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Confidentiality in the Clinic: A Qualitative Analysis of Adolescent Girls' Experiences of
Confidentiality in Sexual and Reproductive Health Care

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Abstract

Purpose: Adolescents in Connecticut can legally consent to sexual and reproductive health (SRH) care themselves and their parents do not have the right to view their confidential SRH treatment records. A qualitative study capturing information about adolescent girls' experiences when receiving SRH care was conducted to explore how confidentiality and privacy play out in the clinic from the perspective of adolescents, the facilitators and barriers to adolescents' confidentiality and privacy in SRH care, and the influence of family members or other guardians on adolescent patients' confidentiality and privacy.

Methods: A secondary analysis of 31 interviews with adolescent girls was conducted. All girls were interviewed before or after their appointment with a physician they were scheduled to see at either a primary care clinic or any of three adolescent gynecology clinics. Dedoose software was used to facilitate data retrieval.

Results: Four major themes describe experiences and desires of adolescent girls as it relates to confidentiality and privacy in SRH care: confidentiality and privacy as signs of autonomy and respect for the emerging adult; the double-edged sword of parental involvement in SRH care; confidentiality and privacy serving as both a privilege and protection for adolescent girls; and adolescents' desire for more direct and confidential communication with health care providers.

Conclusion: Half of the study participants did not feel that their own confidentiality and privacy was threatened; the other half revealed that they had some concerns about their SRH care needs and information being shared with their guardians. All girls believed that a tool privately capturing their health concerns before appointments would make a difference in patient-provider confidentiality and interactions. This tool would be a welcome addition to adolescent-focused clinics, particularly in those clinics providing care SRH care or mental health care.

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Introduction

A visit to the gynecologist has been described as a “rite of passage into American womanhood” and regular medical visits for gynecological care and pelvic exams have been linked to specifically female biologic life experiences like menarche and maternity.¹ However, in between these major biological events and life experiences, adolescent girls (AGs) may seek gynecological care for specific complaints, such as sexually transmitted infections (STIs) and menstrual problems, or needs such as contraception. These medical visits, between AG patients and healthcare professionals equipped to handle gynecological care, are opportunities for patients to learn more about their bodies by asking and receiving answers to questions about their reproductive organs. They are also opportunities for providers to screen AGs for potential health problems and demystify for AGs the internal and external biological changes that occur during puberty. Importantly, adolescent girls’ experiences with sexual and reproductive health (SRH) care may inform their future SRH care seeking behaviors as adult women.

When caring for adolescents’ SRH care needs, health care professionals should attend to adolescents’ fear, lack of knowledge, and discomfort. With respect to AGs’ fears, attention should be paid to their fears of the unknown, finding pathology, and exposure of genitals.^{1,2} With respect to AGs’ lack of knowledge, professionals should be clear about what is being done during an appointment or exam, why it is being done, and how it is being done.^{1,2} Finally, in consideration of AGs’ physical and/or psychological discomfort, providers should continuously improve upon their empathetic and technical skills.^{1,2} However, in the modern era, health care professionals providing SRH care to AGs should additionally attend to adolescents’ general discomfort about accessing the full range of SRH services that can be provided to them, fear about disclosure of their SRH information to parents or guardians, and their lack of knowledge

about SRH confidentiality and privacy laws. Illuminating these concerns, a Kaiser Family Foundation 2014 report found that 70% of young women ages 15-18 years rated patient confidentiality with respect to health care in areas like family planning services as important.³ However, only 24% of young women in this age range knew that private health insurance plans can send Explanation of Benefits (EOBs) documenting medical services that were rendered for all parties covered under the insurance plan to the principal policy holder (e.g. their parents) for any care they receive.³

Confidentiality, in the clinical sense, is the “protection of privileged and private information shared during a health care encounter and in medical records” that document the patient-provider encounter.⁴ In adolescent SRH care, confidentiality may be defined as information about adolescent’s health care not being disclosed without their permission.⁵ Studies have shown that if confidentiality is not assured, adolescents avoid or stop using health services, are less willing to use family planning services for prescription contraception and STI screening/treatment, will not seek health care or be honest with practitioners, and will not go to a medical home or consistently access medical services at one clinical site – all of which negatively impact health outcomes for adolescents.⁶⁻⁹ The 2016 National Survey of Family Growth revealed that confidentiality concerns significantly impacted the SRH health services adolescents receive. According to data from this survey, approximately 18% of adolescents aged 15-17 reported that they would not seek SRH care out of a concern that their parents might find out about the care they received.¹⁰ Additionally, only about 20% of AGs aged 15-17 who were concerned about seeking SRH care due to their parents finding out about the services they received actually received SRH services within the year, compared to 34% of AGs aged 15-17 who did not have these confidentiality and privacy concerns.¹⁰

