

Beliefs About Papanicolaou Smears and Compliance With Papanicolaou Smear Follow-up in Adolescents

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Objective: To explore qualitatively adolescent girls' understanding of Papanicolaou smears and barriers to compliance with Papanicolaou smear follow-up appointments.

Design: Qualitative analysis, using 3 focus groups and 15 in-depth, semistructured individual interviews.

Setting: Adolescent Clinic and Young Parents' Program at Children's Hospital, Boston, Mass.

Main Outcome Measures: Beliefs and attitudes about Papanicolaou smears and barriers to compliance with Papanicolaou smear follow-up.

Results: The mean (\pm SD) age of the 15 interview participants was 18.7 (\pm 1.9) years. Knowledge about Papanicolaou smears and pelvic examinations was poor. Most participants believed that their peers receive Papanicolaou smear screening and perceived teenagers to be susceptible to cervical cancer. Perceived benefits to getting Papanicolaou smears were prevention and early detection or diagnosis, and reported barriers included pain or

discomfort, embarrassment, fear of finding a problem, fear of the unknown, denial, poor communication or rapport with the provider, not wanting to look for trouble, lack of knowledge, and peers' advice. Participant-generated strategies for how providers could overcome barriers to Papanicolaou smear screening included education and the development of trusting, consistent relationships with providers. Participant-generated strategies for how providers could enhance appointment-keeping among adolescents included telephone and written reminders.

Conclusions: These data support a behavioral theory-based model of adolescent compliance with Papanicolaou smear follow-up, which may help to develop strategies to enhance compliance with Papanicolaou smear follow-up appointments. These strategies include providing in-depth education about Papanicolaou smears, addressing barriers to Papanicolaou smear follow-up, focusing on appropriate provider behaviors, and instituting an appointment reminder system.

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Editor's Note: This small n pilot study provides much fodder for further, larger n studies. I can't wait to read them.

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CERVICAL dysplasia and cancer remain significant public health issues in the United States. The American Cancer Society estimates that 13 700 women will be diagnosed with invasive cervical cancer in 1998, and 4900 women will die of the disease.¹ Adolescent and young adult women are at high risk for cervical dysplasia. National data from the Centers for Disease Control and Prevention indicate that of 31 569 women younger than 30 years screened between 1991 and 1993, 8.0% of Papanicolaou smears revealed atypical squamous cells of undetermined significance, 9.4% low-

grade squamous intraepithelial lesion, 2.1% high-grade squamous intraepithelial lesion, and less than 0.1% squamous cell cancer.² Of 1412 Papanicolaou smears performed on adolescents aged 15 to 19 years receiving family planning services at Planned Parenthood of Boston in 1998, 6.7% showed atypical squamous cells of undetermined significance, 4.5% low-grade squamous intraepithelial lesions, and 0.3% high-grade squamous intraepithelial lesions (oral communication, Cynthia Waldron, PA, 1998). Sexually active adolescents may be at particularly high risk of developing dysplasia because of earlier initiation of sexual intercourse, higher number of sexual partners, increased incidence of sexually transmitted diseases overall, increased incidence of smoking, and the possibility that the adolescent cervix may be more vulnerable to the acquisition of sexually transmitted diseases and initiation of carcinogenesis.³⁻⁶

PARTICIPANTS AND METHODS

Adolescents were eligible to participate in this study if they had ever been sexually active, had had a Papanicolaou smear, and were receiving care in the Adolescent Clinic or Young Parents' Program at Children's Hospital, Boston, Mass. A convenience sample of potential participants for the focus groups and individual interviews was selected.

Three groups of adolescents were recruited for the focus groups and individual interviews: those who had a normal Papanicolaou smear, those who had an abnormal Papanicolaou smear and who complied with a follow-up visit to the colposcopy clinic, and those who had an abnormal Papanicolaou smear and did not comply with a follow-up visit to the colposcopy clinic. For the focus groups, the goal was to enroll 8 to 10 adolescents in each group. Forty adolescents were recruited, 22 consented to participate, and 12 adolescents actually participated in the focus groups. For the individual interviews, the goal was to enroll 15 participants: 5 who had a normal Papanicolaou smear, 5 who had an abnormal Papanicolaou smear and who complied with a follow-up visit to the colposcopy clinic, and 5 who had an abnormal Papanicolaou smear and did not comply with a follow-up visit to the colposcopy clinic. A total of 25 adolescents were recruited, 15 consented to participate, and 15 actually participated (5 in each of the 3 groups). Informed consent was obtained. Participants received \$20 reimbursement and transportation costs for participating in the study. The protocol was approved by the Committee on Clinical Investigation at Children's Hospital.

