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ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

Adolescent Confidentiality and Women's Health: History, Rationale, and Current Threats

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Key points:

- Consent and confidentiality are core components of adolescent health care
- Legal and ethical precedents support autonomous adolescent decision-making
- Nurses must understand complex confidentiality and mandatory reporting regulations in their setting
- EMR and billing systems can improve or compromise confidentiality, and nurses should be aware of their own system's capabilities and safeguards
- Title X funding may be the only source of confidential reproductive care in some states

Synopsis:

Adolescent access to reproductive health services, mental health services and treatment for drug and alcohol use depends on the teen's rights to consent and confidentiality in the State in which they live. This article reviews the history, current practices and potential challenges to confidentiality, including Title X funding, questions about brain development and ability to make autonomous choices, and meaningful use practices in electronic records. Resources are provided for professional position statements and individual state regulations.

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

The adolescent's access to confidentiality, or privacy, in reproductive care, and her ability to consent, or make autonomous decisions, about reproductive care and related emotional issues, are core issues in her overall access to preventive care. This article will review current statistics related to sexual activity and other adolescent risk issues, and review the legal and ethical background to adolescent consent and confidentiality. Recent advances in neuroscience, electronic health records and funding streams for reproductive care that improve or impede confidential access to care will be reviewed, with recommendations for nurses working with adolescents.

Adolescent Risk Behaviors

The National Youth Risk Behavior Surveillance System includes data from national, state, tribal and large urban school district surveys of high school students conducted in the spring of odd-numbered years.¹ In the 2015 survey, the latest from which data are available, over 29% of youth surveyed stated that they had felt so sad or hopeless during the 12 months before the survey that they had stopped some of their usual activities, with 17.7% seriously considering suicide.² Over 63% of high school students had had at least one drink of alcohol, and by 12th grade, 42.1% of students had drunk alcohol within the past 30 days. Over 41% of high school students reported having had sexual intercourse, and by 12th grade, 58.1% of 12th graders over all and 57.2% of 12th grade females had had sex,² 46.5% within the past three months. Use of alcohol, tobacco, and most drugs except for marijuana have decreased over time, following trends since 1991. Sexual activity has also slowly decreased over time, while the use of condoms and all forms of birth control have increased.² The prevalence of youth with at least one

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

symptom of depression (29%) is concerning in the context of confidential care, as depression is linked to increased risk of unintended pregnancy in adolescents.³

Teen pregnancy is associated with lower educational attainments: almost a third of adolescent women who drop out of high school give pregnancy or parenting as a reason, and only 40% of adolescent mothers finish high school.⁴ Adolescent pregnancy rates have been declining steadily since 1991 and were at their lowest point in 2016, at 20.3 births per 100 females, compared with 61.8 births per 1000 in 1991.^{5 6} An analysis of data from the National Survey of Family Growth showed that rates of sexual activity remained stable among teens between 2007 and 2012, and that declining pregnancy risk during this time was attributable to increased use of contraceptives.⁷

However, rates of sexually transmitted infections (STIs) are at an all time high in the United States (US), with the highest rates of chlamydia and gonorrhea in the 15-24 year old age group. (CDC, 2016) Although syphilis rates are higher in young and older adults than in adolescents, they increased by 13% in adolescents in the past two years⁸. These statistics support both the success of and the need for greater access to services.

State standards for confidentiality

In general, the ability of adolescents to consent to a broad range of reproductive, mental health and drug and alcohol services has increased over the past 30 years.⁹ However, the only area of consent on which all 50 states and the District of Columbia agree is in the diagnosis and treatment of sexually transmitted infections (STIs). Even in this area, 18 states allow the provider to notify the parents if the provider believes it is in the adolescent's best interest. In contrast, 26 states and the District of Columbia allow all minors age 12 and up to consent for contraception, while 20 other states place restrictions, such as marriage, presence of a health

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

condition, or determination of maturity.⁹ For example, New York State allows all minors 12 and up to consent to contraception, STI services, prenatal care, adoption, medical care for their own child, and has no policy on abortion consent. Ohio has no policy on contraception, prenatal care or medical care for a minor's own child, allows minor consent for STI services and adoption, and requires parental consent for abortion (See Table 1 for more information).

