Confidentiality in adolescent health care

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INTRODUCTION

The concepts of informed consent and confidentiality are complex when the patient is an adolescent. This is particularly true when the needs and wishes of the adolescent conflict with the opinions and preferences of the parents [1].

The laws governing consent and confidentiality in adolescent health care vary from country to country; within the United States, they vary from state to state. The information in this topic focuses on confidentiality in adolescent health care in the United States.

Clinicians who treat adolescents must be aware of the federal and state laws related to adolescent consent and confidentiality. The circumstances in which adolescents may consent for their own care and the confidentiality laws vary from state to state depending upon the adolescent's status as a minor or adult, the service involved, and the provider's level of concern regarding harm to the patient or others.

The basic laws governing consent for health care are state laws; clinicians who treat adolescents need to be aware of the laws in their state. Confidentiality protections are found in both state and federal law. Clinicians who treat adolescents also must be aware that federal and state funding sources may have specific requirements related to confidentiality for particular services. They should be familiar with the consent and confidentiality policies of the facility in which they practice, and they must be aware of

potential ways in which confidentiality can be compromised (eg, record keeping, billing statements, insurance).

This topic will provide an overview of confidentiality in adolescent health care, including definitions, exceptions to confidentiality, and potential threats to confidentiality. Determination of minor status and how it relates to consent for specific medical services, which is closely linked to confidentiality, are discussed separately. (See "Consent in adolescent health care".)

BACKGROUND

The development of independence from parents is an important task of adolescence [2-5]. It includes the gradual assumption of responsibility for personal health, health behaviors, and medical decisions [2,3,6,7]. Confidentiality protection is essential to this process.

Adolescents are more likely to seek health care if they believe their provider will keep the information discussed during the visit private [8-12]. Concerns regarding lack of confidentiality protection may cause some adolescents to go without health care [12-14].

The importance of confidentiality to adolescents was illustrated in a survey of high school students who were randomly assigned to one of three groups that listened to an audiotape of a clinician assuring unconditional confidentiality (confidentiality would not be violated under any circumstances), conditional confidentiality (confidentiality would be violated if there was risk of harm to the patient or another), or not mentioning confidentiality [11]. Adolescents in the groups that were assured confidentiality reported greater willingness to disclose sensitive information (eg, sexuality, substance use, and mental health) (47 versus 39 percent) and to seek future health care (67 versus 53 percent) than those in the group where confidentiality was not mentioned.

Concerns about confidentiality also may affect the health care-seeking behavior of older adolescents and young adults. In a cross-sectional study, 19- to 25-year-old women who were commercially insured through a parent were less likely to receive reproductive health services and chlamydia testing (if sexually active) than those with other types of insurance [15].

This information notwithstanding, many health care providers do not routinely discuss

confidentiality with adolescent patients [9,16]. Although most clinicians support the concept of providing confidential care to adolescents, the level of support may vary depending upon the type of service provided and provider comfort [2,17].

CONFIDENTIALITY

Overview — Confidentiality refers to the "privileged and private nature of information provided during the health care transaction" [6]. It should be discussed with the patient and his or her parents or legal guardian at the initial adolescent visit (table 1) [2,7,18]. It is important to discuss both what will not be divulged by the provider and what must be divulged by the provider (eg, "conditional" versus "unconditional" confidentiality, defined below) [3].

Although it is important for clinicians to respect their adolescent patients' privacy and the confidentiality of their patients' information, it is also important to encourage the adolescent, when appropriate, to talk with his or her parents about these personal and sensitive issues that affect health even if doing so may be uncomfortable [3,6,7,19]. Parental support can help to ensure that the adolescent's health needs are met [20]. In some cases, even partial transparency, if that is all the adolescent allows, can be of benefit; for example, it is helpful for a parent to know if a patient is being given contraception, even if the exact reason for the contraception (contraception versus menstrual control or dysmenorrhea) is not disclosed. A plan for how to discuss the issue with a parent should be developed with the adolescent, in case the parent presses for further details.

The trust that develops between the provider and adolescent patient surrounding issues of confidentiality can improve adolescent health care and help adolescents view the health care system as a place to which they can go for help throughout their lives. In providing confidential care, it is important to balance the needs of the patient, parents, and provider [3]. Providers who are uncomfortable providing confidential care to competent adolescents may choose to refer the adolescent to another provider where confidential services are offered [19,21].

Some state laws give clinicians the option to inform parents their child is seeking services related to sexual health care, substance abuse, or mental health care. In these states, the decision of informing the parents is left to the clinician's discretion and what he or she

considers to be in the best interest of the minor or necessary for the minor's health [22]. The discretion may be limited to situations in which disclosure either is necessary to protect the health of the adolescent or will not harm the adolescent. In some cases, family involvement may be essential to the treatment [18,23]. As an example, if an adolescent has not come to critical follow-up appointments pertaining to a confidential health issue, a provider may decide that family involvement is an important tool needed to protect the adolescent's health.

