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How Do Adolescents View Health? Implications for State Health Policy

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A B S T R A C T

Objectives: Policy-makers rarely consult adolescents during development of health policies. However, perspectives of adolescents on health can inform public health policies and programs. As part of the development of an Indiana state plan for adolescent health, we used qualitative methods to describe adolescents' "emic" views of health, and discuss implications for a state health policy for youth.
Patients and Methods: We conducted eight adolescent focus groups in geographically and culturally diverse regions of Indiana. Each group was audio-recorded, transcribed, and analyzed using qualitative methods.
Results: Participants described health as a shared responsibility between adolescents and adults in their lives. They identified a key role for supportive adults in initiating and maintaining health behaviors. Physical, financial, and informational environments could support or hinder healthy behaviors and outcomes. Although adolescents' descriptions of physical health and risk behaviors were similar to adult formulations, they described mental health as "stress and fatigue," an interaction between the adolescent and their environment, rather than depression and anxiety which are considered to be individual pathologies. Respect for decision-making capacity, seeking adolescent input, and providing harm reduction messages were identified as particularly important.
Conclusions: Adolescent's perception of health can inform policies and programs, and should be sought before the development of health policies.

The health disparities between adolescents and other pediatric groups related to unmet health care needs, access to care, and health insurance demonstrate that adolescents are poorly served by existing national and state health policies [1–3]. The fact that adolescent health policies frequently focus on individual risk behaviors rather than broader contextual influences likely contributes to this disparity. Thus, adolescent health programs and practices that focus solely on the individual's responsibility for behavior change (e.g., obesity treatment, suicide prevention, sex education) have had limited success [4–7]. The failure of the program may be because of the policy makers not incorporating the views of adolescents and including their own perceptions of health. Qualitative research with diverse adolescent populations, such as Mexican immigrants, gay and lesbian youth, and African young men, has demonstrated that capturing adolescents' "emic" understanding of health aids in reframing health issues and can lead to greater programmatic involvement [8–10].

Although "disease" is a medical concept defined by specific diagnostic criteria, "health" is a socially constructed concept [11,12]. An increasingly prevalent interpretation of health extends this construct beyond the absence of disease to include physical, mental, and social well-being, and takes family, community, and culture into consideration [13]. Extending this construct to health policy, policies and programs that are consistent with a population's social or cultural views of health may be more likely to be accepted, leading to overall improvements in health status. The Centers for Disease Control and Prevention, for example, identified 21 Critical Health Objectives for Adolescents from Health People 2010, and provides a policy framework in

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which the usual focus on individual risk behaviors is complemented by healthy youth development concepts and health-promoting environments [14,15].

This study focuses on adolescents' own views of health in an effort to inform state policy. This "emic" approach is consistent with youth development principles [16], taps into ecological models of health that situate youth in families and communities [17], and links health and well-being to both individual capacity as well as family and community assets [18]. Ideally, adolescents themselves should participate in the process of defining their relevant health issues and proposing solutions [19,20]. However, beyond notable exceptions with international health [20,21], transitioning youth [22], sex education [23], and injury prevention [24], adolescents themselves are rarely consulted in policy formation. In an effort to inform the Indiana Coalition to Improve Adolescent Health's (ICIAH) policy recommendations, we describe Indiana adolescents' views of health and provide implications for state policy.

Methods

Participants

Eight focus groups consisting of 6–12 adolescents were recruited from community organizations across the state of Indiana (Table 1). A purposive sampling approach was used to recruit culturally, geographically, and sociodemographically diverse groups of adolescents aged 15–24 years. Participating organizations included Future Farmers of America, a rural alternative high school, urban youth leaders, a Latino student group, a university freshmen class, a program for parenting adolescents, an outpatient drug treatment program, and a private high school. Indiana University Purdue University at Indianapolis-Clarian Institutional Review Board approved the study, and adolescents' consent and parents' permission for minor adolescents were obtained.

