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ADOLESCENT AND HEALTH PROFESSIONAL PERSPECTIVES ON THE MEDICAL HOME: IMPROVING HEALTH CARE ACCESS AND UTILIZATION UNDER THE AFFORDABLE CARE ACT



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CONTENTS

Acknowledgements	i
Background	1
Methodology	4
Results	5
Study Participants.....	5
Findings From Adolescent Focus Groups	6
Expert Perspectives Regarding a Medical Home for Adolescents.....	14
Conclusions	24
References	27

BACKGROUND

The definition of the medical home has evolved considerably over time and has been expanded as a primary health care delivery model for infants, children, and adolescents, as well as other age groups.¹ The concept of a medical home has been discussed for nearly a half-century, as it first appeared in 1967.² Initially, the medical health home was operationalized as a centralized medical record, but evolved as an approach to providing primary care to address the “whole” child in relationship to health, education, family, and the social environment—with a particular focus on children with special health care needs (CSHCN).¹ In this approach, the primary care pediatric provider is the point of contact for the child and family in order to ensure that care is continuous and comprehensive with linkages between medical and nonmedical resources from birth through adolescence. Hawaii led these initial efforts through their Healthy Start Home Visiting Program and the Emergency Medical Services Program for children. Ultimately, it was integrated into state legislation as part of the Individuals with Disabilities Education Act.¹

The concept of a medical home has expanded considerably under the Patient Protection and Affordable Care Act of 2010 (ACA).³ The ACA incorporated the medical home model as a key component of health care reform, intended to improve patient care outcomes while reducing costs. The model focuses on promoting access to and delivery of quality care through team-based, coordinated care that meets the multiple and concurrent health needs of patients, while also promoting the delivery of preventive health services. In 2014, a total of \$35.7 million in ACA funding was directed to 147 health centers in 44 states, the District of Columbia, and Puerto Rico to support patient-centered medical homes.⁴ Although the medical home has been conceptualized in different ways, the American Academy of Pediatrics (AAP) policy currently states that every child should have a medical home that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.⁵⁻⁷ Figure 1 illustrates this medical home model.

Figure 1: Components of the Academy of Pediatrics (AAP) Medical Home Model



For additional details about the components: <http://pediatrics.aappublications.org/content/110/1/184.full>

The concept of a medical home represents a particularly promising approach for adolescents because adolescence is a unique period marked by rapid changes in physical, emotional, cognitive, and sexual development. The behavioral patterns that are established during adolescence impact both immediate and long-term health outcomes,⁷ and most of the health morbidity and mortality during adolescence is preventable. Specifically, adolescents have the highest rates of sexually transmitted infections⁸ and unintended pregnancy,⁹ and face significant and unmet behavioral, mental, and emotional health needs.¹⁰

In addition, many adolescents experience a range of health risk behaviors that cross multiple domains.¹¹ Thus, adolescence is an important time to promote healthy behaviors and address health risk behaviors using a holistic and comprehensive approach. However, nearly half of all adolescents lack access to a medical home as it pertains to the AAP medical home criteria (i.e., usual source of care, having a personal doctor, receiving needed referrals, effective care coordination, and family-centered care). Rates of medical home access are even lower for adolescents from households with lower socioeconomic

status (SES), non-English speakers, and those with mental health issues.^{12,13} In addition, adolescents' receipt of the suite of comprehensive preventive health services is poor.¹⁴

Despite the potential of the medical home concept in promoting adolescent health, some adolescent health experts have argued that the pediatric and adult medical home models have not been conceptualized to meet the unique needs and service utilization patterns of adolescents.¹⁵ Furthermore, little is known about how adolescents conceptualize and value the various components of a medical home. There are currently no published studies that have examined adolescents' attitudes regarding the medical home, although researchers at Brown Medical School conducted a youth panel on the adolescent medical home.¹⁶ This work is an important first step. Adolescents' perspectives, including what is important to them and what they want from the health care system that they are not currently receiving, have often been omitted as professionals develop new programs and policies. These perspectives are important because they can further inform how we ensure that the medical home for adolescents is more aligned with their needs.

Thus, a primary goal of this study was to better understand adolescents' views on what are considered core components of the medical home and identify barriers to promoting adolescent health in relation to the medical home. In addition, this study sought to better understand the needs and challenges in providing adolescents with access to medical homes—from the perspective of both adolescents and experts in adolescent health and medical home policy. To accomplish these goals, we conducted focus groups with adolescents, presented these findings to experts, and gathered experts' reactions to the adolescents' perspectives. This report includes a detailed description of the methods used for this study, followed by a summary of key focus group findings and the expert reactions to these findings.

METHODOLOGY

This qualitative research study incorporated three main components:

1. **Literature review:** The goal of the literature review was to inform the historical context of medical homes and to develop a framework reflecting the critical components of the model, especially as it pertains to adolescents. The literature review was conducted using a variety of search terms in both PubMed and Google Scholar search engines. Search terms included “medical home,” “medical home model,” and “patient-centered care” both individually and combined with “adolescent.” Articles were then entered into a spreadsheet and organized by theme with a brief description of each article. This review also helped to identify key experts in the field.
2. **Focus groups with adolescents:** The goals of the focus groups were to: (a) gather adolescent perspectives on the key components of a medical home; (b) ascertain what elements may be missing from the current health care delivery system, and (c) identify barriers to implementing the medical home model. Questions were open ended and covered several domains, including experiences with and utilization of health care; knowledge and perceptions of components of the medical home; use of technology to support medical home; knowledge and attitudes about health insurance and coverage; and barriers and facilitators to care. Potential participants were informed about the study and provided written parental and youth consent to participate forms. Focus groups took approximately 90 minutes and were audio recorded and transcribed. Adolescents received a \$20 gift card for participating.
3. **Expert interviews:** The goals of the interviews were to review and discuss key focus group findings, identify barriers, and develop solutions to improve the medical home model for adolescents. After completion of the adolescent focus groups, 1-hour individual telephone interviews were conducted with an invited sample of national experts. Experts were identified from the literature review and input from the research team. During the interview, experts were presented with a synopsis of the data gathered from adolescent focus groups. These findings were discussed in additional detail and key questions were asked to elicit recommendations to improve medical homes for adolescents. Interviews were audio recorded and transcribed for analysis.

