

Adolescents' Needs for Health Care Privacy

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WHAT'S KNOWN ON THIS SUBJECT: Confidentiality is very important to adolescents, and limitations on it can affect health care behaviors. Little is known about other aspects of privacy, such as the psychological, social, and physical dimensions, and how they might affect adolescent health care experiences.



WHAT THIS STUDY ADDS: Adolescents expect and value all aspects of health care privacy. Informational privacy (or confidentiality) is most salient, but psychological, social, and physical privacy also affect adolescents' experience of and willingness to participate in care.

abstract

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OBJECTIVE: To understand adolescents' preferences for multidimensional aspects of privacy, including psychological, social, and physical, and confidentiality (informational privacy) in the health care setting.

PATIENTS AND METHODS: Fifty-four adolescents with and without chronic illness participated in 12 focus groups composed of participants of the same age (11–14 or 15–19 years), gender, and health status. Health care preferences, including privacy and confidentiality, were discussed, and themes were determined. On the basis of a literature review, Burgoon's framework best represented participant feedback. The data were categorized as representations of informational, psychological, social, or physical privacy.

RESULTS: Maintaining informational privacy (ie, keeping information confidential) was most salient to the adolescents. Younger adolescents were concerned with information being disclosed to others (ie, health care providers), whereas older adolescents worried more about information being disclosed to parents. Other privacy aspects (psychological, social, and physical) also were important. To protect psychological privacy, adolescents were cautious about revealing sensitive information for fear of being judged by providers. To protect social privacy, they were reluctant to talk with unfamiliar or multiple providers, and they did not want to discuss issues they perceived as unrelated to their health care. Adolescents who commented about physical privacy said that they thought about their physical safety during physical examinations, as well as their visibility to others, and said that they were more comfortable when examinations were performed by female rather than male providers.

CONCLUSIONS: Adolescents value all aspects of privacy. Providers should address not only informational but also psychological, social, and physical privacy to improve the care of adolescent patients. *Pediatrics* 2010;126:e1469–e1476

The literature extensively documents both the importance of confidentiality, or informational privacy, to adolescents who seek health care and a reluctance to seek care among adolescents who have concerns that they consider confidential or who fear that others might learn of the care.^{1–6} Less is known, however, about the importance of other types of privacy to adolescents.

In 1982, Burgoon⁷ proposed a 4-dimensional model of privacy based on earlier studies of interpersonal communication and environmental context.^{8–20} In this model we defined privacy as an individual's ability to control disclosure of personal information, formulation and disclosure of beliefs and feelings, contact with others in social settings, and unwanted observation of body or intrusion of personal space.⁷ In 1989, Parrott et al²¹ applied the Burgoon⁷ model in a study of adult perceptions of privacy within the patient-physician relationship. The findings supported the conceptualization of privacy as multidimensional, contextual, and subject to potential violation.

Burgoon⁷ and Parrott et al²¹ provide both definitions of the privacy constructs and examples of common violations. Informational privacy, or confidentiality, encompasses a person's right to control to whom their information is released, how much information will be disclosed to others, and how information is transferred. Violations occur after the person has disclosed personal information to the health care professional who, in turn, discloses the information to others without the person's knowledge or permission.²¹

Psychological privacy involves the person's protection of attitudes, beliefs, and values from disclosure to or judgment by others.^{7,21} In the health care setting, patients may be reluctant to

share information if they believe that the information will elicit negative provider impressions or will not be used to advance their health and health care.^{7,21}

Social privacy is the control of one's social or interpersonal interactions, including the contacts, frequency, duration, context, and style of those interactions.^{7,21} Examples include sustained eye contact between the patient and provider and the degree of provider formality.²¹

Physical privacy is the degree to which a person is physically accessible to others.⁷ Violations include (1) surveillance, such as watching a patient undress for a physical examination, (2) physical contact, such as touching a patient without permission, and (3) intrusion into personal space, such as overhearing a patient's intimate conversation.²¹

There has been little research on the effects of these multidimensional aspects of privacy on adolescent satisfaction or use of health care services or whether adolescents value privacy beyond informational privacy (ie, confidentiality). The primary purpose of this study was to understand adolescents' preferences for and expectations of the health care setting in the context of the 4 aspects of privacy. A secondary objective was to explore patterns of preferences based on age, gender, and health status.