Procedures

A focus group approach was chosen over individual interviews to (1) capture the exchange of ideas among participants; (2) assess the degree of consensus and diversity of opinion; and (3) encourage responses with depth and complexity [25]. The facilitator started with a description of the study purpose and focus group procedures. Participants were informed that the purpose was to "gather some information from each of you on your thoughts regarding your health and the health issues that weigh most on your mind at this age"; they were told that they could share their own experience, things they have observed, or experiences described to them by peers, and were informed that they were not expected to reach consensus on issues. They were asked to respect the privacy of others and not to share the discussion outside of the group.

The discussion guide included open-ended questions assessing general health beliefs, health priorities, health information sources, and youth-generated recommendations. Examples included, "What are teenagers health concerns?"; "Who do you trust most to go to for health information or advice?"; and "What solutions would you recommend to help solve the health issues affecting others your age?" Questions were developed by authors (M.O., K.M., J.R.) in collaboration with ICIAH, and piloted with adolescents. The facilitator clarified questions when needed, and encouraged participants to generate and react to the ideas and statements of others. The 1-hour sessions were audio-recorded and the facilitator completed field notes. Participants were provided with pizza and a $10 gift card. Theoretical saturation on key topics was reached.

Data analysis

Textual data were analyzed using a two-stage technique for identifying shared concepts and creating models of social cognitions held by social groups [26,27]. Interviews and field notes were transcribed and entered into Atlas-ti (version 5.2; ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). Preliminary codes were developed from field notes and an early reading of transcripts. Transcripts were then coded, and each code selected, read, and discussed. Key concepts were identified, and a theoretical model was constructed. The process was iterative. Data from new focus groups were compared with earlier data, and the model was further refined. We assessed validity and reliability by (1) testing hypotheses against subsequent data; (2) having two authors (M.O., J.R.) code transcripts and resolve differences by discussion; (3) assessing the theoretical consistency of results; and (4) presenting findings back to youth service providers from ICIAH for review and comment [27–29].

Results

Youth voice

Participants expressed a desire to be heard on all levels of decision-making, from state policies to local programs to individual-provider interactions. Participants described feeling engaged when their opinions were sought, and disengaged when

Table 1
Focus group participant demographics

	Age range	Gender		Ethnicity		
		Male	Female	White	African American	Latino
Group 1	15–18	6 (60%)	4 (40%)	10 (100%)	0 (0%)	0 (0%)
Group 2	19–24	5 (55%)	4 (45%)	9 (100%)	0 (0%)	0 (0%)
Group 3	17–19	3 (50%)	3 (50%)	0 (0%)	6 (100%)	0 (0%)
Group 4	16–18	7 (100%)	0 (0%)	7 (100%)	0 (0%)	0 (0%)
Group 5	16–18	0 (0%)	8 (100%)	4 (50%)	4 (50%)	0 (0%)
Group 6	16–18	6 (67%)	3 (33%)	8 (89%)	1 (11%)	0 (0%)
Group 7	16–18	3 (43%)	4 (57%)	0 (0%)	0 (0%)	7 (100%)
Group 8	15–20	4 (34%)	8 (56%)	10 (83%)	2 (17%)	0 (0%)
Total		34 (50%)	34 (50%)	48 (71%)	13 (19%)	7 (10%)

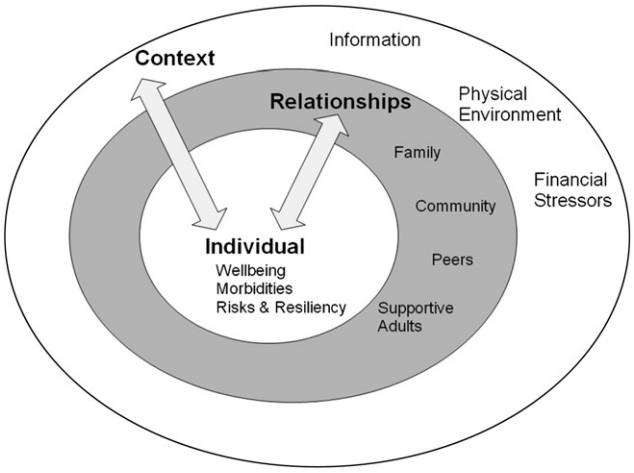

Figure 1. Adolescents' multilevel view of health.

their opinions were disregarded. They felt that their experiences should be a part of the planning process:

> 'Cause a lot of times they say that, but they don't give a shit what we think. They're like 'Oh this is good for them, let's do this.' We are different people, we have different thoughts, and we are unique in every aspect of everything": 19-year-old male participant.