Two independent coders analyzed and categorized the qualitative data from each focus group transcript. Drs. Tebb and Brindis jointly conducted almost all of the expert interviews. Each transcript was analyzed to capture key themes that emerged using pre-set categories and to identify new themes. Data was further analyzed to identify the range of responses within themes, their relative importance, and divergent responses within each theme. The study received approval from the institutional review board at the University of California, San Francisco.

RESULTS

Study Participants

Adolescent Focus Group Participants

A total of seven focus groups of adolescents were conducted. Four focus groups took place in California with a total of 36 participants. Two of these groups were conducted in rural high schools in California's Central Valley and the other two were conducted in urban high schools in the Northern Region of the San Francisco Bay Area. The mean age of these groups was 17 years and represented the racial/ethnic diversity of each of the schools. The majority of adolescents in the rural focus groups were from Hispanic/Latino backgrounds. Adolescents from the urban school were from diverse backgrounds, with the majority non-white. Three additional focus groups were conducted in New York City, with a total of 26 participants (14 females and 12 males). Participants were recruited from two youth internship programs affiliated with a large urban hospital center. The New York-based focus groups also had participants who, on average, were 17 years old; a majority of the participants were African American and Hispanic/Latino.

Interviews With Experts

A total of 14 experts in topics related to medical homes, adolescent health, and adolescent health policy were invited to participate in a 60-minute telephone interview. Up to five attempts were made to contact potential participants. A total of nine experts agreed to participate in the study (see Acknowledgements).

Results are organized according to the key themes that emerged from the focus groups with adolescents. Focus group findings and illustrative quotes are provided. The quotes indicated the gender and region of the participant, whether it was from an adolescent or expert. These key themes are then followed by expert reactions to adolescent focus group findings. Several experts requested that their quotes be anonymous, so names are not provided for each quote; rather, the expert participants are listed in the Acknowledgements. Further, it was not possible to provide the expert's role for each of the quotes presented in this report because almost all of them had multiple roles. Many were specialists in adolescent medicine as well as health policy advocates and were well-versed on the concept of medical homes—especially for adolescents.

Findings From Adolescent Focus Groups

Discrepancies between what adolescents want from a “medical home” and their experiences with the health system

In brief, adolescents, like many adults, were not familiar with the medical home concept or terminology, although they were able to articulate what aspects of medical care they desire. In order to gather their perspectives, focus group facilitators asked adolescents about their experiences with the health care system, barriers to care, and then specifically about the core concepts of a medical home. Consistent with the medical home concept for other populations, adolescents conveyed that a positive caring relationship with a primary care provider is and should be central to the medical home model. They also felt that they should be able to access this provider on a regular basis and talk about issues that are important to them. Also consistent with the medical home model, adolescents wanted comprehensive services that were either co-located with the primary care provider or close by via referral. However, there were many disconnects between what adolescents desire from the health care system and their actual experiences. In addition, there were several areas in which the medical home model did not align with the needs of adolescents. Exhibit 1 highlights the differences between what adolescents want from the health care system and the reality of their experiences. Each of these key findings is further detailed in the following sections of this report.

Exhibit 1. Discrepancies Between What Adolescents Want Compared to What Adolescents Experienced	
<i>What Adolescents Want</i>	<i>What Adolescents Experience</i>
<i>Relationship with primary care provider</i> who knows them and cares about their health; <ul style="list-style-type: none">○ Responds to them as individuals and treats them with respect;○ Can be accessed on a regular basis; and○ Can talk to about issues that are important to adolescents.	<ul style="list-style-type: none">• Lack of an established primary care provider• Lack of understanding and respect from their primary care provider• Barriers to accessing a primary care provider• Insufficient opportunities to talk with primary care provider
<i>Comprehensive care</i> where physical, mental, vision and dental health care needs are met.	<ul style="list-style-type: none">• Concerns about privacy and sharing information between providers• Limited selection of providers and care
<i>Confidentiality assurances and protections</i>	<ul style="list-style-type: none">• Lack of knowledge of existing confidentiality rights and protections for adolescents• Barriers to having time alone with primary care providers

The importance of having a relationship with a primary care provider.

Across all focus groups, adolescents reported that at the heart of their health care experience is the extent to which they feel that they have a positive, caring relationship with their primary health care provider who knows them and cares about their health. When adolescents were asked how providers show they care and what they do to establish a positive relationship, many expressed the importance of establishing rapport, making them feel comfortable, and being nonjudgmental.

“[It is important for providers to be] caring, don’t mislead you, don’t give you a reason not to trust you.”—Female adolescent, New York

*“[It is important that] they make us feel comfortable with what we do and say.”
—Female adolescent, urban California*

*“[They show they care by] not being judgmental [and by being] patient and honest.”
—Male adolescent, New York*

In addition, adolescents felt it was important for providers to treat them respectfully and as individuals. The concept of a medical home incorporates cultural responsive care which involves the provision of “effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.”^{17,18} The importance of this concept was evident in all of the focus groups, especially in discussing how providers show their respect.

“They show respect, they don’t try to baby you or break you down into three things: you go to school you go home, you go to sleep. ‘Oh your life is easy.’ It’s not that easy and they show respect, like wait, it’s not that easy for you. That’s how they show respect.”—Male adolescent, New York

A positive relationship with a health care provider is especially important in making adolescents feel comfortable to disclose health risk behaviors and to ask for help when needed.

“It’s very important to have a doctor we know because we don’t have to meet someone new every time we go to the doctor and get used to them.”—Female adolescent, rural California

“They make me feel comfortable when they say you’re doing good. Even if it’s negative, they make it sound ok. They reassure us.”—Male adolescent, New York

*“I feel for adolescents, you need to see which one [provider] you trust, so you can have that relationship where you’re not afraid to ask for help when you need it.”
—Male adolescent, New York*

A few adolescents also expressed a need for providers to engage them in the decision-making process and not pressure them to answer every question.