METHODS

Study Design

This study was part of a larger project that used qualitative and quantitative methods to explore health care preferences of adolescents with chronic conditions.^{22–24} Data for this study were extracted from the transcripts of focus groups convened in phase 1 of the larger study.

Subjects

The study sample consisted of 54 adolescents aged 11 to 19 years, with and without chronic illness. Subjects with chronic illness were outpatients at Cincinnati Children's Hospital Medical Center and were diagnosed at least 2 years earlier with cystic fibrosis, inflammatory bowel disease, juvenile rheumatoid arthritis, or sickle cell disease. Subjects without chronic illness (healthy adolescents) were recruited from a church, a school, and a summer recreation program. Subjects were categorized according to age (11–14 and 15–19 years), gender, and health status into 12 focus groups. Adolescents with a chronic illness ($n = 29$) were assigned to 7 focus groups, and healthy adolescents ($n = 25$) were assigned to 5 focus groups. Of 29 adolescents with chronic illness, 17 were aged 11 to 14 years (6 male, 11 female) and 12 were aged 15 to 19 years (7 male, 5 female). Of 25 healthy adolescents, 13 were aged 11 to 14 years (8 male, 5 female) and 12 were aged 15 to 19 years (4 male, 8 female). Written informed consent was obtained from the subject if he or she was 18 years of age or older. Written informed consent was obtained from the legal guardian and the subject if the subject was younger than 18 years. The study was approved by the institutional review board at Cincinnati Children's Hospital Medical Center.

Data Collection

One professional focus-group facilitator led each group in a 1.5- to 2-hour audiotaped discussion by using a written guide. A professional facilitator is trained and experienced in the development of an objective discussion guide and the management of challenging group dynamics, such as staying on task, encouraging everyone to participate, and preventing monopolization of the discussion. In addition to the facilitator, 1 or more coinvestiga-

tors attended each group session to observe and record the group process and to debrief with the facilitator. Audiotapes were transcribed verbatim and, along with the field and debriefing notes, edited for accuracy by Dr Britto. Transcripts ranged from 15 to 100 pages in length. The edited transcripts (627 pages total) and the field and debriefing notes from each group were used for the analysis.

Major discussion topics outlined in the discussion guide (available on request to Dr Britto) and introduced by the facilitator included staying healthy, health risks and worries, desired provider characteristics, and visit expectations. The discussion guide was modified during data collection to promote the discussion of new topics raised by previous groups and to discourage the discussion of saturated topics.

Data Analysis

The 3-stage analytic process followed the editing-organizing procedure of Crabtree and Miller²⁵ and Miller and Crabtree,²⁶ in which reviewers progress from summary readings of individual group texts to the development of a comprehensive coding scheme that can be applied across all groups.

In stage 1, 4 investigators prepared independent written summaries of the transcript for each focus group. After team discussion, each investigator re-read each transcript and developed a list of themes to summarize its content. After another series of meetings to reach consensus about themes within each group, the team developed a coding scheme that categorize ideas generated by the groups.

In stage 2, transcripts were imported into N5 (NUD*IST) (QSR International Pty Ltd, Victoria, Australia), the QSR International program for the analysis of qualitative data. Two transcripts were independently double-coded, and discrepancies

were resolved by negotiation, as recommended by Patton.²⁷ The negotiation resulted in the addition of several codes to the original scheme, and all 12 transcripts were coded by using the revised scheme.

In stage 3, text related to privacy was identified by a NUD*IST node search as well as rereading of all transcripts. These and earlier analyses revealed dimensions of privacy important to the adolescents that extended beyond traditional confidentiality, or informational privacy. A literature review was then conducted to identify a theoretical framework for health care privacy based on communication theory. The transcripts were then further interpreted by using this theoretical framework, and the emerging findings were discussed among the research team.