Confidential services and parental notification

In a small survey of parents attending an adolescent clinic with their teens, parents could identify benefits of confidentiality, yet they also wanted to be informed about a wide range of topics, including depression, drug use and sexual activity, even if their teen did not want them to know.¹⁰ A retrospective study of primary care adolescent visits found that providers addressed more issues with teens, including not only sexual health and risk behaviors, but also nutrition, diet and exercise, if their parents were not in the room with the teen and provider for at least part of the visit, compared to visits where parents were present the entire time.¹¹ In this study, only half of adolescents and 30% of parents reported that the teen spent time alone with a provider during their last visit.¹¹

Multiple studies have highlighted the potential or actual change in utilization of confidential services when parental notification or consent is required. Reddy¹² surveyed 814 teens at Planned Parenthood clinics and found that 59% would stop using sexual health services, including STI testing if parents were informed that they were seeking contraceptives. However, only 1% of teens stated that they would stop having sexual intercourse.¹² When Texas instituted parental notification for minors seeking abortions, the overall abortion rate of 15- to 17-year olds declined 11 to 20%, but both the second trimester abortion and birth rates increased.¹³ Minors seeking abortions in Illinois who were questioned about a blocked parental notification law had

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

generally negative views about this law, feeling that the law would result in decreased access.¹⁴ Recently, health economists compared YRBSS results in states with and without parental notification, and found no change in sexual activity rates in states with parental notification, but found that teens in those states were using more contraception than teens in states without required parental notification of family planning.¹⁵ Since the YRBSS is based on self-report to a multiple-choice questionnaire, it is unclear if those teens were accessing Title X funded clinics, which are exempt from State parental consent or notification laws (see below).

Public funding and confidentiality: Title X

The need for publicly funded contraceptive care has been growing since 2000, due to increased numbers of women in poverty.¹⁶ Public funding for contraception and related health care has been available through Title X of the Public Health Act since 1970.¹⁷ Women who earn up to 250% of the poverty line and all women under 20 are eligible for publicly funded contraception. The age specification is due to an assumption that young women under 20 would not be able to access their parents' insurance due to confidentiality concerns.¹⁶ An estimated 1.1 million teens received contraceptive services at publicly funded clinics in 2013, and without these clinics, the estimated unintended pregnancy rate would have been 42% higher; without Title X clinics alone, the rate would have been 30% higher.¹⁶

When Title X of the Public Health Act was enacted, confidentiality and dignity were central to these regulations for all women, and were made specifically available to all adolescents age 19 and younger in 1978.¹⁸ Although family participation in the care of adolescents is encouraged, consistent court decisions, in response to State or Federal rulings since that time, have stated that adolescents must have access to Title X services without parental consent, even if parental consent is otherwise required by State law. The one exception to confidentiality protections, under Title X, is the mandated reporting of child abuse.¹⁸ Medicaid also protects the

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

confidentiality of sexually active minors. The Health Insurance Portability and Accountability Act (HIPAA) recognizes that minors who can consent to confidential services have privacy rights to their confidential health records. Although HIPAA defers to state regulations, minors in states with parental consent or notification still have privacy rights to records for Title X services.¹⁸ There have been attempts to place restrictions on which clinics can receive Title X funding, however regulations in the past stated that clinics could only be prohibited from receiving this funding if they were unable to care for eligible patients.¹⁷ Recently, regulations passed under the current administration have overturned this ruling.¹⁷ As of this writing, it is unclear if Title X will be maintained at its current funding or if funding levels in the FY 2018 budget will be reduced or eliminated,¹⁷ limiting or possibly eliminating confidential sources of reproductive health for adolescents in the 20 states that require parental consent.⁹