The following analyses are based on this perspective of adolescents as "experts" about their own health.

Conceptual model: three levels of health

When the participants were asked "What makes a teen healthy?," all of them initially stated well-known risk behaviors and morbidities, such as obesity, smoking, drinking, and unprotected sex. However, on further discussion, it became clear that nearly all of them viewed health as a much broader construct. Across focus groups, we observed three consistent aspects of discussion about health: an individual level, a relationship level, and a contextual level (Figure 1).

Individual-level factors

At the individual level, participants identified the following common morbidities and risk behaviors: (1) obesity, (2) stress and fatigue, (3) alcohol, tobacco, and substance use, (4) sexual behaviors, sexually transmitted infections, HIV, and adolescent pregnancy, and (5) violence and personal safety. This list was similar to the 21 Critical Objectives of the Centers for Disease Control and Prevention, with two important distinctions.

First, nearly all participants (six focus groups) highlighted the complex interrelationships between risk and protective factors and morbidities. A participant describes the interplay between alcohol, stress, school, and future aspirations:

> "People want to experiment and that's part of your life. But you're being stacked with all this stuff that's supposedly going to be the foundation for the rest of your life. So you're doing things that are gonna take you away from that and then expecting to rise to that occasion at the same time. And, the stress of all that leads some people more in the direction [of alcohol use] because they need a release. It's a balancing act between what you want to do and what you're supposed to do": 20-year-old male participant.

Second, across all focus groups, participants described mental health issues differently. Policy makers focused on depression and anxiety which were diseases within individuals [15], whereas adolescent participants described stress and fatigue which were the result of an interaction between an individual and his or her environment. A participant describes juggling school and work:

> ". . . . you don't ever get a break. It's a constant stress . . . like oh I have to get this done. Oh, but that's done now I have to get this done. It's like so like, draining and you just drone on in the same sort of like, deadlines . . . it really does mess with you": 19-year-old male participant.

Relationships

Supportive relationships with family, schools, and community members were considered necessary to initiate and maintain healthy behaviors, and to create a healthy environment. These relationships provided a connection, remained positive and nonjudgmental, and respected the adolescent's evolving abilities. A participant describes the importance of adult support for losing weight:

> "Someone to help motivate them, keep them going, cause after awhile you just get burnt out on it. You don't have anyone motivating you and . . . [exercise and sticking to a diet] just gets boring and everything": 17–year-old male participant.

An adult who provided a connection talked about difficult issues, lived through similar life experiences (e.g., poverty, drug use, school failure), and expressed an interest in listening to adolescent's issues:

> "I have a pastor at my church that's really good . . . he was the rock n' roll type, you know the partying type. He finally turned his life around. He helps all of the youth at our church. Any kind of problems they have got, he has been through it": 16–year-old male participant.

Participants also differentiated adults willing to "talk with" adolescents as opposed to "talk to" them.

It was important for adults to be positive and nonjudgmental. All participants spoke of the importance of feeling valued and having adults encourage their self-worth. Examples ranged from receiving a simple compliment to being provided with feedback without being criticized. Participants were particularly sensitive to stigma and shame, as illustrated by this parenting adolescent's description of a teacher who commented on her decision to have a child:

> "I mean, like don't use your personal judgment on my schooling. When I'm in school that's my focus. Yeah, I have a kid, but I'm here to learn . . . Your job is to teach me. You're not getting paid to criticize me about having a kid at my age": 16-year-old female participant.

A third characteristic was respect for adolescents' evolving decision-making capacity, especially as it related to the health care setting. Adolescents who were able to provide input into their treatment described being more invested and engaged:

> "At the counseling center they totally give you the option. Do you wanna be prescribed something or do you wanna go a

different route? I totally said different route. The stuff they worked on, like breathing techniques and stuff, I feel totally work a lot better than just being put on something": 19–year-old female participant.

