosen to represent the ethnic make-up of each of the cities: overall, 57% of adolescents were African American, 32% were Hispanic, 6% were Caucasian, 3% were biracial, and 2% self-reported as "other." According to self-reported data provided prior to the sessions, most of the participants lived in families with incomes below the poverty level; some lived in families with incomes below 200% of the poverty level. The proportion of males and females was about equal.

Of the 26 focus groups, 14 groups were comprised of adolescents ages 14 to 16 -- 7 all male and 7 all female -- and 12 groups were comprised of adolescents ages 17 to 20 -- 6 all male and 6 all female. The average number of participants in the focus groups was 8, but ranged from 5 to 13.

The groups lasted 90 minutes. Discussions were led by a moderator from the research firms, using a discussion guide that was prepared by The National Alliance and piloted with 2 groups in Washington, DC. Toward the end of each focus group session, participants were divided into teams of 3 or 4 and asked to identify the services and providers that would be part of an "ideal" health site and report back to the group. Audio and video recorders were used in each of the groups so that transcripts and DVDs could be used for the analysis.

Participants were offered a small gift for their time. Those 17 and younger were required to have a signed parent permission form prior to participating.

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End Notes

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The National Alliance to Advance Adolescent Health provides education, research, policy analysis, and technical assistance to achieve fundamental improvements in the way that adolescent health care is structured and delivered in the United States. Its mission is to enhance the physical and emotional well-being of adolescents, especially those who are low income and minority, by improving the health care delivery model for adolescents and achieving the infrastructure changes needed to support it. The National Alliance seeks to promote comprehensive, interdisciplinary models of physical, mental, behavioral, and reproductive health care that incorporate a youth development philosophy and operate in collaboration with schools and other community-based programs. It also seeks to ensure that all adolescents have health insurance coverage for the services they require.

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