The focus groups were conducted by an experienced focus group moderator. Each took 1½ to 2 hours. The content areas addressed in the focus groups were derived from constructs of several behavioral theories, including the health belief model, social cognitive theory, the theory of planned behavior, and the transtheoretical model and stages of change. Comments for all 3 sessions were recorded on audiotape and notes were also taken by an assistant focus group moderator (V.C.). A debriefing was held after each focus group and major themes identified. The audiotapes and notes were transcribed and transcriptions were reviewed together by a team of 3 investigators (J.A.K., J.D.A., and V.C.) and the focus group moderator. After identification of all themes, consensus was reached on major themes.

An individual interview guide was constructed based on the focus group data. The interviews were structured around specific content areas and themes identified in the focus groups, but open-ended techniques were also used to elicit information. Probes were given after closed or open-ended questions were asked. Content areas included perceived health concerns of adolescents, knowledge about

pelvic examinations and Papanicolaou smears, perception if peers receive Papanicolaou smears, beliefs about Papanicolaou smears (perceived benefits and barriers to obtaining Papanicolaou smears and perceived susceptibility to abnormal Papanicolaou smears and cervical cancer), information-seeking after an abnormal Papanicolaou smear, and adolescent-generated strategies for providers to overcome barriers and enhance appointment-keeping among adolescents.

Table 1 lists the questions asked, grouped by content area. For purposes of analysis, responses to the knowledge assessment were classified as good, fair, or poor knowledge. Good or fair knowledge were grouped together and were defined as being able to describe accurately the purpose of a Papanicolaou smear or describe correctly any aspect of the procedure itself; for example, "I think it is something to check for disease" or "They put a metal instrument inside of you." Poor knowledge was defined as being unable to describe accurately any aspect of a Papanicolaou smear; for example, "I really don't know."

Similarly, responses to the question assessing perceived susceptibility were grouped into high susceptibility, low susceptibility, or don't know. A scenario was given to participants about a young woman named Lisa who had an abnormal Papanicolaou smear. A participant was placed in the high susceptibility category if she reported that Lisa had at least a 20% chance of developing cervical cancer, or if she reported that it was likely or probable that Lisa would develop cervical cancer. A participant was placed in the low susceptibility category if she reported that Lisa had a less than 20% chance of developing cervical cancer or reported that it was unlikely that Lisa would develop cervical cancer.

Interviews were conducted by 2 investigators (J.A.K. and V.C.). Each interview took approximately 1 hour. Interviews were recorded on audiotape and notes were also taken by the interviewer. Audiotapes and notes were transcribed. A team of 3 investigators (J.A.K., J.D.A., and V.C.) independently conducted a content analysis of the transcripts. Multiple readings of the transcripts were performed to identify major themes that emerged from the interviews. Themes were examined across groups (those who had a normal Papanicolaou smear, those who had an abnormal Papanicolaou smear and complied with follow-up, those who had an abnormal Papanicolaou smear and did not comply with follow-up) as well as for all groups combined. Data were analyzed for themes that were consistent with the theoretical framework as well as for novel themes. Representative quotations for each theme were selected. After independent coding, the investigators met 3 times to come to consensus on both content and frequency of themes.

Prevention of cervical cancer by screening for cervical dysplasia is a central public health goal. Compared with other types of cancer, cervical cancer is one of the most treatable if detected early. The 5-year survival rate is 66% if the cancer is diagnosed at a regional stage, but increases to 96% if diagnosed at an early stage.¹ One of the critical factors in decreasing the incidence and mortality of cervical cancer among screened women is ensuring compliance with follow-up.^{7,8} Compliance with periodic Papanicolaou smear screening, evaluation of ab-

normal Papanicolaou smears, and treatment of precursor lesions correlates with decreased incidence and mortality of cervical cancer.^{9,10} Despite this, compliance rates for follow-up of normal and abnormal Papanicolaou smears are low in adults. Typical rates of noncompliance with follow-up appointments for abnormal Papanicolaou smears are 23% to 40%, but estimates as high as 80% have been reported.^{7,11-14}

Although cervical dysplasia is common among adolescents, little is known about maximizing compliance with

Table 1. Content Area and Questions

Content Area	Question
Perceived health concerns of adolescents	"What health problems are girls your age concerned about?"
Knowledge about pelvic examinations and Papanicolaou smears	"Could you tell me what you know about Pap smears?" "Could you explain the difference between a pelvic examination and a Pap smear?"
Perception if peers get Papanicolaou smear screening	"Do most girls your age get Pap smears?"
Perceived benefits to getting Papanicolaou smear	"What are the benefits to getting regular Pap smears?" "What are the benefits of getting a repeat Pap smear if the first is abnormal?"
Perceived barriers to getting Papanicolaou smears	"What stops girls your age from getting Pap smears?" "Which of these reasons are the most important (would absolutely keep some teenagers like you from getting a Pap smear)?"
Perceived susceptibility to abnormal Papanicolaou smears and cervical cancer	A scenario was given to participants, involving a 17-year-old woman named Lisa with an abnormal Pap smear. "How likely is it that Lisa will get cervical cancer now that she has an abnormal Pap smear?" "Where could Lisa go to get more information about her abnormal Pap smear?"
Information-seeking after an abnormal Papanicolaou smear	
Participant-generated strategies: ways for providers to help adolescents to overcome barriers to Papanicolaou smear screening, increase awareness of the importance of Papanicolaou smears, and enhance appointment-keeping	"How could providers overcome barriers to getting regular Pap smears?" "How do you think providers can help teenagers become aware that regular Pap smears and following up abnormal Pap smears is important to their health?" "What can be done to make it easier for teenagers to keep appointments for follow-up Pap smears or the colposcopy clinic?"