The decision to violate confidentiality and disclose information should be undertaken after careful consideration and with the intent of beneficence. If the clinician intends to disclose information, he or she should discuss the reasons for disclosure with the patient and allow the patient to participate in the decision of to whom and in what manner the information should be told [19].

In other cases (eg, seriously dysfunctional parent-child relationships), parental involvement is potentially harmful to the adolescent (eg, places them at risk for being forced out of the home, being forced into unwanted marriage, or physical abuse) [19]. These situations highlight the importance of confidentiality pertaining to adolescent health care. (See "Consent in adolescent health care", section on 'Consent for specific services'.)

Conditional versus unconditional — We recommend that clinicians who care for adolescent patients discuss confidentiality with the patient and his or her parents or guardians at the beginning of the adolescent-provider relationship, explicitly defining the circumstances under which confidentiality is "conditional" or must be broken. Provision of such "conditional" confidentiality is recommended by professional organizations and protected by law [6,24]. (See 'Exceptions to confidentiality' below.)

With conditional confidentiality, the clinician assures the patient that everything that is discussed will be kept private except when disclosure is required by law, such as in situations of abuse, suicidal ideation, or homicidal ideation; the patient also must be informed that certain sexually transmitted infections are reportable to public health departments. In addition, many providers add that behaviors representing a serious threat to patient safety may warrant disclosure to parents. As an example, if a patient is drinking a large quantity of alcohol before driving a car on a regular basis and the patient and/or provider determine that immediate change is not possible, this would be a serious

threat to both patient safety and the safety of others for which parental help might be enlisted. It is critical to present the conditions in a way that assure the patient that safety and concern are the driving forces, not control and punishment. The following is an example of how to convey conditional confidentiality:

"I want you to understand that when we talk about things that have to do with sex and drugs and your feelings, it is confidential. This means that what we talk about is just between you and me and that other people, including your parents, will not find out about it unless you want them to know. One exception to this is if I am concerned someone has abused or hurt you. Another exception is if I am concerned you are at serious risk of harm or are planning to or behaving as though you may hurt yourself or someone else. In these situations, I would have to talk to other adults, but I would talk to you first so we could figure out whom we should talk to and the best way to handle it" [11].

Some clinicians who discuss confidentiality with their adolescent patients promise "unconditional," rather than "conditional," confidentiality [16]. A promise of unconditional confidentiality implies that everything that is discussed will be kept private from the parents or anyone else unless the patient wants them to know.

Although it may not be their intention, clinicians may convey a promise of unconditional confidentiality by not being explicit about the conditions under which confidentiality may be broken; unconditional confidentiality is conveyed in the following example:

"I want you to understand that when we talk about things that have to do with sex and drugs and your feelings, it is confidential. This means that what we talk about is just between you and me and that other people, including your parents, will not find out about it unless you want them to know" [11].

A promise of unconditional confidentiality is not in accordance with the guidelines set forth by professional organizations, which recommend discussion of conditional confidentiality with the teen and his or her parents. In addition, "unconditional" confidentiality is outside the legal boundaries of confidentiality protection [6,24].

Nonetheless, statements assuring conditional confidentiality may affect the adolescent's willingness to return for future health care. In the survey described above, in which high school students were randomly assigned to listen to an audiotape of a clinician assuring unconditional confidentiality, conditional confidentiality, or not mentioning confidentiality,

those who heard the tape assuring unconditional confidentiality reported greater willingness to return for a future visit than those who heard the tape assuring conditional confidentiality (72 versus 62 percent) [11].

One explanation for this finding is that adolescents are unable to distinguish between the confidentiality granted to routine health issues that can be managed solely by the clinician and that granted to serious issues that require outside assistance for management (eg, abuse, suicide) [11]; therefore, any mention of "exceptions" to confidentiality causes the teen to worry that his or her confidentiality will be violated unnecessarily [11]. The provider who understands this can help assuage unnecessary fears by providing a clear explanation of the conditions under which confidentiality will need to be breached.

Public health perspective — In general, confidentiality protects the individual patient. From the public health perspective, however, some confidentiality laws that restrict access to data – especially population-based data, such as immunization registries and other large databases – may impede research efforts and gains. These laws pertain even when data are deidentified within the database. Thus, a huge epidemiologic resource is lost based solely on the implementation and enforcement of laws that were instituted to protect the very individuals who could benefit from the research conducted on the data. As we move forward with the development of these substantial and valuable databases made possible by the electronic age, the public health community must advocate for a change in the confidentiality policies pertaining to the deidentified data in order to allow for effective public health research [25].

EXCEPTIONS TO CONFIDENTIALITY

Within the context of the provider-patient relationship, it is critical that the clinician explain the legal, clinical, and ethical limits of confidentiality [20]. If a parent or other adult is involved in the treatment of an adolescent patient, he or she should be included in this discussion. (See 'Conditional versus unconditional' above.)