In contrast, when adolescents' input and preferences were not acknowledged, participants described feeling disengaged from provider and their treatment.

Parents were considered the most important people in supporting healthy decision-making and outcomes. Criticism was acceptable, if the parents remained supportive:

"If your parents or your friends they support you, they basically have your back. Or they don't have your back, and they should give you positive criticism if criticism is needed. Nobody wants to be down all the time. You need that type of support and encouragement": 17-year-old male participant.

Peers, teachers, and other adults were called upon in situations in which the parent was unable to provide support, or the adolescent was uncomfortable asking for it. Topics generally involved relationships, sex, contraception, or substance use.

Participants varied in the amount of responsibility they placed on an individual for their own behaviors and health, versus the responsibility they placed on adults and environments. Conversations with some participants (particularly those from higher income groups) reflected a tension between the individual versus the collective responsibility. Here a participant not only recognizes individual responsibility, but also the important role of adult support, regardless of poor decision-making on the part of the adolescent:

"The way she talks to you, she keeps it real. She be like 'You do this, you do this, you gonna have these consequences. But if you need somebody even if you make a mistake, you can come to me.' See, people don't say that, they just tell you your mistake and your consequence": 17–year-old female participant.

Environment and contexts

All focus groups identified their environments (i.e., physical, financial, and informational) as critical to initiating and maintaining healthy behavior.

Physical environment

The physical, or built, environment included the structure of, and the way people use neighborhoods, schools, buildings, roads, and green-space. Participants described their physical environment as either health promoting or inhibiting. One participant described safety concerns regarding walking between home and work:

"I used to live close to my job and I didn't have a car so I would walk over there, but I didn't like it because there were no sidewalks. I had to walk on top of the grass": 16–year-old female participant.

Participants linked the presence or absence of a physical environment conducive to exercise and with access to healthy foods to obesity. Participants belonging to lower income group described the following characteristics of their physical environment: a lack of green space, lack of public transportation, little access to grocery stores or restaurants with healthier food options, and physically unsafe neighborhoods.

Participants who lived in areas marked by violence and crime described risks of physical injury, emotional stress, and lack of physical activity as characteristics of the environment, with multiple effects on health. A 17-year-old male adolescent describes the limitations of this type of environment for those not directly involved in violence:

"I used to stay outside past a certain hour, but thanks to people around my neighborhood, stayin' outside went out the window. People stay on the Internet all the time": 17-year-old male participant.

Financial and other resources

Resources included family income, neighborhood and school amenities, and access to health care. Like the physical environment, participants identified their families' financial contexts as health promoting or inhibiting. Several participants described needing to work to contribute to family income or to support themselves. Several described time and stress related to this factor:

"If you're working however many jobs and school and everything, you don't have time to make healthy foods . . . You throw a hot pocket in the microwave before you leave for work": 16-year-old male participant.

Others described their parents working long hours and having no one at home to cook meals or provide support.

Access to health insurance and quality health care providers was identified as important resource issues. Some participants mentioned having access to emergency departments only. Others said that cost was a barrier to necessary services. A college freshman said:

"When I turned eighteen I didn't have [Medicaid] anymore. If I go to the doctor I pay. The only reason I have any coverage is because my mom gets a little bit of insurance through work. So most of the time I'm sick I don't go to the doctor."

Informational environment

Participants described concerns regarding the health information provided by schools, programs, parents, and other adults. They placed a priority on honesty and truthfulness, and described multiple scenarios in which they felt that honesty and truth-telling had been compromised. Participants were skeptical of over-simplified messages around sexual behavior, drugs, and alcohol use, and generally felt that harm-reduction approaches were most appropriate. "Just say no" approaches were felt to be unhelpful, and did not reflect the complex reality of alcohol and drug use among adolescents:

"I mean, you can tell them it's better to just not [drink], but I think the best way, especially in our generation, is to teach them how to be safe while they're doing something like that. Not to do stupid stuff": 16–year-old male participant.

Respect for youth and their decision-making capacity was perceived to be important. Participants wanted to be treated in a serious, respectful way:

"Last year, this family came [to school] and juggled and did circus acts, and then they're like, 'Don't have drugs! So you can do what we do.' I think it was almost worse than actually helpful. I think it's better for someone to just be serious with

them, someone from a town or a place like theirs and just be serious and talk to them": 17–year-old male participant.