follow-up visits. The specific factors that influence compliance for follow-up of normal or abnormal Papanicolaou smears are beginning to be examined. Several retrospective studies have explored primarily demographic predictors.^{7,12,15,16} The results are not consistent across studies, but they suggest that noncompliant patients are more likely to be unmarried, less educated, younger, have fewer total health problems, have Medicaid or no insurance, and have lower-grade lesions. A limitation of these studies is that demographic predictors may not be useful for understanding behavioral predictors of compliance and designing interventions to increase compliance.

Several recent studies have qualitatively explored beliefs about Papanicolaou smears and barriers to Papanicolaou smear follow-up in adults.¹⁷⁻¹⁹ Using interview techniques, these investigators explored adult women's attitudes and beliefs about abnormal Papanicolaou smears and identified barriers to follow-up. Adolescents may differ from adult women with respect to reasons for non-compliance. Adolescents may be less educated, may have more difficulty with practical barriers such as missing school, may be more concerned about confidentiality, and may have different beliefs regarding their susceptibility to cervical cancer and the benefits of early detection. There is an urgent need for exploratory research that examines adolescent-specific beliefs about Papanicolaou smear follow-up and barriers to compliance. Behavioral theory increasingly is being used to provide the structure for conducting formative research to determine predictors of specific behaviors in specific populations.^{20,21}

The aim of this study was to qualitatively explore adolescent girls' understanding and perceptions of Papanicolaou smears and barriers to compliance, using behavioral theories as a guiding structure.

The 4 theories chosen for this study were the health belief model, social cognitive theory, the theory of planned behavior, and the transtheoretical model and stages of change. They were selected because components of these

models have been useful in predicting Papanicolaou smear screening beliefs and behaviors.²²⁻³⁰ The health belief model hypothesizes that preventive health behavior depends on the desire to avoid illness and the belief that a specific health action will prevent illness. Its dimensions include perceived susceptibility to illness, perceived severity of an illness or of leaving it untreated, perceived benefits of recommended actions to prevent or treat a disease, and perceived barriers to following recommendations.³¹ Social cognitive theory is based on the assumption that an individual's behavior is determined by the interaction between behavior, personal factors, and environmental influences.³² Constructs of the model include the individual's capacities to learn by observing others, to have confidence in performing a behavior (self-efficacy), to anticipate the outcomes of a behavior, and to self-regulate behavior. The theory of planned behavior assumes that behavioral beliefs, normative beliefs (perceptions of whether important individuals approve or disapprove of performing the behavior), and perceived control over behaviors predict behavioral intentions, which in turn predict behaviors.³³ The transtheoretical model states that behavioral change is a process involving progress through 5 stages: precontemplation, contemplation, preparation, action, and maintenance.³⁴ Processes of change are activities that people use to progress through the stages, and include consciousness raising and helping relationships.

Although a major goal of the study was to be exploratory and hypothesis generating, we began with several hypotheses linking behavioral theory constructs with adolescent girls' attitudes about Papanicolaou smears and compliance with Papanicolaou smear follow-up. For the health belief model, we hypothesized that adolescents would perceive they are not highly susceptible to cervical cancer but that cervical cancer is a serious illness, and that they would understand the benefits of Papanicolaou smear screening to be prevention and early detection of disease. We hypothesized that they would perceive different barriers from

adults; for instance, confidentiality issues and transportation difficulties. We further hypothesized that adolescents would seek information and model behavior based on advice from physicians, family members, and friends if they had an abnormal Papanicolaou smear, and would perceive that their friends receive Papanicolaou smear screening. These are consistent with specific constructs of social cognitive theory such as observational learning, self-efficacy, situation, and environment. We also hypothesized that adolescents intend to comply with Papanicolaou smear follow-up, although they may experience barriers to compliance, constructs relevant to the theory of planned behavior. Finally, we hypothesized that adolescents would report that education and trusting relationships with providers, which are consistent with the transtheoretical model constructs of consciousness raising and helping relationships, would be important in overcoming barriers to compliance.