When considering adolescents' ability to receive confidential care in the United States, the following factors have to be considered: U.S. state laws, patient age, patient developmental level, and patient relationship with parent/guardian.⁵ Upon reviewing adolescents' autonomy in medical care across the United States, particularly their decision-making capacity, confidentiality, and privacy in SRH matters, adolescents in Connecticut (CT) appear to have their rights to care well protected. Although adolescents under the age of 18 years (minors) generally cannot make routine healthcare decisions for themselves, in CT, adolescents age 13 years and older can make critical healthcare decisions and consent to treatment in sexual and reproductive health, as it is a protected area of care.¹¹⁻¹⁵ Additionally, the 2002 Standards for Privacy of Individually Identifiable Health Information, also known as the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, provides protection against parents' access to protected health information for minors who can legally consent to services or receive services without parental consent or notification according to state or other applicable law.^{16,17} As adolescents in CT age 13-17 years can legally consent to SRH care themselves, parents do not have the right to view their child's confidential SRH treatment records in the healthcare or school setting without their child's consent. Once a child has reached 13 years of age, they must explicitly authorize or permit parental access to their SRH information and medical records.¹³

Although these protections exist, adolescents in CT themselves may not be aware of their protected rights when seeking and receiving SRH care. Additionally, it is unclear as to how such information about their protected confidentiality and privacy is regularly being imparted to adolescents, if at all. As such, adolescents may not be accessing all the SRH care they are interested in or require. Therefore, it is of interest to gain an understanding of adolescents'

specific concerns (or lack thereof) about confidentiality and privacy, as well as to see how adolescent agency is promoted (or undermined) when adolescents access SRH care.

A qualitative study capturing information about adolescent girls' experiences when receiving gynecological care and adolescent healthcare providers' opinions on adolescent care in CT was conducted to collect input for a pilot program. The pilot program has goals of strengthening patient-provider communication between adolescents and their healthcare providers and increasing adolescent agency in receipt of their care. In the interviews with adolescent patients and providers in the main analysis, adolescent privacy and confidentiality emerged as an important supplementary theme. However, this theme was not fully addressed in the main study. The purpose of this secondary analysis, therefore, is to conduct an in-depth exploration of this theme and describe how confidentiality and privacy play out in the clinic from the perspective of adolescents, the facilitators and barriers to adolescents' confidentiality and privacy in SRH care, and the influence of family members or other guardians on adolescents' confidentiality and privacy.

Methods

Theory

In this secondary analysis, the examination of the data was guided by the grounded theory approach. Grounded theory sets out to discover or construct theory from data, systematically obtained and analyzed using comparative analysis.^{18,19} Grounded theory proves to be a useful methodology when little is known about a phenomenon and the research aim is to produce or construct an explanatory theory that uncovers a process inherent to the substantive area of inquiry.

As little is currently known about gynecological healthcare experiences from the adolescent perspective, as well as adolescents' perspective of their patient confidentiality and privacy when receiving SRH care, grounded theory is most appropriate for this analysis. The principal investigator of the main qualitative study, Marie Brault, Ph.D., and I used a modified framework approach to grounded theory because we had some ideas of codes and themes that we were looking for, but we also allowed codes and themes to emerge throughout our iterative review of the data.^{20,21} Some of these *a priori* codes included indicators of adolescent-friendly care and suggestions on the pilot program to improve adolescent/provider communication through an adolescent appointment planning tool.