"I like for them [providers] to give us choice and freedom. If they ask a question and we don't want to answer, they won't force us."—Female adolescent, New York

While most adolescents want a relationship with a primary care provider, many, especially from rural regions, do not have such an established relationship. The extent to which adolescents reported having a primary care provider was mixed across the focus groups. For instance, while almost all adolescents from urban regions reported having an established primary care provider and that they have a positive relationship with that provider, only half of the youth from rural regions reported that they have such a relationship. However, even among urban youth, a few adolescents felt that their providers did not understand them or treat as individuals.

*"They think all teenagers are the same. Doctors just treat us the same way."
—Female adolescent, urban California*

"They didn't understand where I was coming from."—Male adolescent, urban California

"They just try to, like, give you, like, the minimum – maybe they have a lot of patients to talk to, so they don't really wanna take time out of the day to, like, really focus on one person and what they're going through, what's going on with them."—Female, rural California

Adolescents experience a number of barriers in accessing a primary care provider and appropriate health care services. While the experience and relationship with the primary care provider is critical, logistical factors, such as cost and transportation, continue to be factors that influence adolescents' ability to access their provider. Many adolescents also felt it was difficult to make appointments. These barriers were expressed across all of the focus groups. Furthermore, for adolescents living in rural communities, the availability of health services is problematic. In addition, participants from rural areas felt that they had limited resources to access health care and health information; some said they had to travel to neighboring towns to access health services.

"We would go to the doctor more if maybe the services were free, or more affordable."—Adolescent female, urban California.

"You can't just walk into the doctor and be, like, 'I want to see my doctor' 'cause, you know, there's people who have an appointment within that day. Or sometimes I want to make an appointment and I'll tell them I have Wednesday available and they're like, 'Oh, we don't have Wednesday. You have to wait until, like, the 30th.' Yeah, so it's kind of hard to, like, get an appointment sometimes."—Adolescent female, rural California.

“Some of us either don't know how to drive or we don't have a car, so it is harder for us to, like, you know, if we do have a question, for us to drive to Selma or drive to there. But if it's here [close by], maybe we can just go ourselves and we won't have to worry about, you know, our parents.”
—Adolescent female, rural California.

Participants expressed that little health information was made available through their schools. While this came out in several focus groups, it was expressed most strongly in rural California focus groups.

“The last time I remember, like, some – like, an actual health person coming into the school was, like, my freshman year in high school. And that was for my health class. So it's been, like, a really long time.”—Adolescent female, rural California.

“We don't get information in school, not for a long time anyway. I remember in the fourth grade, they would tell us about the process of how we were gonna change and go through puberty and stuff, but I don't think they do that anymore. I've asked my brother and he said that there hasn't been anything like that.”—Adolescent male, rural California.

Several adolescents expressed that at times they were reluctant to go to their health care provider out of fear they might have a problem. This situation is further confounded when adolescents who have made the effort to obtain care feel they do not get the help they need.

“If you find out something you don't want to hear, you wouldn't go back. You'll just be depressed.”—Female urban California

“You don't go back if you hear something you don't like or not getting the information you need.”—Male, New York

Some adolescents also felt that while they had a relationship with a provider, they rarely had access to their provider. When accessing care, they end up seeing different providers and finding that experience frustrating, which is expressed in the following quote:

“My doctor, I never see her, I always get a random doctor. I'm waiting for one person and I get someone else. I hate that.”—Female adolescent, New York

Adolescents report having insufficient opportunities to discuss personal health issues with their provider. The overwhelming majority of youths, even those with a positive relationship with their health care provider, stated that they do not have the opportunity or time to talk about things that are important to them during their visits. They want to discuss important health topics with their provider, but often do not have the opportunity to do so. Some adolescents felt that their health care provider rushed them through the visit.

"Sometimes, like, when I go to the doctor, I have questions I wanna ask, but because [the doctor] walks out, like, a lot or she will just leave and I won't have the time to ask her my questions. I think just, like, availability and being able to reach her and, like, not feel rushed through the appointment, I think it would be better—Female adolescent, rural California

"I feel like it's very, like, shallow, what we go into in our appointments. It's, like, if we do have more questions, they'll just knock it out with a simple answer. Like, 'Oh, maybe you just need more sleep. Maybe you just need, like, to eat a little bit more. Or maybe you should exercise.' What if you already do those things and we think there's something else going on or maybe we just want a more in-depth answer? If they would provide that for us, I think we would feel a little bit more comfortable."—Female adolescent, urban California

A couple of adolescents felt that the provider felt that the provider did not value or respect them as individuals. As one adolescent noted:

"I had a lot of doctors where, in the middle of my appointment, they would sit there and have like a watercooler conversation about who ate somebody's lunch, I'm sittin' there with the blood pressure cuff on my arm and they are going off about other things and I'm right there for like an hour."—Male adolescent, New York

The importance of comprehensive care for adolescents.

Another cornerstone of the medical home is that adolescents should be able to receive all the different types of health care that they might need, either all in one place or close by via referral. When adolescents were asked what they felt about this medical home concept, almost all expressed a desire for this type of health care delivery model. They felt this approach makes accessing different health services easy, convenient, and efficient.

"[Having all different types of health services in one location,] that would be cool. Then you can have a dentist appointment and an eye appointment and you're done!"—Female adolescent, urban California

"All in one place is best; it's easy and convenient."—Male adolescent, New York

"How great! You can do it all in one day."—Male adolescent, rural California

"It's easy, you're there for one thing and they tell you that you need something else, you can just take care of it right there."—Male adolescent, New York

While most adolescents desired to have services available in the same location, adolescents expressed a great deal of concern about their privacy and felt it might increase the risk of it being compromised.

"I don't feel comfortable. Having it in one place would abuse your privacy. If everyone is there, they will see you going to get STI testing. I don't want to go in there because everyone is here."—Female adolescent, urban California

"Let's say I'm sick and I have a mental issue. If I go to a place and those two doctors work in the same building, I feel they might talk about me."—Male adolescent, New York

"You'll have less privacy and that's a disadvantage."—Female adolescent, rural California

Privacy concerns also came up when adolescents discussed their feelings about the sharing of sensitive health information across different health care providers.