RESULTS

The mean (\pm SD) age of focus group participants was 17.6 (\pm 2.3) years and of interview participants was 18.7 (\pm 1.9) years. Eight of the 15 interview participants reported they were black, non-Hispanic; 3 reported white, non-Hispanic; 2 reported Hispanic; and 2 reported other. Five of the 15 interview participants had children. Thirteen reported English and 2 reported Spanish as their first language. Eleven were in school, and the mean grade was 11th. Five had a self-reported history of *Chlamydia trachomatis*, 1 had a history of genital warts, and 1 had a history of genital herpes simplex virus.

The following are results of the interviews grouped by content area. Results from the 3 groups are combined, because we could not detect differences in themes between the 3 groups. Quotations representative of each content area are reported in **Table 2**.

PERCEIVED HEALTH CONCERNS OF ADOLESCENTS

Most participants (13 of 15) reported that girls their age were concerned about sexually transmitted infections. Other health concerns were pregnancy (reported by 5 participants), breast cancer (reported by 4 participants), abnormal Papanicolaou smears or cervical cancer (reported by 3 participants), and smoking (reported by 2 participants).

KNOWLEDGE ABOUT PELVIC EXAMINATIONS AND PAPANICOLAOU SMEARS

Overall, knowledge about pelvic examinations and Papanicolaou smears was poor. Four participants had good or fair knowledge and 11 had poor knowledge of Papanicolaou smears. Twelve participants were unable to distinguish between a pelvic examination and a Papanicolaou smear.

PERCEPTION IF PEERS GET PAPANICOLAOU SMEAR SCREENING

Nine reported that most of their peers get Papanicolaou smears. Five thought that most did not, and 1 did not know.

PERCEIVED BENEFITS TO GETTING PAPANICOLAOU SMEARS

All fifteen participants reported that prevention and early detection or diagnosis were benefits to getting Papanicolaou smears. Several participants verbalized the concept that it is possible to have an abnormality even if one is asymptomatic or cannot visualize an abnormality. Other perceived benefits included checking for or treating sexually transmitted infections, ensuring that the result of the first Papanicolaou smear was correct, and having peace of mind by knowing the Papanicolaou smear result.

PERCEIVED BARRIERS TO GETTING PAPANICOLAOU SMEARS

Pain and embarrassment emerged as major themes. Pain or discomfort with a Papanicolaou smear was reported spontaneously by 13 of 15 participants. Participants reported frequently that pain or discomfort was associated with provider behaviors or style. For instance, 1 adolescent linked lack of education or preparation for the examination with pain, explaining that "the pain [and] the uncertainty . . . go hand in hand." Similarly, several adolescents reported that pain could be minimized if the examination was performed in a gentle manner. Comments revealed that many adolescents believe the pelvic examination to be a remarkably negative experience. One participant described the speculum as a "steel piece," similarly to how one might describe a gun, and attributed a lifelike quality to it: "I worry about . . . what it's going to see when it gets up there."

Ten participants reported that embarrassment was a barrier to getting a Papanicolaou smear. Participants frequently described the embarrassment associated with having a stranger examine one's body or having a male provider perform a pelvic examination.

Eleven participants reported fear of finding a problem and fear of the unknown. Several participants explained that they would feel unclear or blame themselves if they were told that they had a sexually transmitted disease or an abnormal Papanicolaou smear. Denial or invincibility was reported by 6 participants, several of whom described the belief that if abnormalities were "left alone," they would eventually disappear. Six participants reported that provider characteristics were a barrier: common themes included having a male provider or not having a good relationship with a physician. Four participants reported that not wanting to look for trouble was a barrier, 4 reported lack of knowledge as a barrier, and 3 reported that peers advising them against having a Papanicolaou smear was a barrier. Other barriers included fear of parents finding out, prolonged waiting time at the clinic, fear of being diagnosed with pregnancy, denial, having a medical student in the room, and impulsiveness. The issue of impulsiveness emerged in the context of asking adolescents why they would or would not keep a follow-up appointment in the clinic. Several adolescents reported that they intended to keep their appointments, but at the last minute made alternative plans. For