In addition to state laws that require reporting of certain events or conditions (eg, child abuse, knife or gunshot wounds, sexually transmitted infections [STIs]), confidentiality may be violated by laws that grant parents explicit access to the minors' complete medical records [3]. (See 'Potential threats to confidentiality' below.) [20].

Child abuse/neglect — Clinicians must report known or suspected emotional, sexual, or physical abuse or neglect of a child to appropriate authorities, usually child protective services. Irrefutable proof is not necessary to trigger the reporting requirement, only suspicion. The minor should not be allowed to leave with or return to the parent or guardian if the parent or guardian is suspected of perpetrating the abuse. (See "Evaluation of sexual abuse in children and adolescents" and "Management and sequelae of sexual abuse in children and adolescents" and "Physical child abuse: Diagnostic evaluation and management" and "Child neglect: Evaluation and management".)

Consensual sexual activity — State requirements for reporting sexual abuse and sexual activity vary. Every state has laws that require the reporting of sexual abuse and laws that specify when sexual activity of an adult with a minor or between minors is illegal, (sometimes called "statutory rape") [26,27]. Depending upon the state, consensual sexual activity between two 17-years-olds, two 13-year-olds, or a 14-year-old and a 17-year-old may or may not be considered illegal and may or may not be reportable as child abuse [27].

The laws vary widely in terms of whether consensual sexual activity involving a minor is considered child abuse [26,28]. Many state laws consider sexual activity between an adult and a minor to be abuse. These laws assume that all sexual activities involving individuals younger than a certain age are by definition coercive, even if both parties consider the activity to be voluntary [27]. In such states, parents can be reported for abuse or neglect if they are aware of their minor's consensual sexual relationship and assist him or her in obtaining reproductive health care [26]. However, not all states have adopted this interpretation [29].

The statutes for consensual intercourse typically incorporate the ages of, or difference in age between, the patient and his or her partner(s) and whether the older person is in a position of authority; they also may include specific types of sexual behavior (fondling versus oral-genital contact versus anal or vaginal penetration) and, in some states, sex of the partner (eg, Texas law) [27,28].

The requirement to report consensual sexual activity involving minors or "statutory rape" depends upon the state's definition of child abuse; statutory rape is not always a reportable offense. In approximately one-third of states, reporting is mandated only if the sexual activity involving the minor or "statutory rape" was committed or allowed by a

person responsible for the care of the child [27]. In the remaining two-thirds of states, reporting mandates are independent of the relationship between the involved parties. The guidelines for the reporting of sexual activity involving minors or "statutory rape" in individual states are usually found in the section of criminal code dedicated to child abuse [27].

It is the view of the American Academy of Family Physicians, American Academy of Pediatrics, American College of Obstetricians and Gynecologists, and the Society for Adolescent Health and Medicine that sexual activity is not synonymous with sexual abuse, that access to confidential health care is essential for adolescents, and that the vast majority of reportable cases of sexual abuse and sexual coercion can be identified through careful clinical assessment [26]. (See "Evaluation of sexual abuse in children and adolescents".)

Factors to be considered in this assessment include:

- Whether the adolescent is in a sexual relationship with a family member, person of authority, or member of the clergy
- The adolescent's ability to comprehend, make informed decisions about, or consent to sexual activity (eg, whether he or she was/is incapacitated by mental illness, intellectual disability [mental retardation], drugs, alcohol)
- Whether the sexual relationship involves violence or coercion
- The age of the adolescent and the degree to which he or she understands the consequences and responsibilities of sexual activity

Nonetheless, health care providers have a legal duty to report cases of sexual abuse to the proper authority in accordance with the laws of their state [26,28]. This legal duty may be in conflict with their ethical obligation to maintain their patient's confidentiality and/or their ability to exercise sound medical judgment [26,28].

Suicidal ideation or attempt — When an adolescent is at risk for harming himself or herself, confidentiality must be breached in deference to the safety of the patient [30]. When a patient reports suicidal ideation, particularly if he or she has a history of suicide attempt, it is critical to keep him or her safe until the suicidal state diminishes or abates. This usually involves working with the family or other supportive individuals who can

address safety concerns (eg, remove access to means) and are willing to stay with the child or adolescent at all times. Immediate psychiatric evaluation (through the emergency department or psychiatry crisis clinic) and/or hospitalization may be warranted [30,31]. (See "Suicidal ideation and behavior in children and adolescents: Evaluation and management".)

In such circumstances, the clinician should discuss the need to violate confidentiality with the patient. The discussion should include formulation of a plan regarding whom should be told and how the disclosure should be made.