"I don't want my mental and psychologist doctor to be the same doctor that I get my medicines from because they are different issues. I don't want one person knowing too much about me."—Male adolescent, New York

Few adolescents report having access to comprehensive health care services. In one of the New York focus groups, participants reported that they were able to get all their health care needs in one place; however, this was the exception. Across all of the California focus groups (rural and urban) and the other New York focus group, adolescents were surprised at the concept of comprehensive health care services because none of them felt they had access to such services. One adolescent female, in the urban focus group, reported that her medical doctor and eye doctor were located in the same building and felt this limited her choices.

"At my doctor's office, you can get glasses there. But, what if you don't like that brand of glasses? You can't just go to a different place. You may not have all the choices you want."—Female adolescent, urban California

Adolescents reported having forgone care for mental health services because they felt their concerns are not taken seriously. Adolescents across all of the focus groups expressed a great deal of stress and anxiety and stated that they avoid seeking care because they perceive that their mental health issues will not be taken seriously. Adolescents, especially those of color, felt that their mental health concerns and needs were not well understood or addressed in health care.

"Communities of color, they avoid getting mental health. If you say there's a problem, they'll be like, 'No, no, you're just making it up. It really doesn't exist.' Stuff like that"—Male adolescent, New York

"I think stress is a big one. I have, like, a thing where I have, like, insomnia and I used to get really bad headaches. So, like, that was the one thing I brought up with my doctor too. He said it was due to stress, but that's it, he didn't really help me with it." —Female adolescent, rural California

The importance of confidential health care for adolescents.

In addition to confidentiality concerns expressed with regards to the co-location of various health services, across all of the focus groups, adolescents expressed a need to be able to talk to their provider in private without fear that information disclosed would be shared with their parents.

"I personally wouldn't feel like telling my mom. ... She would get mad at me, so I don't think I would want to, like, tell her. ... I would rather tell my doctor." —Female adolescent, rural California

"If I'm telling my doctor I have an STD, or I'm sexually active, I don't want anybody else to find that out. My mom or the kids at school, rumors – all kinds of stuff connected from that. ... [My parents] would kick me out." —Female adolescent, urban California

It should be noted that there were a few adolescents who acknowledged that many teens share health information with their parents and confidentiality is less of an issue.

"It depends on your relationship with your parents – some are comfortable and tell them everything and some don't." —Female adolescent, urban California

While confidentiality is important, adolescents have limited knowledge of existing confidentiality protections. Few adolescents knew much about their confidentiality rights and protections. Three focus group participants exchanged the following dialogue, which is illustrative of the overall confusion around confidentiality:

"Is everything we say [at a doctor's office] confident?"

"I heard there's like an age."

"Once you're 16."

—Male and female adolescents, urban California

Participants in the New York focus groups had a greater understanding of confidentiality protections, but echoed the other groups' views that confidentiality concerns are a tremendous barrier to care.

"I think with the confidential thing, not many teens are informed about that. So they think that whatever they say to the doctor will be told to their parents. I think that's one of the reasons why they are not comfortable to tell their doctor anything." —Male adolescent, New York

Adolescents experience significant barriers to receiving the confidential care they desire.

Major medical health organizations recognize the importance of adolescents' access to confidential health service and recommend that all adolescents have time alone with a provider to promote confidential discussions about sensitive health topics that are particularly important in promoting adolescent health.^{19 , 20 , 21} However, many adolescents—both in the focus groups as well as in other research studies—reported that they never had time alone with their provider for confidential health discussions.²² Most adolescents in these focus groups stated that their parent, usually their mother, stays in the exam room for the duration of the health care visit. As noted previously, the parent's presence makes it difficult for adolescents to ask questions, discuss sensitive health topics and have their health risk behaviors addressed. In addition, participants from rural regions reported that it was extremely difficult to obtain any health services confidentially because their communities were relatively small and most people know one another.

"Our community is small, there's always someone at the clinic who will recognize you and tell your parents."—Female adolescent, rural California

Expert Perspectives Regarding a Medical Home for Adolescents

After the adolescent focus groups were conducted, experts in adolescent health, adolescent health policy, and patient-centered medical home were interviewed to discuss the focus group findings. In addition to reacting to the themes that emerged in the focus groups, experts also brought up additional issues and challenges in implementing the medical home model for adolescents. The following section presents the main findings from the expert interviews.

It is important to understand adolescents' perspectives in creating and implementing a medical home in order to meet the needs of this special population.

All of the experts interviewed felt that the concept of a medical home for adolescents was an important one. Most experts expressed a need for the adolescent “voice” to be an important, yet missing, part of the current health care reform dialogue. Several felt that adolescents would find the concept of a medical home to be appealing if they had a better understanding of the specific elements of a medical home. As one interviewee articulated,

“I think the medical home concept really hasn’t been thought of or thought of in respect to ‘How are we going to pitch this and engage adolescents?’ So it’s important for us to listen to them ... and they need to tell us what they need. ... I think if you explain the core concepts of a medical home to an adolescent in their language, they’ll say, ‘Cool. When can I make an appointment?’”—Expert

In addition, experts noted that there are multiple systems that intersect with and influence the health of adolescents, making the medical home concept a particularly appealing one for addressing the special needs of adolescents. These systems include traditional health care settings and linkages with specialty services that are particularly important for adolescents, such as mental, behavioral, and sexual health services. In addition, linkages between schools and other community-based organizations and other support services play a critical role in promoting adolescent health. However, as many experts noted, the current linkages of care across these different systems are typically not well coordinated. As one interviewee noted,

“From a big system level, [we need to] build better bridges that are easier to cross – between the health – the traditional health care system for instance, and school, mental health and behavioral health systems.”—Expert

There was widespread overlap among the perspectives of adolescents and experts in many aspects of the medical home.

There were a number of core components of the medical home where adolescents and experts expressed similar views, both in terms of what is needed and where the current health care delivery system falls short of meeting those needs. In particular, the experts

echoed the needs expressed by adolescents with regard to having a relationship with a primary care provider, and being able to access and have a relationship with that provider over time. They also emphasized the importance of providing adolescents with access to confidential health information and services.