Table 2. Content Area and Quotations

Content Area	Quotation
Knowledge about pelvic examinations and Papanicolaou smears	Good/fair knowledge “They take some of the cells off your cervix with a swab and . . . then they examine it in the lab to make sure that the cells are not precancerous.” “It’s hard to explain it. Abnormal cells could turn into cancer.”
	Poor knowledge “I think it was that I had a yeast infection that wouldn’t go away.”
Perceived benefits to getting Papanicolaou smears	“I think the benefits are if something’s wrong, that you cannot physically see, the Pap smear will bring that to the surface.” “To catch things early on. I guess if it is to look for cancer cells, to catch abnormal cells before they get to cancer cells.” “It can help you. If you don’t treat it, it can get worse and become a bigger problem . . . even if it’s normal, it’s important to go back on a regular basis even if it’s normal just to make sure it stays like that.” “(A benefit would be that I would have) peace of mind that nothing is wrong with me.”
Perceived barriers to getting Papanicolaou smears	Pain or discomfort “I know the pain, the uncertainty is the biggest one. They kind of go hand in hand. Pain, not knowing what’s going to happen, who’s going to do what.” “When doing a Pap smear, they can be rough sometimes and it hurts, but they go on. A Pap is uncomfortable no matter how they do it; if it’s rough, then forget it.” “I think when I think of a pelvic exam I think of the steel piece that’s the thing for me. I worry about whether it is going to be cold, what it’s going to see when it gets up there. I don’t even know how far.”
	Embarrassment “Somebody you don’t know is actually looking at your body. It’s not like it’s a guy you’re engaged to or something. It’s not your mother that knew you when she was changing your diaper. It’s somebody you don’t know.” “(My friend) really felt uncomfortable going for a Pap smear because her doctor was a male and he was really old . . . and when she saw him she thought of her father and said: well, you don’t want your parents seeing your body and therefore seeing someone who resembles your dad is uncomfortable.”
Fear of finding a problem/fear of unknown	“Fear of finding out something’s wrong, fear of finding out they have an STD [sexually transmitted disease] or something’s abnormal. Some people can’t deal with stuff like that because they feel nasty. And they blame it on themselves.” “I think a lot of people think that the unknown is better than not knowing at all and yes I agree with that. Just finding out that something may be wrong is definitely the biggest fear of all.”
Denial or invincibility	“I think the number one reason is a lot of people my age or younger think that they are invincible. Certain things just don’t happen to them so it’s not a primary concern for them.” “Some girls probably think that okay if I leave it alone this is going to go away.”
Provider characteristics	“I didn’t have a regular doctor. I saw a whole bunch of doctors and I saw so many and I wasn’t with anyone steady so just staying with a whole bunch of people and just knowing they’re gonna see my body and see things that are personal to me and that upsets me. You need to have a regular person you can talk to.” “When I was pregnant, the male doctor I saw was threatening to call my mom and pressuring me to tell my mom I was pregnant. Because of that I didn’t get care for 4 months. . . . When you’re young, you don’t need someone hounding you, you’re already depressed. The attitude of the doctor that’s dealing with you and how he treats you when he greets you and how he talks to you. People can deal with 2 to 3 minutes of pain, but not being hounded or put down.”
Not wanting to look for trouble	“I think it’s because they gonna tell me something I do not want to hear. I don’t, and that’s why I’m not in a rush to make the appointment.”
Lack of knowledge	“They probably don’t know enough about it to even know that they should come in once a year or if they need to.”
Peers advising against having a Papanicolaou smear	“The reason I didn’t get mine done is because I was afraid, afraid because I hear stories. Girls talk about the experience of a Pap smear, how it feels, it hurts or it was like this; they’re very descriptive if you ask questions. I’ve heard only bad stories.” “I’m sure their friends probably told them; ‘girl you don’t want no Pap smear’.”
Other barriers: impulsivity	“Like when they are on the bus [they think] oh gosh, this is the stop—but maybe I will go to McDonald’s instead.”
Information-seeking after an abnormal Papanicolaou smear	“I had to really catch a doctor. I kind of got upset because they were all busy. I was there having a Pap smear and they said they would call the next day. I said I wanted to ask more questions about it, but she said she didn’t have time. That made me mad. I used to think of a million questions the night before, but couldn’t ask them because the doctor was always too busy to answer them.” “I know a lot of people go to out of the way clinics, like really small ones. Because they know that there is some type of anonymity there if you are going and people don’t know who you are.”

example, one participant reported that if a friend were to call her just prior to the clinic appointment and ask if she were interested in going to the mall, she would not hesitate to go to the mall instead of the clinic. When asked why other girls might not keep appointments for Papanicolaou smears,

one participant reported, “Like when they are on the bus [they think] oh gosh, this is the stop—but maybe I will go to McDonald’s instead.”

Participants were also given probes exploring potential barriers. Issues that adolescents reported to be

Table 2. Content Area and Quotations (cont)