Homicidal ideation — Approximately one-half of states have statutes that require mental health care providers to disclose a patient's intent to do harm by warning the victim [32]. These laws are based upon a California Supreme Court decision in a case in which a patient told his psychotherapist that he intended to kill a woman and subsequently killed her (Tarasoff versus the Regents of the University of California) [33]. The California Supreme Court determined that when a therapist determines (or should have determined based upon the standards of the profession) that a patient poses a serious danger of violence to an identified victim, the therapist has a duty to use reasonable care to protect the intended victim.

Many primary care providers feel the same duty to report patient homicidal ideation. In one case where a primary health clinician warned a third party of possible danger, he was sued by his patient but not held liable because the courts thought he had a "legal duty" to inform the potential victim [32].

Violent injuries — In most states, regardless of patient age, clinicians are required to report all gunshot wounds and wounds inflicted by stabbing if the wound appears to have been caused by a criminal act [34].

Sexually transmitted infections — STIs must be reported to public health departments since they are communicable diseases. State law specifies which STIs are reportable. Follow-up of these reports is done confidentially [20]. In some states, the finding of an STI or pregnancy in a minor patient requires documented screening for sexual abuse.

Mental health care — Mental health care providers have long been mandated to break confidentiality in instances in which there is threatened harm to self or others [35]. (See 'Suicidal ideation or attempt' above and 'Homicidal ideation' above.)

In addition, pediatric care providers may feel ethically obligated to break confidence and inform parents about an adolescent's risky behavior if the behavior would result in injurious outcomes. Although most adolescents engage in some risky and/or compromising behavior, the provider must use his or her professional judgment to determine at what point the frequency and/or duration of the behavior is a threat to the safety of the patient or to others [36]. Although lawsuits based on either disclosure of an adolescent's confidential information or failure to disclose are infrequent, when the outcome involves serious harm a lawsuit could occur; such a case may be based on a variety of state or federal law claims, depending on the specific circumstances.

Parental notification — In some states, parental notification is mandatory when a minor patient consents to certain health services (typically abortion); in others, it is permitted when it is determined by the clinician to be in the best interest of the patient; and in still others, it is not acceptable to betray confidentiality without a good cause. When parental notification is going to occur, the adolescent should be informed that parental notification is going to occur and why it is necessary [19]. He or she should participate in the decision of to whom and in what manner the information should be told.

The adolescent's perception of parental notification for prescription contraception was evaluated in a national survey of 1526 female adolescents attending family planning clinics [10]. Among the adolescents surveyed, 60 percent reported their parent or guardian knew they were seeking reproductive health care, and 59 percent reported they would continue to use prescription contraception even if their parent or guardian were notified. Others would use nonprescription contraception or go to a private clinician. Only 1 percent reported they would stop having sex as a response to parental notification.

POTENTIAL THREATS TO CONFIDENTIALITY

Medical records — The physical (or electronic) medical record belongs to the clinician, practice, or institution that is responsible for maintaining it, not to the parent. Nonetheless, the confidentiality of adolescent patients may be inadvertently breached through documentation of their health care visits. Many health care providers do not distinguish between information that is confidential – either based upon legal protections or ethical principles – and nonconfidential information when they document (ie, they may document confidential health behaviors on the same page as the physical examination

without specifying that such information is confidential) [2]. When parents request copies of the medical record (eg, for transfer to a new provider or referral to a specialist), they generally receive the entire medical record [37].

State law may determine what type of information can be considered confidential. It may be helpful to consult mental health statutes as well as consent for treatment laws to determine what type of information recorded by specific providers may be considered mental health notes and therefore qualify for additional protections.

One way that providers can avoid this scenario is to transfer records directly to the new provider or referral source rather than to the parent [2]. Another is for the provider to distinguish between confidential and nonconfidential information, which makes it easier to redact the confidential portions before the medical record is released to the parent.

The ability to redact information and to segregate confidential from other information in a medical chart depends upon the policies of a particular institution or practice setting as well as state laws.

Some states now have laws allowing parents the right to see all medical records unless otherwise indicated by law. One way to manage these "Parent Bill of Rights" statutes is to offer the parent a waiver to this right to obtain areas of the record noted to be confidential in the "consent to treat" form presented at the initial visit. Excerpts from the form used at the Oklahoma University Children's Physicians Adolescent Medicine Clinic are provided as a sample (table 2).

HIPAA — The health privacy regulations (sometimes referred to as the Health Insurance Portability and Accountability [HIPAA] Privacy Rule) issued under the HIPAA Act of 1996, which took effect in 2002, provide important protection for minors. Under HIPAA, adolescents who are legal adults (18 years and older) and minors who are emancipated or who are considered "individuals" under the regulation can exercise the same rights as other "individuals," such as access to their medical records, the ability to obtain copies and to request corrections, and the right to authorize disclosure of protected health information. (See "Consent in adolescent health care", section on 'Emancipated minor'.)