Professional organizations and confidentiality

The World Health Organization,¹⁹ the United Nations Children's Fund,²⁰ the American Academy of Pediatrics,²¹ the Association of Women's Health, Obstetric and Neonatal Nurses,²² and the Society for Adolescent Health and Medicine,²³ all have policies supporting adolescent confidential access to reproductive health services (See Table 2). In addition, *Bright Futures*,²⁴ published by the American Academy of Pediatrics, with partial support from the US Department of Health and Human Services and input from nursing, sets guidelines for pediatric and adolescent services. The fourth and current edition of *Bright Futures* recommends that pediatric practices develop formal confidentiality policies, which are explained to parents and children by ages 7 to 8, and that starting before or at the 12-year-old well child visit, early adolescents should have dedicated time with their pediatric provider, without their parent in the room. *Bright Futures* also recommends discussions about sexual attraction, advantages of delaying sexual

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

activity, contraception, STI prevention and screening, and specific care for youth are lesbian, gay, bisexual, transgender, questioning or gender nonconforming.²⁴

Legal and ethical issues underpinning adolescent confidentiality

Until the 20th century, children in the U. S. were considered to be “chattels” of their parents, without independent rights.²⁵ The concept of a mature minor, able to understand and consent to some medical procedures, evolved in the 1970s and 1980s: in 1967 the Supreme court recognized that the due process clause of the 14th Amendment to the Constitution applied to children as well,²⁶ and by the late 1970s, several Supreme court rulings acknowledged a right to privacy for adolescent consent to contraception and abortion.²⁵ Court rulings generally do not specify the determinants of whether a particular minor is mature enough to consent, although subsequent laws may specify a minimum age.^{25,27} Twenty-six states allow minors to consent to general medical care if they are living apart from parents, either because of explicit law or because the state allows minors to consent to some or all medical care.^{27,28} Minors may be considered to have many rights of adulthood, or emancipation, depending on the state, if they are married, serving in the military, have gone to Court seek emancipation, or in some states by declaration of parents.²⁷ In general, the mature and emancipated minor laws are exceptions, as U.S. legal policy recognizes that human rights belong to adults, rather than children, and this legal tradition may explain some of the resistance to the United Nations Convention on the Rights of the Child,²⁰ which the U.S. has never ratified.²⁸ (See Table 2)

Nursing articles about adolescent confidential services²⁹⁻³¹ have stressed principles of biomedical ethics,³² such as autonomy, nonmaleficence, beneficence, and justice, as well as legal precedents for confidentiality.^{29,31} International policies, such as the Convention on the Rights of the Child²⁰ and the World Health Organization's policy on access to contraception,¹⁹ stress the

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

individual human rights of children and adolescents. U.S. professional organizations that have endorsed access to confidentiality also support the ability of the adolescent to exercise autonomous decision-making (See Table 1). However, with increasing research about adolescent neurologic, cognitive and emotional development and their interactions,³³ the concept of the mature minor in specific, and the adolescent's ability to make autonomous decisions in general, have come into question.

According to Beauchamp and Childress,³² autonomy, or self-rule, depends on freedom from external or internal controls, the capacity of the individual to understand the choice in question and the implications of the various options. Although they do not endorse any particular test of competency nor specify the age at which children become autonomous in decision-making, these criteria are similar to those of the MacArthur competency tests, discussed below. These ethicists also stress a real-life, rather than ideal definition, noting that individuals are rarely completely free of internal or external pressures when making decisions. They do not specifically discuss adolescent confidentiality, but they view the right to privacy, which has been the chief underpinning in US law for the right to make decisions about contraception,³⁴ as closely related to autonomous decision-making.¹

Children's competence to understand the implications and details of medical treatment have been evaluated more closely for research than clinical practice.³⁵ The MacCAT-CR³⁶ and the MacCAT-CT³⁷, developed for adults, test four domains of decision-making competence: comprehension of information about research, reasoning ability to decide on participation with an understanding of the available alternatives, appreciation of the effects of a particular treatment, and ability to express a choice about participating. Hein and colleagues tested 161 children who were eligible for clinical research and found the MacCAT-CR, a semi-structured

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

questionnaire, to be an adequate measure, with the four domains taken as an aggregate.³⁸ In general, children of 11.2 years and up were generally judged to be competent to make decisions, while children of 9.6 years or less were not judged to be competent, with varying results between those ages.³⁸ Other researchers have shown that scores on the MacCAT-CR are higher in adolescents from more affluent backgrounds and higher degrees of health literacy.³⁹