Content Area	Quotation
Participant-generated strategies: ways for providers to overcome barriers to Papanicolaou smear screening, increase awareness of the importance of Papanicolaou smears, and enhance appointment-keeping Education	<p>"I think maybe like an in-depth explanation. Because they use a lot of things for a pelvic exam, so what is each thing, how is it used, what is it going to do."</p> <p>"Just break it down into simple language. Like some doctors say, okay you have this abnormality and I will refer you to gynecology for colposcopy and a lot of people say wow there is really something wrong with me and they really don't take it in. It needs to be explained not more in medical terms but in terms people can understand and so they can say okay I understand but how will it affect this and this is what you need to do, and in the colposcopy they will cut off a piece of you with a biopsy. A lot of times there's a language barrier because people just don't understand the medical language and doctors are always using it assuming that people just understand it. So I think you should go over some written information with the patient also, and say, are you sure you really understand it, do you have any questions."</p> <p>"I think that what happens is that the doctor just goes on and on and you say 'yeah, yeah, yeah.' But you get out and you realize you really didn't know what they were talking about."</p>
Developing a trusting, consistent relationship with providers	<p>"I really like my doctor, she's someone I can really talk to . . . I can really trust her and . . . she takes care of me . . . cause if you have a doctor you don't like, you're not going to let them do a Pap smear, nuh uh."</p> <p>"You feel vulnerable, scared, if you don't know what's coming next . . . I just feel strongly that doctors really take the time to walk people through. And also to bring up things that should be brought up. Things that the doctor might take for granted that the patients should know. Because pelvic exams can be so scary. Doctors do these all the time but they should appreciate that the patient can be very scared, and that it's not routine for the patient."</p> <p>"I think it would be important to build a close relationship with patients because if they trust you they will come in. If you are open to them they will be more open to you. They trust your judgment, so if they ask you to come in or whatever then you will do it."</p>
Telephone and written reminders	<p>"I think it's more personal that the doctor calls and I think it's more intimate and it shows that wow this person is really concerned about me and they really do care about my well-being so I will give him the courtesy of showing up for the appointment and I know they are going to take care of me because they are concerned that I come."</p>
Ensuring a person answers the telephone	<p>"I always get the answering machine. I never leave an answer on a machine because I'm afraid I'll stutter or something. I would only make an appointment if someone answered the phone."</p>

barriers only after a probe was given included cost, taking time off from school or work, finding child care, not having transportation, the clinic being too far away, not having the time or energy to make the appointment, and fear of finding cancer.

PERCEIVED SUSCEPTIBILITY TO ABNORMAL PAPANICOLAOU SMEARS AND CERVICAL CANCER

Several participants reported that an adolescent with an abnormal Papanicolaou smear was at significant risk for cervical cancer. Seven of 15 participants reported high perceived susceptibility to cervical cancer. Four of these reported that the chance was 50% or greater. Seven of 15 participants reported low perceived susceptibility to cervical cancer. One participant reported she did not know.

INFORMATION-SEEKING AFTER AN ABNORMAL PAPANICOLAOU SMEAR

Eleven participants reported that an adolescent with an abnormal Papanicolaou smear could go to her physician for information, but some reported dissatisfaction with their own interactions with physicians with respect to communication about Papanicolaou smear re-

sults. A theme commonly reported was that the physician seemed too busy to answer the adolescent's questions. Five participants reported that she could go to a hospital or clinic within a hospital for information. Three participants each reported that she could go to a gynecologist, a school nurse, the library, or her mother for information. Two reported that she could go to another clinic where she was not known. Two participants thought she could do her own research; for example, through the Internet. One participant each reported the following potential sources of information: another hospital for a second opinion, pamphlets, counselor, sister, other relative, friend, another patient in the waiting room, or telephone "hot line."

PARTICIPANT-GENERATED STRATEGIES: WAYS FOR PROVIDERS TO OVERCOME BARRIERS TO PAPANICOLAOU SMEAR SCREENING, INCREASE AWARENESS OF THE IMPORTANCE OF PAPANICOLAOU SMEARS, AND ENHANCE APPOINTMENT-KEEPING

Themes that emerged included education and the development of trusting, consistent relationships with providers. All 15 participants reported that education would overcome barriers and enhance awareness of the importance of Papanicolaou smears. Participants emphasized

the importance of providing in-depth, one-on-one information that is understandable to adolescents. Communication and rapport with the provider also emerged as a major theme, mentioned by 11 participants. Developing trust, having a consistent provider, making the patient feel at ease, and being able to communicate well were mentioned most frequently. Other themes included performing a gentle examination, ensuring confidentiality, and educating teenagers in schools.

Most participants believed that reminders were the best means of enhancing appointment-making and appointment-keeping. Telephone reminders were mentioned by 10 participants, and most participants believed that their physician should make the call. Mail reminders were mentioned by 8 participants. Some adolescents believed that the letter should go into some depth in explaining the procedures that would be done. Others were concerned that too much detail would frighten recipients. A participant who had not complied with a referral to the colposcopy clinic described her reaction to the letter informing her that her Papanicolaou smear showed low-grade squamous intraepithelial lesion. "I think that it [the letter] shouldn't really go in depth into what the problem is. I read it: abnormal cervical cells, dysplasia, SIL [squamous intraepithelial lesion] and that stuff, and I said what the hell is wrong with me. I don't know what it is, and it scared me. I was just like wow, there is no way . . . I had no clue what dysplasia was you know, no clue what the word SIL or whatever that word meant and a letter did nothing to calm my nerves and there was no contact with another human being who could answer my questions or whatever."