Minors who are not emancipated have a "personal representative," usually their parent or guardian, who has the right to make health care decisions for them, and that personal representative has access to their personal health information or records. However, when

a minor is considered an individual under the rule, the parent is not automatically the personal representative of the minor. A minor is considered an "individual" in three specific situations:

- When the minor has the right to consent to health care (eg, for treatment of a sexually transmitted infection [STI], request for birth control, treatment for substance abuse) and does consent (see "Consent in adolescent health care")
- When the minor may legally receive care without parental consent and the minor or a third party, such as a court, can consent to the care (eg, when a minor goes through a judicial bypass proceeding to obtain an abortion without parental involvement) (see "Consent in adolescent health care", section on 'Judicial bypass')
- When a parent is in agreement with a statement of confidentiality between the health care provider and the minor, which should be formally documented in the patient's records (figure 1)

In the above situations, the parent is not a personal representative and does not automatically have access to the minor's records and personal health information. With respect to anyone other than a parent, the minor has the same rights with respect to his or her records as any other adult individual. With respect to the question of whether parents have access to the information, the rule defers to "state or other applicable law" [38].

Disclosure of information to parents when the minor is considered an "individual" under the rule is deferred to other applicable federal or state laws or, in some cases, to the judgment of the provider. If state or other law explicitly requires information to be disclosed to the parent, the provider must do so. If state or other law prohibits disclosure of information to parents without the permission of the minor, the provider must honor that. If a state or other law permits, but does not explicitly require, the disclosure of information, the provider must use his or her own judgment in determining whether disclosure is in the best interest of the patient. If there is no state or other law regarding disclosure, it is again up to the discretion of the provider whether disclosure is appropriate [38].

Under the HIPAA privacy regulations, a minor acting as an "individual" may request that providers and health care plans communicate with him or her in a confidential manner

(eg, email or personal cell phone). He or she also can request that the information disclosed for treatment, payment, or other services be limited [38]. The HIPAA rule specifies the circumstances under which health care providers and health insurance plans are required to honor such requests. Unfortunately, this request may not always be honored, sometimes because it falls outside the legally required circumstances, sometimes because of oversight, and sometimes because the provider or third-party payer is unaware of this legal provision and has not set up procedures for honoring it.

FERPA — The Family Educational Rights and Privacy Act (FERPA) allows parents access to their unemancipated minor's educational records. If these records contain any health information, that information is also accessible by the parents. However, if the health records are kept separately as part of a school-based health center, where confidentiality has been addressed, these records cannot be accessed as part of FERPA. Instead, they would be covered by HIPAA and the parents may or may not have access, depending upon the state laws governing the minor's ability to consent to health care and the confidentiality of information and records pertaining to that care [38]. (See 'HIPAA' above.)

Electronic records — The electronic medical record is another potential area where the confidentiality of an adolescent patient could be breached [39,40]. The records for a particular visit should be accessible only by those who need to know the details [41].

Each state has its own laws regarding the confidential treatment of adolescents. When choosing an electronic medical record system, it is important to consider whether the system complies with or can be adapted to comply with the requirements of the state and individual practice regarding confidentiality [42,43]. This is particularly true when documenting sexual health, mental health, and behavioral issues. Some systems address this issue by restricting access to visit records to the "authoring" department, avoiding the possibility that another provider may inadvertently have access to or reveal confidential information.

Safeguards must be taken to prevent "hacking" into the electronic medical record by unauthorized individuals [44]. In addition, confidential electronic records should be reviewed by the treating provider before release to assure the preservation of patient confidentiality when appropriate.

Patient portals — Patient portals, which parents and patients use to access information regarding scheduling and laboratory test results through electronic medical

records systems, pose another potential risk to confidential care.

Some institutions have addressed this concern by blocking portal access pertaining to patients of a certain age (eg, 13- to 18-year-olds) or developing forms for teens to sign granting permission to parents to access the patient portal. Neither of these options is ideal: the first provides no access to the patient portal to adolescent patients; in the second, the patient may feel pressure to provide consent for parent access when they would prefer that the parent(s) not have access. Issues pertaining to electronic medical records and patient portals as well as the maintenance of confidential care with all of its complexities continue to challenge institutional systems [45].

Payment for services — The potential for breach of confidentiality related to payment for health care services depends to some extent upon who is liable for payment and the method of payment.

Who is liable? — Treatment for which a nonemancipated minor consents is often the financial responsibility of the minor [18]. The parents may not be financially liable unless they have agreed to pay for treatment, they are involved in the treatment decision, or the minor lives at home and the treatment is considered necessary [46-48].

Emancipated minors also are typically financially responsible for the care to which they consent (whether or not it is an emergency) [47]. The parents are unlikely to be liable unless they have agreed to pay.

Method of payment

- **Private insurance** – To receive payment for services, clinicians are required to share medical information with third-party payers. The adult policy holder may choose to waive the right to confidentiality to ensure payment. If so, minor children covered by their parents' policy may be bound by the same waiver, whether they know this is the case or not [44]. Even though certain health care services can be performed without parental consent or notification, confidentiality may be breached when the bill or a detailed insurance statement is sent to the patient's parents [6,49,50].