The framework of Burgoon,⁷ later refined by Parrott et al²¹ with applications to health care, was the most comprehensive findings we located and incorporated much previous research on privacy.^{8–20} The transcripts were then recoded using the elements of this framework, and the findings were summarized by using procedures similar to those in the earlier stages of analysis.

RESULTS

The 4 dimensions of privacy are presented from the most to least frequently discussed by the focus groups. Illustrative verbatim quotes that correspond to informational, psychological, social, and physical privacy are noted in Tables 1, 2, 3, and 4, respectively.

TABLE 1 Participant Comments Pertaining to Informational Privacy

Finding 1: Disclosure of information to parents	
11- to 14-y-old male subject, cystic fibrosis	"When I'm living on my own, I think that's the time for that to happen because then I wouldn't <i>have</i> to share with them, I could just keep it to myself."
15- to 19-y-old female subject, sickle cell disease	"I think that's why a lot of people don't go to the doctor . . . they think like, well, what if they go back and tell my mom, or what if it comes up on their insurance paper."
15- to 19-y-old female subject, healthy	"Some people haven't like done anything. Like, I know for me, it doesn't matter to me if my mom's in the room or not because I have nothing to hide. . . . I think they should have your parents stay in the room, and it's your own fault if you're embarrassed about it [referring to talking about risk behaviors] . . . you should have considered the consequences before you did it."
15- to 19-y-old male subject, sickle cell disease	"My parents will know, but I'd rather my doctor come tell me because I'm trying to grow up, I'm trying to take responsibility for myself."
15- to 19-y-old female subject, inflammatory bowel disease	"I'd just rather have the doctor himself. He talks to me. With most doctors, if your parents are in the room, they kind of talk through you and they talk to your parents, and you're like, hello, they're not the one who has this. And so he talks directly to me. . . . They talk to my parents too, but it's really a nice thing about him."
Finding 2: Disclosure of information to others	
11- to 14-y-old male subjects, healthy	
Male subject 1	"Some doctor, a doctor a long time ago when I was say about 6, he like, sent my records all the way down to Children's and it was not like a normal doctor would do."
Male subject 2	"Like they were telling them everything."
Male subject 3	"And then next time you come, 'Oh there's the sick boy' "
11- to 14-y-old male subject, inflammatory bowel disease	"Keep whatever they [the patient] want confidential, not telling other doctors, like he or she did this."
11- to 14-y-old male subject, cystic fibrosis	"Like only discuss medical stuff with the other doctor. . . . Just not that other stuff, the between friends kind of thing."

TABLE 2 Participant Comments Pertaining to Psychological Privacy

Finding 3: Discussing sensitive topics

11- to 14-y old male subject, healthy

Moderator: Like if you bring up a topic about drugs . . .

Male subject 2: "They might think you're doing drugs or something. They jump to conclusions that aren't true sometimes."

15- to 19-y-old female subject, healthy

"Everybody thinks teenagers are so bad now, and really they're not. I mean, we do a lot of things that people overlook. On the news, it's like a teenager kills somebody, a teenager does this, and we really do so many good things. Like at our school, we do so many service projects and it's like for certain things . . . we're not all bad, you know, and I kinda think when she asks me that question [referring to sex and drug abuse], I'm just like, she thinks I'm bad, she thinks I did it [in response to being asked about having sex and using drugs]."

11- to 14-y-old male subject, healthy

"It sometimes may be uncomfortable if they ask you some questions about something like sex or whatever because sometimes like kids might . . . be uncomfortable about that or, umm, might not want to talk about something like that . . . and then people start jumping to conclusions, thinkin' you might be doin' something or you might have done something that you shouldn't have."

Finding 4: When to disclose personal information

11- to 14-y-old female subject, healthy

"The only way I'll talk to my doctor, if, about my family, like, if it's making me depressed and I'm like feeling sick because I'm suicidal [in response to being asked if she would talk to her provider about family or personal issues]."