Other suggestions for enhancing appointment-keeping included expanded hours for the colposcopy clinic, avoiding long waits for an appointment, providing babysitting or transportation, and ensuring that a person answers the telephone when a patient calls to make an appointment.

COMMENT

These findings have implications for the clinical care of adolescents receiving Papanicolaou smears as well as future research. Results of this qualitative analysis indicate that knowledge about Papanicolaou smears and pelvic examinations among adolescent girls is poor. This is consistent with previous research demonstrating only fair agreement between reported history of an abnormal Papanicolaou smear and documented cytological abnormalities.³⁵

Several themes relevant to behavioral theories emerged from analysis of the interviews. Most participants believed that their peers receive Papanicolaou smear screening, and half reported that a young woman with an abnormal Papanicolaou smear is at high risk for cervical cancer. Perceived benefits to getting Papanicolaou smears included prevention and early detection or diagnosis, checking for sexually transmitted infections, ensuring that the result of the first Papanicolaou smear is correct (if this is a repeat Papanicolaou smear), and having peace of mind by knowing the result. Perceived barriers to getting Papanicolaou smears included pain or

discomfort, embarrassment, fear of finding a problem, fear of the unknown, denial, provider characteristics and style, not wanting to look for trouble, lack of knowledge, and peers' advice. Several of these barriers have been reported in the adult literature. Kavanagh and Broom¹⁷ examined adult women's attitudes and beliefs about abnormal Papanicolaou smears qualitatively using semi-structured interviews. They reported that women received inadequate information about the significance of the abnormal Papanicolaou smear, that a physician's communication and personal skills were important to women, and that women's understanding of the abnormality often conflicted with their physician's opinion. Paskett et al¹⁸ conducted in-depth, open-ended interviews with women who had abnormal Papanicolaou smears, then developed a hierarchically weighted utility model that was administered to an additional group of women with abnormal Papanicolaou smears. Predictors of compliance with follow-up included physician's opinion, perceived accuracy or seriousness of the Papanicolaou smear result, belief in the importance of early detection, familiarity with the treatment procedure, time hassles involved in further treatment, femininity concerns, fear of cancer, and perceived risk of cancer. Lerman et al¹⁹ found that the most frequently reported barriers to keeping a colposcopy appointment were unclear purpose, fear of cancer and/or treatment, and forgetting the appointment.

The data from this study suggest that certain barriers predominate in adolescents as compared with adults, namely, pain and embarrassment, denial, provider characteristics, and peers' advice. Issues that seem to be less relevant to adolescents are practical barriers such as time, cost, transportation, and child care. These results are consistent with a study that explored sources of anxiety about pelvic examinations in adolescents,³⁶ in which the concerns most frequently reported were fear of the discovery of abnormalities, fear of pain, and embarrassment. The most frequent information source about pelvic examinations was peers, and the most common message heard from peers was that a pelvic examination was painful.

Participant-generated strategies for how providers could overcome barriers to Papanicolaou smear screening and enhance appointment-keeping among adolescents included education and the development of excellent communication and rapport with providers. Many adolescents reported that developing a trusting and consistent relationship with a provider was essential to improve compliance with appointment-keeping. Conversely, several adolescents reported dissatisfaction with physician interactions when given abnormal Papanicolaou smear results. Adolescents expressed frustration that their physician often seemed too busy to answer questions or gave an explanation of the abnormal test result that was perceived as inadequate. These findings are consistent with a recent study that examined determinants of adolescents' satisfaction with providers and intentions to keep follow-up appointments.³⁷ The investigators reported that perceptions about providers' style of behavior predicted visit satisfaction, and that visit satisfaction was associated with intention to keep follow-up

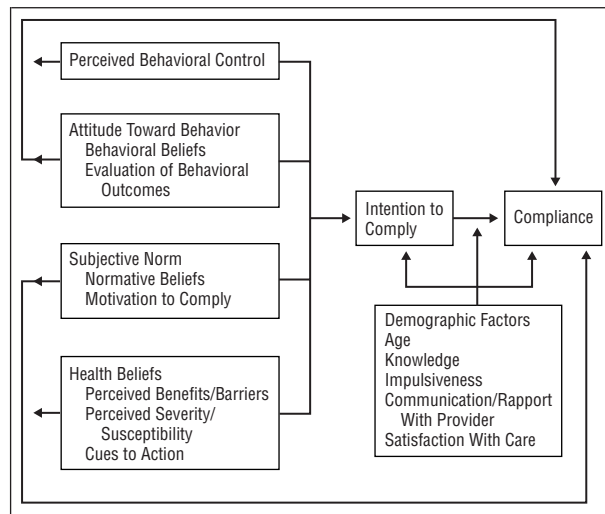
appointments. Litt and Cuskey³⁸ have also reported that higher scores on a scale measuring satisfaction with health care predict appointment-keeping in adolescents. Items included in the scale measure communication skills and other provider characteristics.