  Confidentiality breaches associated with billing and private insurance claims affect not only adolescents who are minors but also young adults age 18 and older who are covered on their parents' health insurance [13,51]. This problem has received increasing attention because the Affordable Care Act has allowed young adults up to

age 26 to remain on parents' insurance; several states are adopting regulations or enacting statutes to address the issue [50,52,53].

To help protect the confidentiality of their minor patients, some clinics may choose to waive the fees for Papanicolaou (Pap) smears, STI testing, and pregnancy tests, resulting in decreased income for the practice. Others refer their patients to facilities that offer free or reduced-fee services, potentially causing a disruption in the continuity of care [51,53].

One other option is to set up a self-payment plan with an adolescent patient. Adolescents sometimes are willing to pay for their health care if it protects their confidentiality and they can afford to do so [49,54]. One private practice evaluated the possibility of providing adolescents with individual billing accounts to cover the charges that the adolescent wanted to keep confidential (eg, laboratory tests) [49]. Such accounts were offered to 42 patients and 40 enrolled. The adolescent's account was charged a reduced fee for laboratory services (mean charge was $42, range $10 to $120); clinician charges were billed to insurance under nonconfidential codes. The patients agreed to pay whenever and whatever they could; at the end of the first three months, 38 percent of the total charges had been reimbursed.

- **Medicaid** – If a patient is covered by Medicaid, billing is confidential and sent directly to Medicaid, and statements generally are not sent to the parents, although there may be exceptions to this in some states; clinicians should be familiar with policy and practice in their own state [53].

- **Clinics funded by the Title X Family Planning Program** – Patients who receive their care at Title X-funded clinics receive reproductive care on a confidential basis and are charged a sliding-scale fee based on the patient's – not the family's – income [20,53].

- **State-funded programs** – Requirements for state-funded reproductive health programs vary by state. Two states (Texas and Utah) prohibit a minor from receiving contraception from state-funded programs without parental notification; other states allow notification of the parents [55]. Additional state laws related to minor consent for contraceptive services are discussed separately. (See "Consent in adolescent health care", section on 'Contraceptive services'.)

- **School-based health centers** – School-based health centers usually require a general

parental consent before provision of services. Typically, the parent is presented with a list of services offered by the clinic and made aware that some, but not all, of the services may be confidential. The clinics then follow the notification guidelines provided by their state and funding source.

Parents may or may not have access to confidential information discussed during visits to school-based health centers. Most school-based health centers' information and health records are maintained separately from the educational records and are subject to HIPAA requirements, not FERPA. Unless the health records are part of the educational records, they are not provided to parents who request records under FERPA. (See 'FERPA' above.)

- **Religious-based clinics** – Religious-based clinics may not allow the prescription of hormonal medications for contraceptive use, although prescription of hormonal medications for noncontraceptive use (eg, heavy menstrual bleeding, dysmenorrhea, etc) may be permitted. In these circumstances, the patient may be using the hormonal medications for contraceptive and noncontraceptive purposes and the parent may or may not be informed or aware of the patient's sexual activity.

Ancillary staff — Even if confidentiality is assured by the clinician, it may be violated by another provider or member of the clinician's staff. Individual practices and health care sites should develop an official confidentiality policy and train all employees on its nuances [56,57]. Some clinicians create a written confidentiality agreement for the patient, parent(s), and provider to sign after discussing the confidentiality policy (figure 1).

Pharmacists — Pharmacists may refuse to fill a prescription for contraception for a minor without the consent of a parent, even if the prescription was provided confidentially and the state permits minors to consent for contraceptive services [58].

The Pharmacist Conscience Clause created by the American Pharmaceutical Association (APhA) states that the APhA "recognizes the individual pharmacist's right to exercise conscientious refusal and supports the establishment of systems to ensure patients' access to legally prescribed therapy without compromising the pharmacist's right of conscientious refusal" [59]. State laws regarding pharmacist conscience clauses and refusal to provide contraceptive services vary from state to state (see the Alan Guttmacher Institute and the National Conference of State Legislatures).

The attitudes toward and practice of pharmacists were evaluated in a survey of pharmacists in Indiana (a state in which there was no law addressing the provision of contraception to minors) [58]. The pharmacists reported that they were more likely to contact a parent or provider before dispensing contraceptives to a 14-year-old than to a 17-year-old [58]. Another survey noted that approximately 50 percent of pharmacists believed the following incorrect statements: that emergency contraception was harmful to adolescents, that oral contraceptive pills caused birth defects if taken during pregnancy, and that the repeated use of emergency contraception was associated with health risks [60].