In recent literature about adolescent decision-making ability, there have been two schools of thought:⁴⁰ those who would promote the autonomy of the child by lowering age of consent, and those who advocate for a more conservative approach to consent, in order to protect the child. Although cognitive processes and cognitive tests, such as the MacArthur tests noted above, indicate that children have the capacity to make research and some medical decisions at age 12, emerging knowledge about the developing adolescent brain suggests that decisions are more influenced by emotional states than had previously been acknowledged.⁴¹ Specifically, the prefrontal cortex is a less developed control system, and the ventral striatum, or reward system is less sensitive to small rewards in adolescents than in adults. Piker and others^{40 41} suggest that “hot” decisions, those that are emotionally laden or driven by time pressure, would benefit from more adult support, while “cold” decisions, those with less emotional charge, fewer long-term consequences and less time pressure, may need less adult support. This literature addresses research and treatment for chronic conditions, areas in which parental consent has traditionally been sought, and don't specifically address confidential care, where the “mature minor” doctrine has typically been applied.^{33,42}

However, some authors are applying advances in developmental neuroscience to the area of confidential care and questioning the mature minor's capacity to consent.^{43,44} At the same time that adolescent medicine specialists continue to advocate for confidential care, they acknowledge

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

the implications of this research,³³ suggesting variable decision-making abilities between the ages of 12 to 15. Still others, recognizing that early initiation of sexual activity is connected to adverse childhood experiences, and may itself be coerced or exploitative,⁴⁵ advocate for confidential services as a way to connect vulnerable early adolescents with supportive and protective care.⁴⁶ Nurses and other health care practitioners can maximize the decision-making capabilities of adolescents by making sure to give a full explanation of the alternative choices, and exploring any possible coercion.³³

Confidentiality and Mandatory reporting

Women's health practitioners working with adolescents must be cognizant of several overlapping regulations: Title X regulations, if they are working in a setting which receives Federal Title X funding, state mandatory child abuse reporting regulations, and as part of these regulations, laws that may mandate reporting of consensual acts between disparate age minors or between minors and adults.^{47,48} All 50 states have laws that mandate child abuse reporting, and Federal minimum standards define child abuse as acts or failure to act by a parent or caretaker that result in "death, serious physical or emotional harm, sexual abuse, exploitation, or an imminent risk of serious harm."⁴⁹ States vary in their definitions of whether to report a reasonable suspicion that child abuse has occurred, versus a suspicion that a child is at risk for abuse⁴⁹ (See Table 1).

There is also a great deal of variability in specifics of sexual abuse reporting,⁴⁹ and the most controversial parts of these laws for nurses working in women's health are the State child abuse laws that mandate the reporting of statutory rape, or the consensual relationships between disparate age minors or between minors and adults.⁵⁰⁻⁵² Many of these laws were revised starting in the 1990s, with the desired impact of lowering teen pregnancy rates by prosecuting adult

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

males who were in relationships with adolescent minors.⁵³ There was also concern for protecting adolescents from coercive and abusive relationships with disparate age partners.⁵⁴ A more recent change to Federal child abuse reporting law is the inclusion of sex trafficking as child abuse⁴⁹ and the introduction of Safe Harbor laws that encourage decriminalization of sexually exploited children and referrals to child protection agencies instead.⁵⁵ Although this is an important policy change, there are two concerns with this approach:⁵⁶ first, that child welfare agencies may not be adequately resourced and oriented to protecting commercially sexually exploited children (CSEC), given that many CSEC are recruited by traffickers from the foster care system; and second, that CSEC might avoid nurses and other health care practitioners because of mandatory reporting laws (See Table 1).