Adolescents also believed that telephone and written reminders would increase compliance with follow-up visits. Most participants reported that they would prefer if a physician made the telephone call. Telephone and written reminders have been used successfully to enhance compliance with follow-up in adult women.^{19,39,40} Other suggestions included expanded hours, avoiding long waits for an appointment, providing babysitting or transportation, and ensuring that a person answers the telephone when a patient calls for an appointment.

The major limitations of the study include the small sample size and nonrandom design, which limit the ability to generalize the results to the larger adolescent population at risk for cervical dysplasia. The primary purpose of the study, however, was an in-depth exploration of adolescents' beliefs and attitudes about Papanicolaou smear screening and follow-up, and identification of themes that could ultimately allow for testing of a model in a larger sample. In addition, the finding that many adolescent girls preferred a female provider may have been influenced by the fact that the focus group moderators were female. Finally, several questions assessed a participant's beliefs about other young women her age, rather than assessing the participant's personal beliefs. For example, perceived susceptibility was examined using a scenario of a young woman with an abnormal Papanicolaou smear. While this technique is common in qualitative research and may help the investigator to elicit sensitive information in a less threatening way, these global beliefs may not necessarily be extrapolated to represent individual beliefs.

Several themes emerged from data analysis that are consistent with 4 behavioral theories: the health belief model, social cognitive theory, the theory of planned behavior, and the transtheoretical model. Other investigators have demonstrated that components of these models are useful in predicting adult women's cervical cancer screening beliefs and behavior.²²⁻³⁰ These studies provide valuable information, but have addressed only the beliefs and behaviors of young adult and adult women. In our analysis, although each model provided insight into the predictors of Papanicolaou smear follow-up, no single theory emerged as explanatory.

Gritz et al^{41,42} have described a heuristic framework that explains adherence to cancer control interventions and incorporates constructs of the aforementioned behavioral theories and other external factors. Based on our qualitative analysis and published studies examining adolescent beliefs and attitudes about pelvic examinations and Papanicolaou smears,^{36,37} we propose that a modified version of this model (**Figure**) could provide a framework for understanding compliance with Papanicolaou smears in adolescents. Components of the theory of planned behavior and social cognitive theory such as perceived control over returning for a Papanicolaou smear, attitudes about Papanicolaou smear follow-up, and subjective norms are hypothesized to be the an-



Compliance model.

tecedents of intention to comply with Papanicolaou smear follow-up and compliance with follow-up. Components of the health belief model such as perceived benefits, barriers, susceptibility, and severity are also hypothesized to precede intention to comply and compliance. Intention to comply is hypothesized to predict compliance with follow-up visits. Factors that may influence intentions, compliance, or the path from intention to compliance are demographic factors, age, knowledge, impulsivity, communication and rapport with the provider (the latter consistent with the transtheoretical model construct of helping relationships), and satisfaction with health care. Factors such as knowledge, age, impulsiveness, satisfaction with health care, and communication and rapport with the provider were not part of the Gritz et al model but have special relevance to understanding the adolescent population.

The new model provides a structure for clinical care recommendations and suggests directions for future research. First, an understanding of the antecedents of intention to comply and compliance, which include adolescents' beliefs and attitudes about Papanicolaou smears, can be critical for providing care and designing interventions to improve compliance with follow-up. Adolescents believe that their peers receive Papanicolaou smear screening and rely on their physicians, mothers, and other relatives for information about abnormal Papanicolaou smear results. These may be valuable resources for educating young women about Papanicolaou smears and enhancing follow-up. Adolescents in this study understood the concepts of prevention and early detection and several believed that knowing the result of their Papanicolaou smear would give them self-confidence and peace of mind. These concepts should be emphasized in educating adolescents about normal and abnormal Papanicolaou smears. Adolescents cited many barriers to obtaining Papanicolaou smears. Addressing these barriers, which include pain, embarrassment, fear of finding a problem, denial, and lack of knowledge, may enhance compliance with Papanicolaou smear follow-up.

Second, factors that may influence intention to comply, compliance, and the path between intention and com-

pliance may include knowledge, demographic factors, age, impulsiveness, communication and rapport with the provider, and satisfaction with health care. Many adolescents have poor knowledge of Papanicolaou smears and need in-depth, understandable education, particularly if they have an abnormal result. Younger adolescents may benefit from more intensive education because of differences in cognitive ability, including difficulty with abstract thinking. Improving patient satisfaction by ensuring that the provider is consistent, communicates well, and assures confidentiality may improve compliance as well.

Further research should test this model prospectively, with larger numbers of adolescents, to determine which components predict intention to comply and compliance with Papanicolaou smear follow-up. Further study will also help elucidate the complex issue of the path from intention to compliance; that is, why adolescents may intend to comply with follow-up appointments but do not consistently follow through with their intentions.

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