RESOURCES

Resources related to consent and confidentiality in adolescent health care are provided below:

- The Alan Guttmacher Institute provides updated information regarding state policies for specific services, including access to emergency contraception
- The Center for Adolescent Health & the Law
- The Legal Information Institute at Cornell University Law School provides information regarding the emancipation laws in individual states
- The National Conference of State Legislatures provides information on a number of related topics, including:
  - Pharmacist conscience clauses
  - Human papillomavirus legislation

SUMMARY AND RECOMMENDATIONS

- Adolescents are more likely to seek health care if they believe their provider will keep the information discussed during the visit private. (See 'Background' above.)
- Confidentiality refers to the "privileged and private nature of information provided during the health care transaction" [6]. It should be discussed with the patient and his

or her parents or legal guardian at the initial adolescent visit. (See 'Overview' above.)

- Although it is important for clinicians to respect their adolescent patients' confidentiality, it is also important to encourage the adolescent to talk with his or her parents about issues that affect health. (See 'Overview' above.)

- Clinicians who care for adolescent patients should discuss "conditional" confidentiality with the patient and his or her caregivers, explicitly defining the circumstances under which confidentiality must be broken. (See 'Conditional versus unconditional' above.)

- Exceptions to confidentiality include mandated reporting (eg, child abuse, violent injuries, sexually transmitted infections) and mandatory parental notification. Some states also permit parental notification for specific services if the health care provider believes it is in the best interest of the patient. (See 'Exceptions to confidentiality' above.)

- Confidentiality also may be threatened by laws that grant parents explicit access to the minors' complete medical records, financial obligations, and ancillary staff. (See 'Potential threats to confidentiality' above.)

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Topic 106 Version 20.0

GRAPHICS

An adolescent office visit that supports confidentiality

In consultation with	The clinician should
Patient and parent(s) or guardian(s)	Outline structure of visit Obtain general medical and family history Discuss confidentiality
Patient	Obtain health history, including risk-taking behaviors Address patient concerns Provide health guidance Address billing issues
Parent	Address parental concerns Provide guidance about adolescent development
Patient*	Perform physical examination, as indicated
Patient	Summarize findings and recommendations Determine parental involvement Determine method of notification of laboratory results
Patient and parent(s) or guardian(s)	Summarize findings and recommendations, as appropriate Address billing issues

* Parent may be present at patient's discretion. Some states require parental permission to examine the patient alone.

Graphic 70738 Version 5.0

Sample of a consent to treat an adolescent patient that includes a limited waiver of parental rights

Oklahoma University (OU) adolescent medicine consent to certain treatment of an adolescent patient and limited waiver of parental rights

Welcome to the OU Children's Physicians Adolescent Medicine Clinic!

Our goal is to treat you and your child with respect and provide thorough and complete care. Please let us know if you ever have questions, as we want you to be a participating partner in our adolescent's care. This document is meant to prepare you for your adolescent's visit so that you and your child can have the most productive visit possible. We specifically want to address expectations you may have for: 1) scope of the visit; 2) confidentiality issues; 3) discussion with patient regarding contraception.

Scope

As a clinic that treats adolescent patients, we may have policies that differ from those of your other physicians. As adolescents become adults, it is important to help them understand their own health care needs and make sure they are capable of maintaining their health independently. In order to fully evaluate your child as he/she moves towards adulthood, it may be necessary to ask him/her questions about past actions and potential exposures, current behavior, and family/friend dynamics. A physical exam may be necessary. The scope of the physical exam will be discussed with you and your child prior to the exam, so that any questions can be addressed.

Parental rights under Oklahoma law

Oklahoma law specifically confers the following rights on parents:

- The right to make health care decisions concerning their children'
- The right to provide written consent for a provider to treat the child, including, but not limited to, performing physical examination or prescribing prescription drugs, or to deny such consent; and
- The right to access and review all of their children's medical records.

Confidentiality of medical records

Studies have shown that adolescents are more likely to share important health information with providers if the adolescents are offered qualified confidentiality. Qualified confidentiality means that as providers, we will ask to have private time (without the parent present) with the child, and we will ask that the parent agree in writing that the child's confidentiality should be broken only if we have reason to believe that the child is at significant risk of harm. We always encourage our minor patients to discuss with parents/guardians any and all health information that we discuss in private; however, in the event they do not feel comfortable doing so, we believe it is important to provide this opportunity for them to receive health advice from a health care provider rather than unreliable source. In the event that your child discloses information that causes the health care provider to believe your child is at significant risk for injury or death, the health care provider will disclose this information and discuss his/her concerns directly with you.

Federal and Oklahoma law allows parents/guardians to have access to all medical records of a minor, except in limited circumstances. In order to improve the health care that our adolescent patients receive, we will ask you to waive your right to access certain portions of your child's records which will be marked "confidential" and document your waiver by signing a written consent. Your agreement not to access the records pertaining to your child generated by our providers allows our providers to assure your child that the information your child shares related to their exposure to sexual activity or other risk behaviors, including but not limited to drug and alcohol use, will be maintained in confidence. Research indicates that this assurance of confidentiality improves the health care that adolescents receive. *By signing the Limited Waiver of Parental Rights and Consent to Certain Treatment of Adolescent Patient below, you agree that you will not request access to or copies of your child's confidential health information that is designated in a special section of the medical record as "confidential."*

As providers, we value the independent health information provided by parents regarding their children's health. Whenever possible, we prefer that such conversations regarding the child take place with the child present. If that is not possible, we are happy to discuss your child with you separately with the understanding that we will not tell you

information that the child has told us in confidence.