Sampling Method and Description of Sample

The sample for this secondary analysis included 32 of the 42 individuals who participated in one-on-one in-depth interviews as part of the main qualitative study conducted from late August 2018 to early March 2019 at the Yale School of Public Health. Interviews were conducted to the point of thematic saturation. The 10 individuals eliminated from this analysis were the healthcare providers who were interviewed to collect information from the provider's

perspective on barriers and facilitators to their relationships with their adolescent patients. Provider interviews were excluded from this secondary analysis because I was primarily interested in adolescent girls' perspective on the patient-provider relationship, and the particular successes and challenges AGs believe that they face in maintaining confidentiality in the healthcare they receive and their medical records. While providers may feel strongly about a particular issue in adolescent confidentiality and privacy in healthcare, adolescents may or may not feel similarly or bring these points up. The resulting sample included young women whose ages ranged from 14 to 18 years who were in grades 9 through 12 or in their freshman year of college (Table 1). Youth in the sample identified as various ethnicities and races: African American or Black (12), Caucasian (9), Hispanic or Latinx (8), and multi-racial (2). All adolescents were interviewed immediately before or after their appointment with a physician they were scheduled to see at either one primary care clinic (PCC) or any of three adolescent gynecology clinics (PAGs); ten adolescents were interviewed at the PCC, and twenty-two were interviewed at the PAGs.

Clinic Setting

It is worth noting that the PCC primarily serves an urban population and has about two adolescent-specialized physicians on staff to see adolescent patients one day each week, as well as two nurse practitioners, and two social workers. In considering the layout of the clinic, the PCC has a separate, small waiting area for adolescents but no dedicated examination rooms specifically for adolescent care. On the other hand, the PAGs serve a mix of patients from urban, suburban, and rural locations. The PAGs have two adolescent-specialized gynecologists on staff, as well as one part-time social worker, and one practice nurse. At the PAGs, there is a general pediatric waiting area, where all pediatric patients visiting any specialized care at the sites are

Table 1

Description of the sample

Characteristic	N (%)*
Race/ethnicity	
African American / Black	12 (38.7)
Caucasian	9 (29.0)
Hispanic or Latinx	8 (25.8)
Two or more races / Multi-racial	2 (6.5)
Age (years), mean \pm SD	16.1 \pm 1.3
Education	
High school freshmen	4 (12.5)
High school sophomores	8 (25.0)
High school juniors	6 (18.8)
High school seniors	10 (31.3)
At least some college	4 (12.5)
Religion	
Christian	21 (65.6)
Muslim	1 (3.1)
None	10 (31.3)
Caregivers	
Two-parent household	16 (55.2)
Single-parent household	11 (37.9)
Other relatives	2 (6.9)
Birth order	
Eldest child	10 (45.5)
Middle child	6 (27.3)
Youngest child	4 (18.2)
Only child	2 (9.1)

* Numbers may not sum to 32 due to missing data, and percentages may not sum to 100% due to rounding

required to wait as the PAGs are housed at clinics providing other pediatric specialty care. On the days in which PAG is occurring, PAG is allocated two exam rooms for the day that are specifically for gynecological care of their patients. As such, PAG staff make a binder containing printouts of all types of information for their patients to peruse while waiting to be seen by their healthcare provider; the binder contains information on items such as contraceptives, menstruation, body image, and more. Adolescent girls are able to receive sexual and reproductive health services at both sites, such as testing for STIs and counselling on/receipt of contraceptives.

Data Collection Procedures

Face-to-face semi-structured interviews were conducted by the principal investigator of the main study who is affiliated with the Yale School of Public Health and has years of experience in mixed methods research and expertise in qualitative research. All 31 interviews were audio recorded and conducted in English; 30 of the 31 interviews were conducted individually. One interview included two participants, two sisters who requested to be interviewed together, which resulted in a total of 32 participants. In three other interviews, another individual was in the room in addition to the interviewer and interviewee: these being a friend or parent who attended the appointment with the interviewee and whom the interviewee requested to be in the interview room with them. Participants provided verbal consent to participate in the study.

At both the PAGs and PCC, nurses or doctors would mention the study to their patients and direct them to the interviewer for further information if they were interested in participating in the study. As such, doctors and nurses used their best judgment to direct patients who were able to give informed consent to the interviewer for an interview. Due to this, participants unable

to give informed consent (e.g., those who were non-verbal or developmentally delayed) were excluded from the study. The interviewer would then read over an information sheet about the study with each participant, explaining the purpose of the project and participants' rights, and asking participants if they had any questions about the study. At that point, participants would either provide consent and be interviewed, or self-select out of the interview. Interviews at the PCC were conducted in a meeting room often used by social workers to discuss care with patients, or in patient exam rooms. Interviews at the PAGs were done in a patient examination room or the pediatric specialty clinic sick child waiting room if it was not in use. During the interviews, adolescent girls were asked general demographic questions and were then asked to share about their experiences in receiving gynecological care (including facilitators and barriers to their care), from whom they seek information about SRH when they have questions, whether or not they have used birth control and how they came to decide on the contraceptive method of choice (if using any), and were finally asked for their thoughts on a pilot project providing AGs with a pre-appointment planning tool allowing them to communicate their health needs and questions to their gynecological healthcare provider in advance of an upcoming appointment. Throughout the interviews, probes were used to encourage girls to provide detailed information about their experiences.