15- to 19-y-old male subject, inflammatory bowel disease

"If I thought it [referring to the personal information] was jeopardizing . . . if it could jeopardize something in my life [in response to being asked when he would tell his provider about personal information]."

Informational Privacy

Participants commonly discussed the sharing of information they considered confidential with parents, other health care providers, or patients (Table 1). Groups with younger adolescents tended to desire more parent involvement than the older adolescents, although we did not identify any pattern in this preference according to gender or health status (finding 1). Younger participants (ages 11–14 years) tended to say that providers should tell parents about all medical or personal information discussed during visits, whereas older participants (ages 15–19 years) tended to say that they preferred that providers not disclose medical or personal information they consider confidential to parents, noting that some adolescents might avoid health care to prevent such disclosure. Younger participants tended to prefer having parents present during the history, physical examination, and discussion, whereas older participants tended to prefer

that providers see them alone without their parents present, speak directly to them, and speak with them before speaking with parents.

Younger adolescents expressed concern about the disclosure of information to people other than parents (finding 2) and considered the protection of this information an indication of a provider's respect for the patient. Only 1 group of older adolescents with chronic illness commented on this concern, implying that they did not expect their providers to keep information from other health care providers. In addition, adolescents with a chronic illness were less concerned than healthy adolescents about provider disclosure of medical information to other health care providers. However, some of them said that certain non-medical information should remain private.

Psychological Privacy

Healthy adolescents in both the younger and older age groups said

they would avoid the discussion of sensitive topics with providers (finding 3) if they thought the provider might think less of them or "jump to conclusions" (Table 2). One group of 15- to 19-year-old female subjects felt that a provider who asked about risk behaviors believed the patient already was involved in those behaviors. Participants also indicated, however, that they would disclose personal information to their provider under some circumstances (finding 4). Some of them stated that they were willing to disclose personal information, such as involvement in risk behaviors, if they were comfortable discussing it or knew that their behavior was acceptable. For example, 1 participant commented that it was okay for his provider to ask about sexual activity because he had not had sex yet. Others said that they would talk to providers about issues that might pose a threat to their health.

Social Privacy

Social privacy included comments about when and with whom to discuss sensitive topics (finding 5), which topics should be discussed (finding 6), how to approach the discussions (finding 7), and the desired formality of the interactions (finding 8) (Table 3). Younger adolescents said they avoided personal discussions with providers they did not know or like or if they believed that the provider did not need to know the information. In contrast, 1 older adolescent girl said that she was more likely to disclose information to providers she did not know well. One group of older boys with chronic illness felt that their interactions with residents and fellows often represented unwanted intrusions by multiple providers.

Groups discussed which questions should and should not be asked by providers (finding 6); participants tended to say that questions were inappropriate

TABLE 3 Participant Comments Pertaining to Social Privacy

Finding 5: When and with whom to discuss sensitive topics or disclose personal information

11- to 14-y-old male subject, cystic fibrosis
 "It's like confidentiality. If you don't like that doctor very much, then you don't want to share very much confidential stuff."

15- to 19-y-old male subject, healthy
 "I'd say after 2, 3 visits if your doctor, like, informs you, like basically lets you learn about him. After 2 or 3 visits you'll feel open too . . . you come and see him, you talk to him, he tells you about his family, if he got kids, talk about his kids, stuff like that, you start learning about that doctor, then that's when you start feelin' like you're able to trust him because like he got kids too. . . ."

15- to 19-y-old female subject, healthy
 "I find it easier to ask questions of people that I don't know. . . . I've gone to doctors on my own, to ask them questions because I knew that I was never going to see them again, and I could ask them anything and they would never know who I was, and that would be the end of it. . . ."

15- to 19-y-olds male subjects, cystic fibrosis (male subject 1) and inflammatory bowel disease (male subject 2)

Male subject 1
 "When I've been in the hospital . . . at like 3 in the morning, and they bring 10 medical students in to watch the doctor take your temperature . . . maybe they could not do 10 or 15 people, so that you can't breathe, or you're in there. Maybe just do 2 or 3. I know when I've been in clinic, they've had just one person come back, and I'd prefer that."