First, experts felt that a positive relationship between a primary care provider and individual patient is important for all populations. However, establishing a good rapport and trusting relationship is particularly important for adolescents in order to make them feel comfortable enough to share their personal health information. This element is critical to understanding and addressing an adolescent's individual health needs.

"We can't really have [a coordinated, comprehensive health care delivery system] without having a good relationship and trust with the adolescent." – Expert

"Trust is the most important thing in the relationship, always, and especially with adolescents. It takes time to build that trust." – Expert

"We need to figure out ways to build trust with the adolescent. Make them feel safe. Make them feel that it's worth their time. Meet them where they are – through the media that they're comfortable using using – whether it's their texts or their social media." – Expert

Second, the expert interviews also emphasized the importance of continuity of care. They felt adolescents need to have a relationship with a primary care provider in which they can see that same provider on an ongoing basis in order to appropriately promote and support the adolescent's health. However, most felt that the health care delivery system is not always set up in ways that support that continuity. In particular, they noted the challenges that adolescents have in planning ahead and making and keeping appointments. In addition, adolescents utilize care primarily for urgent and sick issues. Their primary providers may not be available for these same-day appointments and/or urgent care visits, and adolescents may have to see a provider who they do not know or with whom they do not have a relationship.

"We may have to kind of tweak our systems because continuity is hard to achieve. Adolescents have a hard time making and keeping appointments consistently, so there are challenges from a lot of angles. But I think the more we can focus on continuity, the better we'll do." – Expert

Third, experts emphasized the importance of ensuring and protecting adolescents' confidentiality. Experts felt that the inability of many providers to deliver confidential care is an important barrier in establishing a full-fledged medical home for adolescents. A key indicator, time alone with the provider, has been shown to be an important element in assessing whether or not the health care system has been set up to respond to adolescents' need for privacy. One interviewee referred to research that supports what

adolescents, especially those from rural areas, reported. This expert cited a study that found few adolescents have time alone with their provider, a proxy for a confidential visit and rates of youth who had time alone were even lower for adolescents from low socioeconomic status, rural communities and racial/ethnic minorities.¹⁴ Interviewees further reported that confidentiality is a barrier at many levels: parents/family, community, and communications across different health care providers. Some experts noted that even existing confidentiality protections for adolescents are not getting the attention they deserve as part of health care reform efforts. As one interviewee noted,

“We're in this period of time where the last thing on most people's minds is adolescent confidentiality. I think the policy movement is to first, advocate for adult privacy especially around sex, drugs, mental health, and genetic testing and in advocating for that make sure that teenagers aren't lost, and then the nuance of parents and teens are in there.”—Expert

A couple of expert interviewees noted that secure text messaging and/or other forms of secure electronic communication may be particularly helpful in helping youths access the health care system confidentiality.

“You could say, ‘you're afraid you're going to see somebody that you know. So, let's try this. Let's communicate via a secure message. I'm very concerned about your confidentiality and privacy.’ If there's a secure way to communicate via social media or e-mail, I don't know how you would do that, but that could help our teens.”—Expert

Challenges in Achieving a Medical Home for Adolescents

While there was widespread overlap across the perspectives of adolescents and experts, there were also some inconsistencies between adolescents' perceptions and those of experts, particularly related to preventive health care services. An important objective of a patient-centered medical home is to promote the delivery of recommended preventive services. However, this study revealed a disconnect between expert consensus on the importance of preventive care for adolescents and what adolescents understand about the value of preventive services. This theme is detailed in the following section, followed by a discussion of a number of challenges that experts identified during the course of the interviews.

There is a disconnect between health experts' recommendations for comprehensive preventive health care for adolescents and adolescents' understanding about the importance of preventive care.

Experts frequently commented on the importance of a medical home to promote adolescents' access and utilization of preventive care. This is due to the fact that most adolescent health morbidity and mortality is preventable (e.g., caused by injury, violence, mental health, substance use, sexually transmitted infections, obesity).²³ In our focus

groups, when adolescents were explicitly asked what adolescent health means to them, they mentioned all of these health issues. Further, the language they used to describe adolescent health largely reflected a problem-focused or disease orientation. Then, when asked about when and why they seek medical care, the majority of participants across all of the focus groups stated they only access care for specific problems and, beyond getting treatment for a specific problem, injury, or illness, many did not understand what other services health care providers offer or the value of those services to their health.

“I want more information about health care. How does it benefit us? What are they providing?” – Female adolescent, urban California

Those who accessed preventive care services in the form of a routine physical or well-check did not place much value on this type of health service. The following quote illustrates what was expressed by many of the focus group participants:

“When I go to the doctor, it’s an obligation. It’s for my yearly check-up and it’s just like ‘this is your height, this is your weight, this is your past – your medical history’, and that’s just physical thing. It has nothing to do with my mental health. I feel like that doesn’t really help me with anything.” – Female adolescent, New York

Challenges with the time and structure of the adolescent preventive health visit.

Experts reported that, while the focus of preventive care is to promote screening for risk factors, providing health promotion messages, and treating identified health risk behaviors, they acknowledged that most adolescents do not necessarily share these concerns. Experts felt that adolescents are more interested in getting their questions answered and having the provider address their immediate problems. They felt that the health care delivery system needed to be realigned with the needs of adolescents in order to achieve a medical home model.

“What adolescents want is not necessarily aligned with what the system thinks we should deliver to them.”—Expert

Challenges with the structure of the preventive health visit. Experts felt that the structure of the preventive health visit does not sufficiently meet the needs of adolescents. The duration of the preventive health visit typically lasts about 20–25 minutes. Building rapport and trust, assessing health needs, and providing adolescents with behavioral health counseling and services is complex and requires a great deal of expertise and sensitivity. They also expressed a great deal of frustration with the number and range of preventive health topics that are recommended to be provided in a single preventive health visit. One study found that providing the full range of recommended health screenings for adolescents would involve a minimum of 40 minutes.²⁴

“It’s really hard, as a provider, when you have a list of 10 things that different standards-based groups are telling you that you should cover, and you only have 20 minutes. And the adolescent is interested, not in the things that you think you should cover, but in what they think should be covered, and you still only have 20 minutes. So trying to find some time and space for both in the context of it is really important.”—Expert

Most also stated that it was essential to first identify and address the adolescent’s expressed needs in order to build a trusting relationship. This increases the likelihood that the teen would return for follow-up visits in which the provider could spend additional time addressing other preventive health guideline priorities.