Data Analysis

The audio recorded interviews were professionally transcribed verbatim. In the main analysis, central themes identified by analyzing initial interviews were used to code all of the data. Dedoose, a software program designed for qualitative analysis, was used to facilitate data retrieval. All data coded in the following categories were used in this secondary analysis: (a)

youth-friendly attributes and experiences: confidentiality and privacy, (b) sources of support: parents or relatives, (c) successes/facilitators, and (d) challenges/barriers.

The first step undertaken in data analysis involved a careful reading of retrieved data; excerpts were pulled with the four codes of interest. All data segments were reviewed line by line and important ideas were highlighted. Views of different participants were compared and contrasted. Major themes were identified after reviewing all applicable excerpts. When variations in adolescents' experiences were identified, they were explored and described. Examples of young women's experiences and direct quotations were used to provide supporting evidence to the themes derived. Preliminary findings were shared with the principal investigator of the main qualitative study who has an in-depth knowledge of the clinics where interviews were conducted and the youth interviewed. Insight from the principal investigator was used to refine study findings.

Results

Four major themes were identified that describe experiences and desires of adolescent girls as it relates to confidentiality and privacy in SRH care: confidentiality and privacy as signs of autonomy and respect for the emerging adult; the double-edged sword of parental involvement in SRH care; confidentiality and privacy serving as both a privilege and protection for adolescent girls; and adolescents' desire for more direct and confidential communication with health care providers (Table 2).

Theme 1: Confidentiality and privacy are indicative of respect for and the autonomy of the emerging adult

Many participants expressed that being directly spoken to, and having their conversations held in confidence by providers made them feel both responsible for their wellbeing and respected in the health care setting. In a time of great change, between childhood and adulthood, the young women interviewed often felt patronized when providers and their caregivers spoke about the care they required without seriously taking their needs into account. Additionally, some felt that being directly involved in their care plan as the main point of contact or reference highlighted that providers respected their emerging adult autonomy, as it was indicative of them being allowed and encouraged to make the choices that are best suited to their specific needs.

Subtheme 1a: On the cusp of adulthood, respect for adolescent girls' confidentiality and privacy shows respect for the young adult

Acknowledging AGs as "young adults" or "young women" is not merely enough to make them feel as though they are being treated fairly in the medical office. As AGs gain greater responsibility for their own health and health care, it is important that providers show respect for AG patients' confidentiality and privacy. Doing so helps to facilitate honest conversations

Table 2

Primary qualitative themes and subthemes

Themes	Subthemes
1. Confidentiality and privacy are indicative of respect for and the autonomy of the emerging adult	<ol style="list-style-type: none">a. On the cusp of adulthood, respect for adolescent girls' confidentiality and privacy shows respect for the young adultb. Confidential and private care allow adolescent girls to think and act for themselves with respect to health care
2. Parental involvement is a double-edged sword in sexual and reproductive health care for adolescent girls	<ol style="list-style-type: none">a. Parents play an important role in coordinating and facilitating care for adolescent girlsb. The presence of parents at sexual and reproductive health care appointments directly and indirectly influences patient-provider communications, for better or worse
3. Confidentiality and privacy as privilege and protection for adolescent girls	<ol style="list-style-type: none">a. Lack of confidentiality and privacy threatens a patient's relationship with their guardians and family dynamicsb. Confidentiality is a protection against serious repercussions
4. Adolescent girls' desire for direct and confidential communication with health care providers	<ol style="list-style-type: none">a. Adolescent girls are interested in, but unaware of, MyChart communication capacitiesb. Additional resources are needed to establish comfort in the patient-provider relationship

between patients and providers, wherein the real medical concerns of AGs can easily come to the forefront because the adolescent patients feel a level of respect and comfort in disclosing their concerns. One participant described the level of comfort and the type of patient-provider relationship established when AGs are respected and provided with confidentiality and privacy, saying:

“I think what works well is the fact that everybody here doesn’t seem to judge. I know especially for teens they want to be accepted, they want to feel like they’re safe. When you come in here and everyone is smiling and they’re nice and they say, “You have no reason to be afraid. It’s confidential. We don’t have to tell your parents unless you plan on hurting yourself or others.” That just gives me a sense of security, like a security blanket. I know that what I say isn’t going to be said to others or let loose. If I were to tell a friend I don’t know 100 percent if they’re gonna tell someone or not. I know here if I say something, as long as it’s not for harm against me or someone else, it’s going to be kept between the people in the room. I think that’s great about here.”

- Hispanic/Latinx AG, age 15

This participant states that a guarantee of confidentiality and privacy from staff and providers at clinics serving adolescents makes her feel safe and secure in the information she provides and the care she ultimately receives. Making it absolutely clear that patient confidentiality and privacy is of the utmost importance to the clinic and providers can facilitate better appointments for AGs. Confidentiality policies and privacy statements that are clear to AGs can allow AGs to take their guard down and have productive appointments with their health care providers.

Subtheme 1b: Confidential and private care allow adolescent girls to think and act for themselves with respect to health care

A number of AGs interviewed have experienced instances where physicians or nurses spoke directly to their parents or caregivers instead of them, the patient, during appointments. In these instances, physicians took parents' questions first or made their questions the priority over those of the AG. Adolescents experiencing this mentioned feeling disrespected and belittled when this occurs. Although AGs interviewed largely understood and appreciated parental involvement in their care, their experiences indicated that some removal of parents, or a limitation to parental chaperoning during exams and appointments, allowed them to make health care choices that were best for them, whether it was speaking up about a particular concern, asking uncomfortable questions, and/or opting for particular procedures or medications that they wanted. For example, one participant said,

"I looked at the sheet. There's a sheet that says what's really strong, what's okay, what's pretty good, and what's not good [for contraceptives]. I've thought about just the pill. You know? My aunt and uncle really wanted me to do a shot or something that would be longer, instead of every single day, because they were afraid that I would forget or something. I still really wanted the pill, cuz it's like I found this out that once you're 13, then you can choose how you wanna do it. They stepped out of the room, and I talked to the doctor. I found out that the rod [Nexplanon] is probably one of the easiest ways, cuz you don't have to remember about it. It's just, like, one and done, and then a couple years go by, and you get it done again. That's what happens, so that's how I decided [on which contraceptive to select]."

- Hispanic/Latinx AG, age 14

This participant was being swayed by her guardians to opt for birth control that she did not particularly want, and was unable to have the open and honest conversation she wanted to have about contraceptives with her health care provider when her guardians were in the room.

However, after her guardians left the room in accordance with state regulations, this participant was able to be more autonomous and proactive in her care, learning more about the types of contraceptives available and making a choice that she felt comfortable with and confident in.

Theme 2: Parental involvement is a double-edged sword in sexual and reproductive health care for adolescent girls

As seen in Theme 1, although parents and guardians can be well intended in their involvement in SRH care for AGs, their involvement can either strengthen the patient-provider relationship or harm the patient-provider relationship. The effect of such involvement on AG health care is dependent on a number of factors though, such as patients' relationship with their parents and patients' openness with their parents.

Subtheme 2a: Parents play an important role in coordinating and facilitating care for adolescent girls

Most of the AGs interviewed spoke about how their parents and caregivers strengthened their own patient-provider relationship by performing actions required for health care that AGs cannot or may not be able to do themselves. Girls provided examples of their parents initiating care and following up on care, for example sending physicians messages and contacting medical staff outside of the appointment, to support their health care needs. Particularly young AGs are often unable to do this themselves, mainly because they are in school or simply because they do not have the information required to follow up on their health care needs (e.g. insurance information, scheduling information, billing information). With their parents or caregivers supporting them in the logistics of obtaining care, a number of AGs interviewed mentioned that they don't see parental involvement as a problem, despite knowing some peers who may take issue with parental involvement. One such participant said:

“...I’m pretty close to both of my parents, so I don’t really care. They already know pretty much everything about me ’cause they bring me here and stuff and they’re in the room, which is fine. I’m totally fine with that. I know some kids would probably be not—not suspicious but a little less—what’s the word? I don’t know. Maybe they wouldn’t answer it [patient intake forms] accurately if that’s a word—”

- Caucasian AG, age 16

As seen, some AGs have no direct issue with their own parents being involved in their care. Others are more hesitant to involve their parents in their care. Participants were evenly split with respect to a potential aversion to having parents involved in their SRH care, but all understood a need for AGs’ privacy and confidentiality noting that some peers or friends would need such protections.