Electronic Health Records and confidentiality

Electronic medical records (EHR) can help protect or inadvertently compromise the adolescent's confidential information. A survey of Federally Qualified Health Centers (FQHCs) found that although most had written policies in place to protect adolescent confidentiality, only a few had separate medical records for confidential services, and a minority had security blocks on medical records release or separate contact information in their EHR for parents and adolescents.⁵⁷ Those who also received Title X funding had more confidentiality protections in place in their records, highlighting the multiple ways in which Title X funding supports adolescent reproductive health. Under the Affordable Care Act, clinics are rewarded for showing Meaningful Use of an established government set of quality criteria in their EHRs,⁵⁸ which include screening for chlamydia, depression and substance use in adolescents. Compliance with this requirement may inadvertently release information about these confidential services in the visit summary that is given to the adolescent and/or her parent.^{59,60} Private insurance may release

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

an Explanation of Benefits (EOB) to parents about their minor and young adult children's use of confidential care; California has recently enacted legislation that allows adolescents and young adult to receive this information directly.⁶⁰ Recommendations for providers who want to ensure adolescent confidentiality in their EHR include a thorough grounding in their state and Title X confidentiality laws, an understanding of their specific EHR functionality, and careful attention to maximizing that functionality to avoid inadvertent releases of information in medical records, EOB and meaningful use documents,⁶⁰ and use of a specific adolescent portal⁵⁹ (See Table 3).

Additional Considerations and Nursing Implications

The history of health care in the US has included deceptive, unethical and coercive practices against poor and minority women and men.⁶¹ Parents whose own relationship with health care providers is marked by distrust, due to personal and historic experiences of racial discrimination,^{62,63} may be more resistant to clinician assurances that they are providing high quality care for their child and may pass this distrust to their adolescents. Immigrant families, many of whom have unauthorized family members,⁶⁴ may fear that any contacts with the health care system, including confidential care, would alert immigration officials.⁶⁵ Ongoing contact with diverse and culturally responsive health care providers, who are sensitive to power dynamics within their own institutions, may be able to bridge these historic and current chasms of distrust.⁶⁶ At the same time, nurses should advocate for policies that support confidential access,³⁰ and guard against inadvertent breaches of confidentiality, to ensure that adolescents have the full range of reproductive and health care options.

Confidential care highlights the transitions of adolescents toward adulthood and changes in parent-child relationships, and as such can become the focus of conflict, when the underlying issue is often the transition itself.⁶⁷ Most parents support the concept of confidential

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

communication between adolescents and health care providers, as discussed above, yet they are also conflicted and unclear of the extent of confidentiality protections.^{10,11} Nurses can aid this transition through anticipatory guidance,²⁴ active listening and empathetic acknowledgment of parent and teen concerns, while maximizing the adolescent's access to confidential care.

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ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

Table 1

Adolescent Confidentiality Policies

Organization	Year
Association of Women's Health, Obstetrical and Neonatal Nurses (AWHONN) http://www.jognn.org/article/S0884-2175(15)30258-6/pdf	2010
American Academy of Pediatrics (AAP) http://pediatrics.aappublications.org/content/138/2/e20161347.long	2016
Society for Adolescent Health and Medicine (SAHM) http://www.jahonline.org/article/S1054-139X%2804%2900086-2/fulltext	2004
World Health Organization http://apps.who.int/iris/bitstream/10665/102539/1/9789241506748_eng.pdf	2014
United Nations Children's Fund (UNICEF) – Convention on the Rights of the Child http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx	1989

ADOLESCENT CONFIDENTIALITY WOMEN'S HEALTH

Table 2

State by State Guides to Minor Consent and Mandated Reporting

Organization	Year	Specific information	Website
Guttmacher Institute	Frequently updated	Minor consent for contraception, STI services, abortion, prenatal care, adoption, care of minor child	http://www.americaspromise.org/sites/default/files/d8/legacy/bodyfiles/teen-pregnancy-and-hs-dropout-print.pdf
Center for Adolescent Health and the Law	2010	Mature minor consent for general medical care	https://www.freelists.org/archives/hilac/02-2014/pdf/Ro8tw89mb.pdf
Child Welfare Information Gateway	2016 Update every two years	Child abuse and neglect reporting, Overview, includes reporting statutory rape and trafficking	https://www.childwelfare.gov/topics/systemwide/laws-policies/state/
Dept. of Health and Human Services (prep. by	2004	Statutory rape, detailed laws and reporting requireme	https://aspe.hhs.gov/system/files/pdf/75531/report.pdf

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