*“It is critical to provide what [adolescents] need at the moment, building in and working on developing that trust and then having follow-up appointments to deal with some of the other items that are on the [preventive health] ‘check list.’”
—Expert*

In addition, several also felt that some of the recommended guidelines were not relevant to the patient. In particular, a few noted that the quality of preventive care is measured by the number of preventive services provided and not by the quality of how those services were provided or by the extent to which adolescents value the preventive screening topics that are assessed.

*“We have a dashboard that lets us look at quality indicators and get feedback on how we are doing, if we’re doing a good job with flu and HPV vaccines, the annual visit, screening for chlamydia, and it helps to know what we need to do better. But, the system asks kids a lot of questions about a lot of issues and there are no metrics on whether patients value all of these screening questions. The extent of these questions are really a bit intrusive. I never ask all of the questions, I try to be more targeted.”
— Expert*

A couple of experts stated that in order to effectively deliver preventive health care services, it is important to identify and understand the adolescent’s own self-identified goals and tie those goals with preventive health priorities.

“Health care in general needs to be tied to other goals that [adolescents] have—which are going to be related to having a job or income, having a place to live, having a social life, having fun—otherwise, the things being prevented seem like invisible or far off.”—Expert

“If the goals that a health care provider has for a teen can be melded with the life goals that the teen has for him or herself, it will be more effective. They are elicited by asking, ‘What are you looking forward to in the next year, in the next 5 years?’”—Expert

Challenge in striking the balance between protecting adolescent confidentiality and providing “family-centered” care. As noted previously, experts and adolescents were in agreement about the importance of protecting the confidentiality of sensitive health services for adolescents. There is a wide body of evidence that shows that confidential care increases adolescents’ access to care, their disclosure of health risk behaviors, and the likelihood they will return for follow-up care.^{25,26} Adolescence marks the transition between childhood and adulthood, which results in increased need for autonomy and greater responsibilities for making decisions about their own health. At the same time, providers are charged with encouraging partnerships with parents/caregivers in the delivery of adolescent health services.²⁷ A family’s values may be at odds with the adolescent’s need for confidentiality, which creates a paradox for providers. On one hand, they are supposed to provide comprehensive, preventive health services, including those deemed confidential; on the other hand, they are supposed to provide “family-centered” care, which may conflict with confidentiality protections.

Helping parents/caregivers and adolescents understand that confidential health services are an important and normative part of this transition takes time, effort, and knowledge about federal and state confidentiality laws. Providers often lack the knowledge and time to address this in an already time-constrained visit.^{28,29} Interviewees stressed the importance of educating parents about confidentiality early on to help families understand what to expect in adolescent health visits. They felt that this approach would also help “normalize” confidentiality as the routine standard of care for adolescents.

We need to emphasize that [confidential care] is a normative part of care and it’s a really good, constructive part of care. And parents and community members are partners, but the clinician has a really important role in helping adolescents become prepared consumers of the health care marketplace.”—Expert

Challenge of communicating across multiple systems of care and delivery settings while maintain adolescent confidentiality. The concept of a medical home is a model in which care is provided seamlessly across different delivery settings and then communicated back to the adolescent’s “medical home.” There is a great deal of concern that cross-system communication, while important, can potentially compromise confidentiality, yet there were few concrete solutions or recommendations to address this issue. One expert stated that currently the responsibility falls on providers who share these concerns and who take the time and effort to communicate with the adolescent about how information will be shared. These same providers take specific actions to protect the confidentiality of patient’s sensitive health information.

“I think if you present that to adolescents and make sure that they know that their information will be kept confidential in between the two [health delivery systems], and especially make sure that you have provisions for keeping it in, for example, a restricted part of their chart that maybe their parents might not have access to it. You need to do that.”—Expert

“When care is received at any other place that’s not your medical home, whether it’s an urgent care, a retail clinic, family planning clinic, or anything like that, communication is really key. And as much as adolescents might go to one of those places to be anonymous, it’s still important that their medical home know about the care that they’ve received.”—Expert

Experts also expressed the challenges of communicating back to the medical home when care is provided across different providers and/or health delivery settings. This is key in order to ensure continuity of care. While many felt the electronic health record has the potential to improve this type of communication, experts were concerned about the capacity for health systems to adequately protect adolescents’ confidentiality.

“This is a rapidly moving scenario with my chart, patient portals, etc. From a policy perspective, we have to advocate for privacy. We need to advocate for adult privacy and make sure teens are not lost. The reality is that the nuance of parent-teen confidentiality is just not there.”—Expert

Health prevention extends beyond the traditional health setting—providers face a challenge in addressing “social determinants” of health. There is growing recognition of the influence that social factors (income/poverty, education, access to adequate food/nutrition, safety, etc.) have on adolescent health. Social determinants include the broad economic, social, and political factors that shape the environment in which adolescents live. They include more proximal factors such as relationships with caregivers, schools, peers, etc., community resources, and opportunities that can either protect adolescents from engaging in health risk behaviors, or increase their health risks.³⁰

Under the ACA, health care providers must incorporate social supports aimed at addressing social determinants of health in the health care delivery model in order to be certified as a patient-centered medical home or Medicaid health home.³¹ Experts interviewed expressed this shift in the role of health care providers as both an opportunity and a challenge. Several participants stressed the importance of their role as providers in addressing these social determinants of health.