Subtheme 2b: The presence of parents at sexual and reproductive health care appointments directly and indirectly influences patient-provider communications, for better or worse

While the presence of some parents and caregivers at a medical appointment can help AGs remember important things – main questions for the appointment, date of last menses, immunization records – the presence of parents and caregivers in an exam or appointment can cause many AGs discomfort. AGs may be less likely to discuss sensitive subjects when parents are in the room, for fear of retribution or harassment from parents after the appointment.

Illuminating this concern, one participant said,

“I know a lot of people come to [the clinic] with their parents and they don’t really want to check off certain things [on the intake form] because they don’t want their parents to know about it.

- AG, age 16

Well-balanced conversations between patients, parents/guardians, and providers can exist in the medical visit. However, the AG patient must feel comfortable enough to express their needs and opinions. If the AG is unable to do so in the presence of parents and caregivers, more opportunities to discuss needs outside of the physical appointment or exam should be considered.

Theme 3: Confidentiality and privacy as privilege and protection for adolescent girls

Besides confidentiality and privacy being something afforded to adults, and therefore something young or emerging adults believe they are deserving of, AGs expressed that privacy and confidentiality were crucial to their protection.

Subtheme 3a: Lack of confidentiality and privacy threatens a patient's relationship with their guardians and family dynamics

Some girls interviewed were less forthcoming about their health concerns and issues with their parents, particularly when those concerns were around SRH. Speaking up about a need for birth control, discussing a possible pregnancy, or talking about an intimate relationship with a physician, while a parent is in the exam room, may be the first time the parent hears about any of these things. However, if an adolescent does not mention these concerns or needs at the time, they risk not getting the information they need. One participant captures this conversational dilemma, saying:

“If your parent come and you wanna ask different questions and stuff it's like you don't want your parent to know. Or you haven't talked about it with your parents yet so it's difficult when they come sometimes to the doctors. You want to say something to them, but you really can't.”

- African American/Black AG, age 15

Subtheme 3b: Confidentiality is a protection against serious repercussions

Not only is AGs' patient confidentiality a protection against upsetting family dynamics over an adolescent's health choices when they do not align with those of their guardians, but clinical confidentiality can protect AGs from serious harm. For example, when providers are screening AGs for physical, sexual, and/or emotional abuse, it is imperative that these screening conversations are discussed one-on-one between providers and AGs. It can be difficult for an AG to come forward and report abuse, but it can be particularly challenging to report abuse if the perpetrator of such abuse is a parent or guardian who is present in the examination room and witness to the screening conversation. One participant summed this dilemma up, saying, *"One of the nurses, my mom was right in front of me, and he said, "Do you feel safe at home?" I'm not gonna answer that question while my mom's right in front of me if I didn't, which I don't not feel safe. I'm just saying in general, someone's life could really be in danger. The kid's not gonna answer right in front of them. That's not gonna happen."*

- Hispanic/Latinx AG, age 17

If a parent or guardian is abusing an AG patient, nurses and physicians will likely be unable to inspire the AG patient to disclose abuse if the parent or guardian has not been asked to leave the patient examination room before broaching these topics and asking screening questions. By ensuring that questions about child abuse and exploitation are only discussed between AGs and providers, health care providers create safe spaces that may allow AGs to raise concerns about their personal safety that they otherwise may be unable to.