Male subject 2
 "It's almost intimidating too, when there's too many people around and when there's maybe a small group of people, it's a little bit easier."

Finding 6: Questions providers should and should not ask

11- to 14-y-old male subjects, healthy

Male subject 1
 "Oh, maybe, like . . . what you doing at home? How much you exercise or whatever, or something like that, but if you do start doing stuff like going into really, really personal business, like how are you being treated at home, getting into like family business and all this. . . . Some doctors they like, they ask you questions, but they dippin' into your business a little too far."

Male subject 2
 "They shouldn't be like asking if . . . how's your mom or dad doing, how'd your dad die, or something like that, they should be asking about me."

11- to 14-y-old female subject, healthy
 "Well, like, if I'm like sick . . . if I'm like nervous or something's wrong and I don't know it, I'll get a really bad stomachache and sometimes I even make myself throw up . . . sometimes I'll go to the doctor because it's really bad, and she'll ask, is everything ok at home, and that's the only time I'll say yes. . . . I don't want them to pry into my business, but maybe if they ask, it might make me feel comfortable, that they kind of care. Even if they really don't."

Finding 7: How to raise discussion about sensitive topics

11- to 14-y-old male subject, healthy
 "I would like ummm, ask the person who I'm talking to if this, if a question would be appropriate . . . like, asking . . . ummm, how do they feel about sex, I'd ask if that's appropriate with them first, then if they don't, if they don't think it's appropriate, then I won't bring it up [in response to being asked how he would talk to a patient if he was the doctor in charge of the medical visit]."

11- to 14-y-old male subject, healthy
 "Giving you information about it [sex] [would be better]. Not like asking you did you do it, or have you done it [in response to being asked if it would be better to be asked if he was having sex or just to get general information about sex]."

11- to 14-y-old female subject, healthy
 "I would just say like . . . whenever you want to talk about this [referring to talking about a sensitive topic], bring it up and we'll talk about it, whenever you're comfortable to [in response to being asked how she would bring up sensitive topics if she was the doctor]."

Finding 8: Provider's behavior and demeanor

15- to 19-y-old female subject, healthy
 "My knee doctor . . . he's really cool, like he, you know, like you feel comfortable and it's a guy you know, and he's one of the guy doctors that I feel comfortable like with . . . he like talks to you while he's doing the stuff, so it's like you don't even notice what's goin' on, you know, and I think like talking to the person while you're doing something kinda helps, just kinda it keeps you comfortable. But I think the biggest thing would be being a friend with the patient. Not just being an authority, being a friend, because I, I can talk to friends about anything, but the authority, like, you know, I'm friends with my parents, but they're still my authority, so I can't talk to them about everything, but having a friend you know. . . ."

ate if they had no apparent links to their health. However, 1 participant did acknowledge certain instances in which it was okay for the provider to ask about personal issues such as when she was feeling anxious.

Discussions about how to approach sensitive topics (finding 7) were more frequent among younger than older adolescents. Suggestions included asking a patient if it was okay to talk to him or her about a personal issue, keeping the discussion more impersonal by giving general information about a sensitive topic (such as sex) instead of directly asking about the patient's behavior, and offering to discuss a topic again at a later visit if the patient felt comfortable doing so.

Female subjects spoke about provider demeanor and behavior (finding 8). They described eye contact as uncomfortable with male providers but as "not a problem" with female providers. During the physical examination, they felt provider friendliness increased patient comfort regardless of the provider's gender.

Physical Privacy

Several physical privacy issues included which providers should have physical access to patients, provider violations of physical privacy, and the preferred degree of seclusion (Table 4). Preferences about provider gender (finding 9) seemed to correlate with adolescent gender rather than adolescent age or health status. Female adolescents strongly preferred female providers, whereas some male adolescents preferred female providers some or all of the time.