Comments were similar for information about sex, pregnancy, and sexually transmitted infections. Participants preferred harm reduction approaches that acknowledged the reality of adolescent sexual behavior. They described the need for information and skills, instead of scare tactics:

"They say you need to be abstinent but it doesn't help. They should spend more time showing how to do it safely instead of saying not to do it": 16–year-old male participant.

Most participants expressed a preference for a complex harm reduction message over a simple proscriptive message. This participant felt that sex education should acknowledge the positive aspects of sex as well as the risks:

"Yeah, keep it real ... I hate when people be like 'don't have sex, it is not for you.' I want someone to tell me sex is ok, but if you do this make sure that you do it this way. I am for real, say sex is good just wrap it up": 18-year-old female participant.

Participants were attuned to contradictory health messages. This is illustrated by observations made by several participants about many schools allowing soda machines, but advising against using soda in their health curricula:

"You see it, you walk around the school. They say 'Oh, you guys can't buy sodas,' but there are soda machines everywhere. Why would they have them if they don't want us to buy them?": 16–year-old female adolescent.

Discussion

These data demonstrate how understanding adolescents' own views of health can inform policies and programs. The use of adolescent focus groups tapped into an "emic" perspective, and interactions among participants facilitated a deeper and more complex discussion [25]. Three specific findings are of importance to adolescent health policy.

First, mental health was an area in which current policy approaches are at odds with adolescents' experiences. For example, two objectives related to the mental health of the adolescents are to reduce the suicide rate and to increase access to treatment [15]. However, our participants did not view mental health, such as depression or anxiety, as individual pathologies; instead, they viewed mental health as an interaction between the individual and his or her environment. From this perspective, prevention and treatment need to go beyond individual engagement in mental health services, and include a focus on healthier environments.

Second, participants viewed health as a shared responsibility between the adolescent and adults in their lives. Supportive relationships and healthy physical, financial, and informational environments were considered necessary to support healthy behaviors and outcomes. In areas ranging from food choices to drug and alcohol use to health care, participants pointed out that many times their current environment, family, or school contexts promoted unhealthy behaviors. Although these observations are not new, this structural need for supportive adults and environments is not frequently addressed through policies. For example, obesity and tobacco interventions typically focus heavily on individual adolescents changing their own behaviors. Few focus on modifying home and school environments, such as the availability of healthy food choices, increased opportunities for physical activity, or less exposure to environmental tobacco smoke.

Finally, across socio-demographic groups, participants overwhelmingly supported truthfulness and harm reduction in health education, particularly in sensitive areas such as alcohol, substance use, and sexual behavior. Participants believed that adolescents were capable of handling complex health education messages. These findings are consistent with data, such as evaluations of sex education programs, demonstrating the effectiveness of comprehensive and harm-reduction approaches over abstinence-only approaches [4,30,31]. They are also consistent with ethical approaches to public health, which eschew the withholding of information needed to make decisions about health [32].

These findings should be interpreted in the contexts of strengths and weaknesses in the study design. We used a purposive sampling approach, including adolescents from different geographic locations, age groups, and ethnic backgrounds. Although participants spanned a wide range of ages and life experiences, we observed remarkable consistency across groups. The one major exception was that participants aged $\geq$18 expressed high levels of concern about health insurance and access to care. However, we recognize that some groups of adolescents were not included, and that the views expressed may not be representative of all adolescents. We also note that adolescents in our study were only involved in a very basic level of policy making, gathering perspectives, and identifying priorities, and were not involved in higher levels of policy development and decision-making [33].

The strengths of the study include the consistency of our findings with the existing research. For example, participants' belief in the importance of connection to a caring adult is consistent with nationally representative data demonstrating that parent, family, and school connectedness are protective against a variety of health risks [34]. Another strength was our capacity to tap into participants' concern about their health and interest in participating in these discussions. These adolescents' "lived experiences" provided the perspective needed for health providers and policy makers to create an environment in which adolescents can thrive.

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