Theme 4: Adolescents girls' desire for direct and confidential communication with health care providers

Subtheme 4a: Adolescent girls are interested in, but unaware of, MyChart communication capacities

In conducting interviews, participants were asked if they had MyChart. MyChart is an electronic patient information portal powered by and compatible with the Epic electronic medical record software. MyChart allows patients to see all of their health information, such as medications, immunizations, test results, upcoming appointments, and medical bills in a secure online portal. Additionally, patients can schedule appointments, send messages to providers, and even speak with providers face-to-face over video via MyChart. PAG and PCC clinics use Epic and offer MyChart to their patients. For children under 12 years, parents have primary access and proxy access to MyChart, whereby they can view all of their child's patient information and use the portal as they deem appropriate. For children 13 years and older, children are given primary access and can give their patients proxy access if they want to. However, that being said, parents that can log in to adolescents' MyChart with either adolescents' primary access or their own proxy access can view sensitive medical information and conversations with providers, severely limiting adolescents' privacy and confidentiality.

Interestingly, many adolescents interviewed said that they had not heard of or did not know what MyChart was. However, of the few adolescents who knew about MyChart and used the platform, nearly all saw the benefit in the system and spoke positively of it. One participant strongly felt that MyChart helped her gain more control over her medical information and keep it private and confidential from her parents, saying,

"I think it's really good, because I think I've gotten to the point where I can be more responsible with my appointments instead of my mom hovering over. MyChart kinda helps so I could keep it in the back of my mind, like, "I have an appointment coming up," or stuff like that."

- African American/Black AG, age 17

If used correctly, MyChart offers adolescents a way to keep their medical information all together and secure on one site and allows them to speak with providers privately and confidentiality. Patient information tools like MyChart, with their easily accessible electronic design and communication features, can provide AGs with unprecedented direct access to health care, without worrying about “hovering” parents getting involved in their care.

Subtheme 4b: Additional resources are needed to establish comfort in the patient-provider relationship

Throughout the interviews, there were a few AGs who were more than comfortable sharing their health concerns with nurses and physicians. These “active” health care users shared that because of their frank and honest personalities, they were highly likely to discuss with doctors the reason(s) they were visiting, despite the topic of conversation being potentially uncomfortable for teenagers to discuss (birth control, pregnancy, STIs). Some of these young women also stated that because they do not see their doctors often, they do not fear being judged for their questions or specific care needs; they believe they are just another unremarkable patient among the many other patients a doctor sees. When these teens, who were often older, came to the realization that SRH providers have seemingly uncomfortable conversations with many teens regularly, they felt comfortable actively asking questions of their provider and seeking care.

On the other hand, many AGs interviewed mentioned that it can be uncomfortable to discuss topics of sexual and reproductive care with providers. In particular, bringing up a question or a health need face-to-face when bluntly asked if they have any specific issues by providers seems to be an area of great discomfort for young women. Many girls mentioned that there were sexual and reproductive health questions they did not want to come right out and ask to providers, even though those questions and topics weighed heavily on their minds. When

asked about their likelihood of using a questionnaire to capture their health questions and concerns before appointments, which their physician could then see prior to walking into the examination room, all participants were enthusiastic about its use. In response to the draft form of a pilot tool working to facilitate patient-provider conversation in such a manner, one participant said,

“I think it’s really cool what you’re doing because I feel like, when you come to your appointment and you come with your parents, you don’t really wanna say stuff out loud, in front of your parents. When you got this, it’s like your doctor already knows what you wanna talk about, so they could be like, “Oh, Mom, can you leave the room so I can talk to her alone?” I really like this.”

- African American/Black AG, age 15

Like this participant, many girls were excited by the prospect of such a questionnaire, whereby doctors would be the ones to bring up the specific questions or concerns girls have without being actively prompted by the patient. Girls believe such a tool could help them honestly and openly discuss their needs and worries, without worrying about how to phrase their concerns or fear of judgment.

Discussion

The themes and subthemes that emerged in this secondary analysis revealed that among adolescent girls aged 14-18, adolescents have a wide-ranging variety of thoughts and concerns about their confidentiality and privacy in clinical settings. Roughly half of the study participants did not feel that their own confidentiality and privacy were threatened; they did not have blatant concerns about their SRH medical information or health records being shared with their guardians, as they generally maintained honest and transparent lines of communication with their guardians around their health concerns and needs. Many of these AGs with low levels of concern were older in age (16-18 years). The other half of the study participants, who were primarily aged 14-16, revealed that they had some concerns about their SRH care needs and information being shared with their guardians.