Concerns about violations of physical privacy (finding 10) were expressed only by younger adolescents. Some expressed fear that they would be separated from their parents during visits and explained that they saw their parents as protection or as calming dur-

TABLE 4 Participant Comments Pertaining to Physical Privacy

Finding 9: Preferences about provider's gender

15- to 19-y-old female subject, healthy

"I had a guy doctor too, like when I was little and it was right before we moved, and even after we moved, we stayed with him. But, it's like, right when I started developing. . . . I don't really want to go to him anymore, you know, 'cuz I felt weird that he would like . . . touch me. . . ."

15- to 19-y-old male subject, inflammatory bowel disease

"Oh well, on certain occasions it could be female or a male. But like, me, personally, like when I go get my physical, I really don't like men touching all over me. My private parts, I'd rather have a lady do that."

Finding 10: Concerns about violations of physical privacy

11- to 14-y-old male subject, sickle cell disease

"I like to have my mom there just in case something happens. So she can put 'em on their head in case they try to hurt me."

11- to 14-y-old female subject, healthy

"At least they aren't doing anything they aren't supposed to be doing [referring to why she prefers to have her mother in the room during her examination]."

Finding 11: Desire for seclusion during examinations

15- to 19-y-old female subjects, healthy

Female subject 1

"And they have to weigh you and everyone sees. . . ."

Female subject 3

"It's in the middle of the hallway. They're like, ok, let's weigh you now and let's see how high you are."

Female subject 1

"And my mom's standing there and she makes fun of me later."

ing physical examinations. The desire for seclusion during examinations (finding 11) was raised by 1 group of older healthy girls. They wanted as much seclusion as possible during physical examinations.

DISCUSSION

Members of each of the 12 focus groups in our study described concerns and experiences related to all of the privacy domains described by Burgoon⁷ and Parrott et al.²¹ Informational privacy, or confidentiality, was the domain most frequently mentioned, which confirms its known importance to adolescents in the health care setting.^{1,3–6,28} Some of our findings, however, differ from those of previous studies. First, the younger adolescents in our study reported that they rely on their parents to provide historical information and to remember information provided by providers. These adolescents were willing to relinquish some confidentiality in exchange for parental support; others felt that it was the provider's responsibility to disclose personal information to par-

ents. These findings contrast with most other studies,^{2,28} in which adolescents generally preferred complete confidentiality regarding personal issues or sensitive behaviors. As suggested by previous researchers,²⁸ provider explanation and negotiation with adolescents regarding their rationale and method for disclosing information to parents may help adolescents feel less violated.

Our results also highlight the differing expectations of chronic illness and healthy adolescents regarding privacy in the health care setting. Adolescents with chronic illness understood and accepted the importance of information-sharing among health care professionals, whereas healthy adolescents thought such sharing was inappropriate and unnecessary, even when handled judiciously. For example, a healthy male subject (Table 1, finding 2) stated that sending his medical information to another hospital was not something "a normal doctor would do." Although others have described adolescents' discomfort

with casual discussions in public places,² we believe our study is the first to report adolescents' discomfort with information-sharing for the purpose of patient care (eg, sending medical records to a consulting physician). In a study by Carlisle et al,²⁸ adolescent participants also commented on the sharing of their medical information. However, concerns were primarily about nonclinical office staff (eg, receptionists) having access to their medical records, and participants commented that the sharing of such information was acceptable if the staff member needed to access the information for health care purposes. Our findings may reflect increased public awareness of medical record confidentiality since the Health Insurance Portability and Accountability Act.²⁹ Addressing this concern with information-sharing will become more important as the prevalence of electronic health records and electronic data exchange increases. Providers should explicitly discuss with adolescents availability of their medical information, including electronic data exchange, to other medical professionals. The provider should emphasize that sharing personal medical information with other health care providers is strictly for the purpose of improving health care outcomes for the patient. Adolescents also should be informed that their electronic data may be shared with insurance companies for billing purposes and used within a clinic or health plan to improve quality of care or operations. Thus, the patient can understand and feel more comfortable with this process and be less likely to see it as a privacy violation.