Contraception discussions

The state of Oklahoma has one of the highest pregnancy rates in the country. In an effort to decrease rates of unplanned pregnancies, this clinic provides information regarding preventative contraception as well as medically appropriate hormonal contraception to adolescent patients. It is our normal practice to encourage adolescent patients to discuss decisions regarding contraceptive methods with their parents/guardians. We routinely offer to make ourselves available to help a patient initiate such a discussion with a parent, if the patient or parent requests. However, in the event a patient feels uncomfortable discussing this issue with parents/guardians, we would like to be able to protect the patient against experiencing an unplanned pregnancy or sexually transmitted disease. The risks of all hormonal methods of contraception are significantly less than the health risks of pregnancy. *By signing the Limited Waiver of Parental Rights and Consent to Certain Treatment of Adolescent Patient below, you consent to allowing your child to receive information about contraception as well as being provided with hormonal contraception to prevent unplanned pregnancy or to treat other medical conditions, if the patient desires such therapy and the provider determines the therapy is medically appropriate. The provider will advise the patient how to take the medication, the risks and benefits associated with taking the medication, and the potential risks associated with not taking the medication as prescribed.*

Limited Waiver of Parental Rights and Consent to Certain Treatment of Adolescent Patient

Limited waiver of parental rights to access medical records related to risk behaviors, including, but not limited to, the prevention of communicable diseases, contraception, sexual activity, and drug/alcohol use

As the parent or legal guardian of _____, a minor, I understand that I have the legal right to access and review all medical records of my child unless otherwise prohibited or provided by law or unless I am the subject of an investigation of a crime committed against my child. ____ *(initial here)*.

I agree that it is in the best interest of my child to have the opportunity to maintain communications with his/her health care providers within the OU Physicians Adolescent Medicine Clinic in confidence. I agree that my child's physician may deem certain medical records related to risk behaviors, including, but not limited to, prevention of communicable diseases, contraception, sexual activity, and drug/alcohol use, to be confidential and agree that those records shall be marked "confidential" within the medical record. I understand that I will not be able to access or request a copy of the confidential medical records without a court order. ____ *(initial here)*.

Consent to physical examination and discussion outside the parent's presence

I understand that I have the legal right to make health care decisions for my child. I further understand that I have the legal right to consent in writing (or to refuse to consent) to any physical examination, procedure, or prescription drug prescribed for my child. ____ *(initial here)*.

I consent to my child's provider having discussions regarding risk behaviors, including but not limited to prevention of communicable diseases, contraception, sexual activity, and drug/alcohol use with my child outside of my presence so that frank and open health care advice regarding these issues can occur between the provider and my child. ____ *(initial here)*.

I consent to my child receiving a physical examination outside of my presence if the provider determines that it is medically indicated for the purposes of evaluating or diagnosing risk behaviors, including but not limited to the prevention of communicable diseases, contraception, sexual activity and drug/alcohol use. ____ *(initial here)*.

Consent to treatment

I understand that at any time upon request, I am entitled to receive a copy of the risks and benefits associated with hormonal birth control, the proper dosage and administration of the medication, and the risks of my child failing to properly take the medication. I consent to my child being provided information about hormonal contraception and receiving hormonal contraception if indicated by the provider. ____ *(initial here)*.

Revocation

I understand I may revoke elements of this Limited Waiver and Consent at any time by notifying staff of the Adolescent Medicine Clinic in writing. I understand any records of treatment or discussions that have already been documented in the medical record as "confidential" will remain confidential, and that this revocation will affect only treatment and discussion from the time of my notification forward.

Signed: _____	Date: _____
Witnessed: _____	Date: _____
Form created 5/18/16	

Graphic 109404 Version 2.0

Confidentiality agreement for adolescent health care

Confidential Agreement

Parent

I, _____(parent or guardian), allow my daughter, _____ (patient), to enter a confidential patient-physician relationship. I understand that my daughter can make independent health care decisions, but that my input and involvement will be encouraged.

My daughter has permission to schedule appointments and receive confidential reports from this office. I further understand that various laboratory tests may be necessary in medical protocols and accept responsibility for physician charges and laboratory fees.

_____ _____

Parent or Guardian Physician

Patient

I, _____(patient), am entering a confidential physician-patient relationship with _____(physician). I will make an effort to communicate with my parent(s) about issues concerning my health. I accept the personal responsibility of being honest and will follow the health care recommendations my physician and I establish.

_____ _____

Patient Physician

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