“We as providers need to be concerned with and ask: Where does the person live? What community? What neighborhood? What corner? We need to be more attuned to the environment and these social determinants of health if we’re really going to have a real impact. And I do think this ties right back to the medical home.”—Expert

“I do think – and this is not just for adolescents, but particularly for adolescents. We really need to think about health – not health care, in a more holistic way. ... We’ve made some progress on because of the obesity epidemic, but also jobs or the stress of not having one, or the financial stress of not having enough money to have electricity or heat or transportation. I think that there are ways that we could be, as providers, more attuned to the environment that people are living in and not think so episodic about care – even a well visit.”—Expert

However, they also acknowledged the difficulty of addressing these “social” factors because they are beyond much of what can be addressed within the clinician’s office. Thus, they felt that clinic-based strategies alone would likely be insufficient to address these broader factors that influence adolescent health. All of the interviewees recognized the limitations of relying exclusively on clinic-based approaches and expressed a need to create and enhance partnerships across a range of community-based programs, services, and supports. At the same time, interviewees expressed that health care professionals do not have the training or access to strategies to help them address social determinants of health within the office setting, to take on leadership roles in the community, or to participate in more comprehensive community-based interdisciplinary efforts.

“Physicians and nurses can be very influential, but don’t exactly know what to do or how to do it. Maybe if there is a way to empower them/ help them feel more comfortable using their credibility as a doctor or nurse to take on leadership roles in your community and collaborate with trusted leaders in the community around public health problems that affect young people, they would be more likely to do so.”—Expert

“For front-line clinicians, there’s a lot of movement that could be made, especially in supporting interested clinicians. Unfortunately, most primary care providers have no clue on how to deal with, for example, suicide prevention, in order to be an effective resource. We need to increase their self-efficacy and support evidence-based strategies.”—Expert

Finance and structure of adolescent health care. The interviewees acknowledged that the financing and structure of adolescent health care is a significant challenge in implementing the medical home concept for adolescents. They reported that the current health care system is based on high patient volumes and that the time allocated to and reimbursed for adolescent health care is insufficient to meet the complex psychosocial, developmental, and physical needs of adolescents. As noted previously, almost all of the interviewees commented that it is not possible to deliver all of the recommended preventive services in one office visit. Several noted that lengthening the office visit was not recommended as a viable option from the adolescent or provider perspective. Some recommended that preventive care should be delivered over an extended timeframe, rather than crammed into one visit. Yet, this is problematic because most insurance companies allow for one preventive visit per year without patient cost-sharing. If there were multiple visits to deliver preventive services, these additional visits would need to be linked to some other payment mechanism or there should be expanded reimbursement for multiple preventive visits.

“Instead of being judged, like, was this covered in the preventive visit, maybe look at a year’s timeframe in terms of assessing quality of care. There’s only maybe a couple things that adolescents or really any patients are really willing to listen to that they don’t bring to the visit or aren’t that concerned about. And if you talk about maybe two things in one visit, then have them come back and talk about two things in another visit and two things in a third visit, then eventually you’re going to get everything covered. I think that’ll also help build the trust over time, too.”—Expert

Three of the experts stated that in order to change the incentive structure, it was critical to continue to gather evidence on the impact of preventive health visits on short- and longer-term health outcomes.

“We need research that shows that that time spent delivering really evidence-based interventions impacts health outcomes and then, once we have that, that gets approved by the U.S. Preventive Service Task Force or something like that. ... There we have potentially more leverage to get reimbursement.”—Expert

“Payers need a ‘proof of concept’ evidence that new approaches/strategies that support engagement works in a preventive, care-management sort of way. For example, fewer ER visits—and that’s a cost savings to the payer.”—Expert

“It is important to take the payers’ perspective and examine the impact on fewer injuries, motor vehicle related injuries, suicide attempts—the kinds of things that we just see too much of. There are all kinds of measures that might be of interest to payers.”—Expert

Transitioning from pediatric to adult care is a needed—but missing—component of the medical home for adolescents. Adolescents expressed a great deal of concern and anxiety about what it means to become an adult with regard to their responsibilities of understanding health insurance, payments, and copays. Somewhat surprisingly, their concerns were primarily related to insurance coverage rather than where and how they will obtain health care after they age out of pediatrics. Adolescents shared that their parents take care of health insurance and most often make their appointments. They also reported that they know little about what insurance they have, the processes, and that their parents do not explain it to them. Across all focus groups, adolescents reported that they had difficulty in accessing their health insurance information and were unclear what types of health services were covered by their insurance.

“I don’t get it [health insurance].”—Male adolescent, urban California

"I don't know what to do when I turn 18. Like Obamacare, I don't know what that is."—Female adolescent, urban California

Experts validated adolescents' confusion around health insurance and called for improved systems to communicate this importation information to consumers -- especially young ones who are new to the insurance "marketplace".

"Everybody is confused about their health insurance. And especially people who are just starting to learn about the health care system, I'm sure are even more confused. I think getting some standardized packages of services and making those crystal clear in really simple language like most of us speak but health insurance companies tend not to speak, is really important." — Expert

Experts interviewed agreed with adolescents that this is an unmet need. While health care coverage has been expanded under the ACA, understanding the various health plan options, costs, tax credits, and coverage parameters is extremely complex. Almost all interviewees stressed the importance of a transition visit. From a practical approach, a couple of interviewees suggested instituting a "transition-planning visit" that would allow for a longer office visit to discuss and plan for the transition to adult care.

"Transitioning out of pediatric care looms as a priority over other things because otherwise they're just going to fall off a cliff and not continue to get health—I mean, most 20-somethings, if they don't have a chronic condition, they just don't use the health care system much."—Expert

"A true medical home for adolescents should be anticipating with the patient and family that this transition is coming. It's got to be planned for and the individual needs to be as prepared as possible for this transition."—Expert

"Why provide really excellent pediatric care and have it end without a seamless and safe transition to adult care? The handoff is, in some ways, harder to manage with kids who are healthy and don't have reason to continue health care services, at least in their minds."—Expert

Most felt that the structure for supporting this transition was lacking—in terms of the content of the visit as well as the financing for it. A couple of interviewees mentioned that there could be a unique visit code to bill for such a visit; one interviewee noted that this approach is already in place for children with chronic health conditions, so the status of the disease is discussed and the way in which the care is going to be "handed off" is discussed. As one interviewee noted,