Other aspects of privacy, other than confidentiality, described in our study have received less attention in the literature. However, numerous studies^{2,30,31} have addressed similar issues, sometimes as aspects of respect or

trustworthiness. For our participants, violations of psychological privacy related to stigmatization and possible negative regard or judgment by providers, as typified by an older, healthy adolescent girl who said “I kinda think when she [the provider] asks me that question [referring to sex and drug abuse], I’m just like, she thinks I’m bad, she thinks I did it” (Table 2, finding 3). Adolescents were concerned about providers thinking less of them when they reported engagement in certain risky behaviors. Adolescents did not, however, express concern about their privacy being violated when providers told them about the negative health consequences of their behavior. This is in contrast to the Parrott et al²¹ study of adults, in which 40% of participants felt an infringement of their psychological privacy when their provider told them that their behavior was a health threat.

These findings suggest that adolescents who understand the rationale for behavioral health screening may be more tolerant of and engaged in the screening. Before asking about health risk behaviors, providers might explain the importance of the questions to current and future health. Because adolescents worry about how they are perceived by others, providers should avoid judgmental responses or lectures about appropriate behavior. These techniques may enhance adolescents’ comfort and willingness to share personal information.

Adolescents’ view on social privacy partly depended on their relationships with their providers, particularly for younger adolescents, and reflected their familiarity with and trust of the providers. One male subject in the 15- to 19-year-old age group said, “I’d say after 2, 3 visits if your doctor, like, informs you, like basically lets you learn about him. After 2 or 3 visits you’ll feel open too . . .” (Table 3, finding 5). The adolescent may feel

more comfortable with the provider and more willing to disclose information if the provider engaged in small talk or discussed nonmedical issues with the adolescent initially. In addition, providers should consider building a relationship with the patient over several visits before asking questions about sensitive topics if the medical condition does not necessitate inquiries at the first visit. As in the Parrott et al²¹ study of adults, some adolescents considered all personal questions a violation of privacy, including questions about family history.

Another issue raised only by adolescents with chronic illness was the negative impact of medical students on the adolescent’s communication with his or her provider, which mirrors the qualitative findings of the Beresford et al³² study, in which adolescents with a chronic illness felt that the presence of others, especially medical students, prevented open communication even in the presence of a good relationship with their own doctor. Giving adolescents options regarding the presence of learners (eg, students) and other extended team members may be helpful. Participants strongly preferred seclusion during physical examinations, including having their heights and weights measured. One older, healthy female adolescent expressed discomfort over the public location of clinic scales: “And they have to weigh you and everyone sees . . .” (Table 4, finding 11). Providers should place scales in more private locations and avoid stating weights so they can be heard by others. Provider gender also was particularly salient with regard to physical examinations. Adolescents were uneasy having their body examined by a male provider and were concerned that a male provider might touch them inappropriately. In addition, younger adolescents wanted their parents in the room with them

during examinations in case a provider tried to hurt them or do anything unusual or improper, which highlights the importance of having chaperones present during the physical examination of adolescents.

Although our study provides numerous insights into adolescents’ desires and expectations for privacy in the health care setting, this still is an area for future research. We explored patterns of preferences related to age, gender, and health status. However, participants may have specific privacy needs and preferences based on other factors such as their race, sexuality, etc. Research that determines subpopulations and elicits the discussion of individual adolescent preferences would be ideal. Although focus-group discussion is beneficial in illustrating and explaining group norms, peer pressure in the group may prevent dissenting views from being expressed.

CONCLUSIONS

Although maintaining informational privacy often is the primary concern for providers caring for adolescents, our results show the importance of psychological, social, and physical privacy as well. Most studies to date have discussed privacy only in terms of confidentiality,^{1,4,6,28,33} and many relied on feedback from anonymous questionnaire responses.^{1,5,6,34,35} We gathered more comprehensive information by using focus groups and encouraging discussion of new topics from group to group. Minor changes in communication and office practice such as asking permission to discuss sensitive topics, explaining the importance of asking personal questions, and increasing privacy during physical examinations may enhance adolescents’ experience of receiving care.

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