This even split in the level of adolescent self-concern about personal confidentiality and privacy due to parental involvement is seen in the adolescent health care literature.²²⁻²⁶ A 2014 study in the *Journal of Adolescent Health* that found that half of all surveyed adolescents believed that their parent's presence (or absence) in the examination room at their last medical appointment impacted their patient-provider conversations.²⁴ Despite a lack of consensus around self-concern about personal confidentiality and privacy, as seen in theme 2, many girls revealed that their guardians or parents were involved in their health care to some capacity – whether making appointments for them, following up on diagnoses and treatments for them, communicating with health care providers for them, taking care of billing matters for them, or providing them with health advice.

Most participants in this study also believed that assured confidentiality and privacy in SRH are foundational to patient-centered appointments, productive patient-provider

relationships, and the development of care plans that account for AGs' often unspoken health needs, as revealed in themes 1 and 3. When questioned about their ability to ask sensitive SRH questions to providers, many girls revealed that they and their peers were more comfortable doing so when guardians were asked to step out of the exam room and physicians assured them that their concerns and questions would be held in strict confidence. A quantitative study has found that the average number of topics discussed during adolescents' medical visits was significantly higher when a visit was partially confidential, and parents or guardians were asked to leave the exam room for a portion of the visit, versus when a visit was not confidential and guardians were included for the full extent of the appointment.²⁴ Some studies have also revealed that clinical conversations about SRH during adolescents' appointments are positively correlated with confidentiality.^{22,24}

As revealed in theme 4, AG participants in this study showed great enthusiasm and interest in tools that could further protect their SRH questions and sensitive health information from the prying eyes of guardians. Some of these tools, like MyChart, already exist to provide adolescents with a user-friendly and easily accessible platform to ask providers questions, access their medical records, and request SRH services without their parents' input. In this analysis, it appeared that AGs accessing care at PAGs were more informed about and likely to already be using MyChart than AGs at the PCC. As such, there appears to be a clear disconnect between the existence of these services and their utilization. With its sole focus of providing adolescents with SRH care, PAG may be more heavily emphasizing the benefits of MyChart and taking more steps to actively enroll its AG patients in the program. However, further qualitative studies of AG patients, or quantitative survey-based studies, may be required to understand why AGs are not fully utilizing the tools already in existence to protect their confidentiality and privacy.

In considering that many participants revealed that they and their peers were more comfortable asking sensitive questions or providing honest answers to clinicians when confidentiality was assured (e.g. guardians were asked to step out of the exam room), it was unsurprising to find that all AGs interviewed believed that a tool privately capturing their SRH questions and concerns, as well as other health concerns, before appointments would make a difference in their patient-provider interactions. This tool, essentially an adolescent-friendly and accessible questionnaire, could be a welcome addition to adolescent-focused clinics, particularly in those clinics providing care that adolescents may be negatively judged for accessing (e.g. SRH care, mental health care).

In interpreting the findings of this qualitative study, it is important to note its potential limitations. The foremost limitation was that the interview guide developed to collect data for primary analysis did not include many questions deliberately asking AGs about their confidentiality and privacy concerns in SRH care. Further insight into AGs' confidentiality, particularly into the delicate balance between patient autonomy and parental involvement, could have been gained with more targeted questions about confidentiality and privacy.

Conclusion

Adolescence is a time of great change, especially with respect to the body, health needs, and legal rights. Overall, adolescent girls accessing sexual and reproductive health care benefit from assured guarantees of confidentiality and privacy from clinical staff, as this allows girls to honestly ask questions that weigh on their minds and receive the care they believe they are most in need of. Additionally, adolescent girls welcome most tools and programs that can facilitate confidential interactions with health care providers and allow them to discuss their health needs that they would prefer guardians not know about. However, many girls still do not know the legal medical rights they are entitled to, especially as it pertains to sexual and reproductive health care.

When adolescent confidentiality and privacy is not taken seriously in medical practices, girls can feel patronized. If confidentiality and privacy is neglected, and parents are provided with adolescent health information that is not within their rights to access, girls may also be at risk of parental retaliation and resentment that can affect their physical and emotional wellbeing.

With many adolescent girls believing that patient confidentiality and privacy impact their patient-provider relationship and the care they ultimately receive, more research should be done to determine how adolescent girls are learning about their patient rights. Additionally, further research should be considered to provide insight into the types of tools and resources adolescents find useful in actively initiating their own care and autonomously conversing with health care providers. These next steps can help push the needle forward with respect to adolescent girls' confidentiality in SRH care and all medical care.

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