"[Transition visits] can be simply prolonged office calls, 99214, 99215, which are 40-minute visits or longer. And most insurers, including Medicaid, will pay more for those visits, and they're pretty easily justified in the medical record. It's just that primary care settings don't always make such effective use. So it doesn't necessarily need to be some new, special code for this."—Expert

CONCLUSIONS

This is the first study investigating the adolescent medical home from the perspectives of adolescents with the inclusion of follow-up interviews with experts. This study included a bicoastal adolescent sample from urban and rural regions of New York and California. Findings from the adolescent focus groups were shared with experts in adolescent health and/or medical homes to further examine barriers to applying the medical home model to the health care of adolescents and to develop recommendations for practice and/or health policy that would help improve the health care delivery system for adolescents. While the concept of the medical home has been around for decades, little progress has been made in applying this concept to meet the health needs of adolescents. There is renewed attention to and support for the medical home in light of policies under the ACA and with stronger incentives to encourage population health management. However, the pediatric and adult medical home model does not meet the special needs and interests of adolescents as indicated in this report.

This study found that while most adolescents had never before heard of the concept of the medical home, they expressed widespread enthusiasm for many of its key concepts. Specifically, adolescents strongly agreed that it was important for them to have access to a primary care provider who knows them and cares about their health and that they can have regular access to this provider. Most adolescents also felt that it would be beneficial to have all health services located in one place or close by via referral—as long as their confidentiality could be protected. Confidentiality concerns were also raised with regard to the coordination of care and family-centered care—both cornerstones of the medical home model.

Expert interviewees stressed the importance of the medical home as a model for adolescent care, but acknowledged a number of barriers facing the successful implementation and utilization of this multifaceted approach to adolescent care. Most felt that the health system needed to be realigned to meet the needs of adolescents. Some models of this realignment exist (adolescent health centers and many school-based wellness centers), but this approach is not a consistent part of the primary care delivery model. Addressing the financial incentives and reimbursement infrastructure to promote this model is key, as are mechanisms for protecting adolescent confidentiality.

This study also identified a disconnect between the importance of preventive health care services and the value that adolescents place on preventive care in general. While adolescents were well aware of the many health issues facing young people (stress, anxiety, depression, sexually transmitted infections, pregnancy, obesity, and all forms of substance use), they did not readily make the connection between primary preventive care as a way to address and improve health outcomes for adolescents. In contrast to the widespread appreciation of preventive health care for infants and young children, preventive care for adolescents, from the perspective of the consumer (i.e., adolescents

and their parents) is not as well understood or valued. Experts stressed the importance of improving the way in which families are educated about adolescent health. They noted that these efforts need to be done earlier in preparation for the transition from a general pediatric health visit to an adolescent visit that incorporates confidential discussions and services for sensitive health topics.

Experts reported on the challenges of providing comprehensive preventive care that is adolescent-centered within the time constraints of the visit. They also indicated that lack of proper reimbursement made the provision of preventive care as part of a medical home particularly challenging. Only a few of the experts interviewed suggested using a team-based approach, which would include health educators, dietitians, and/or other health practitioners to support the provision of a full array of preventive services.

Traditionally, health has been siloed from education and other ecological supports that impact health. As part of comprehensive preventive care, experts reported that there has been increased attention to the impact of social disparities on health status. While they agree this is a key issue for adolescent health promotion, the current health system is not adequately structured to address this issue. Experts recognized the need for health providers to not only have partnerships with health providers to whom they can refer their clients, but also a variety of community resources that can provide support (e.g., social services, housing, academic skills, employment training).

Expanding the scope of bidirectional referrals as part of the medical home is important in addressing many of the contextual factors that shape adolescent risk-taking behaviors. In addition, linkages to services that can help provide viable alternatives to risk-taking behaviors are also needed as part of a comprehensive, multi-sectoral approach to improve adolescent health. While this is an area for future policy, service, and research development, the Mount Sinai Adolescent Health Center is an accredited patient-centered medical home for adolescents which can serve as a model (see Exhibit 2).

Exhibit 2. Mount Sinai Adolescent Health Center – An Ideal Model of Care for Adolescents

Since 1968, the MSAHC works to break down economic and social barriers to health care and wellness for young people by providing vital services—that are of high-quality, comprehensive, developmentally appropriate, confidential, and free—for all who come to the Center. The MSAHC advances adolescent health as a national imperative by serving as a leading center of clinical care, specialized training, and innovative research. MSAHC is one of two accredited medical homes for adolescents in the U.S. The center offers the following core services:

- Primary Medical Care
- Sexual and Reproductive Health Services
- Behavioral and Mental Health Care
- Health Education
- Optical Services
- Dental Health Care

Other specialized services that are co-located include: legal assistance; violence intervention and prevention services, nutrition, obesity treatment and prevention, substance abuse treatment, and population specific services (e.g., teen parent program; Youth living with HIV; lesbian, gay, and bisexual youths; transgender youths).

Source: <http://www.teenhealthcare.org/>

There are some noteworthy limitations to this study. Focus group participants were drawn from California and New York and their views may not be representative of adolescents in other states. Furthermore, this was a relatively healthy population of adolescents and, as such, the report did not address the concept of a medical home as it pertains to adolescents with chronic health conditions, disabilities, foster care youth, or other special populations with special health needs. While efforts to include rural and urban youths were made, it should be noted that adolescents in the New York focus groups were recruited from health-related programs. These participants may have more familiarity with health-related issues as a result of their participation in these health programs. In addition, experts were identified from the literature and impact in the field of adolescent health; however, this was a convenience sample which may not capture the full range of roles, expertise, and attitudes.

Despite these limitations, this study highlights aspects that are important in applying a medical home model for adolescents. While the ACA has supported the expansion of the medical home, there has been little attention to the special needs of adolescents. Continued efforts to recognize and advocate for this special population of young people are needed, but have thus far not been adequately prioritized in health care reform efforts, with the exception of children with special health care needs. Finally, there is a need to consider how medical homes for families as a unit can also incorporate specific services to adolescents, which enable them to maintain appropriate levels of confidentiality, while also supporting adolescents as they prepare to navigate the health care system on their own.

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