SAM POSITION STATEMENT

Confidential Health Care for Adolescents: Position Paper of the Society for Adolescent Medicine

Position

On the basis of standards of clinical practice, research findings, principles of ethics, and law, the Society for Adolescent Medicine supports the following positions with respect to confidentiality in the delivery of health services to adolescents.

- Confidentiality protection is an essential component of health care for adolescents because it is consistent with their development of maturity and autonomy and without it, some adolescents will forgo care.
- Confidential health care should be available, especially to encourage adolescents to seek health care for sensitive concerns and to ensure that they provide complete and candid information to their health care providers.
- Health care professionals should educate adolescent patients and their families about the meaning and importance of confidentiality, the scope of confidentiality protection, and the limits to confidentiality.
- Health care professionals should support effective communication between adolescents and their parents or other caretakers. Participation of parents in the health care of their adolescents should usually be encouraged, but should not be mandated.
- Health care professionals and delivery systems should review and, if necessary, revise their procedures (including scheduling, billing, and recordkeeping) to ensure that adolescents' privacy and the confidentiality of their health information are protected to the extent possible.
- Health care professionals should receive education and ongoing training to ensure that they know and understand the state and federal consent and confidentiality laws relevant to the delivery of health services to adolescents and have the skills to apply these laws when delivering clinical care.
- Laws that allow minors to give their own consent for all or some types of health care and that protect the confidentiality of adolescents' health care information are fundamentally necessary to allow health care professionals to provide appropriate health care to adolescents and should be maintained.
- Research related to confidentiality and adolescent health care should be placed within a broad research agenda focused on finding ways to increase the numbers of adolescents who receive high quality health care for the wide range of health issues important in this age group. Future research should investigate the impact of providing or limiting confidential adolescent health services on specific health outcomes, inform strategies to address system-level barriers to provision of confidential adolescent services, and define ways that health care professionals can encourage parent-teen communication without losing the trust of adolescent patients.

Background

Introduction

Confidentiality protection for adolescents' health care information is important both to adolescents and to the health care professionals who care for them. A well-established tradition has developed in the United States of making confidential care available to adolescents, particularly for sensitive concerns such as sexuality, sexually transmitted infections (STIs), substance abuse, and mental health. This tradition has been carried on by a wide variety of health care professionals in diverse settings. It is well grounded in ethics, clinical practice, and research. In addition, legal protections for confidential care have been embodied in federal and state laws [1].

Published by Elsevier Inc., 360 Park Avenue South, New York, NY 10010
1054-139X/04/$–see front matter
doi:10.1016/j.jadohealth.2004.03.002

The Society for Adolescent Medicine has long recognized the importance of confidential health care for adolescents [2]. Numerous position papers of the Society have affirmed support for confidentiality in specific contexts [3–9]. In 1997, the Society published a comprehensive statement on the importance of confidentiality in adolescent health care [3].

Since the position paper on confidentiality was released in 1997, several developments have occurred that make it important and timely for the Society to issue a revised confidentiality document. New research has underscored the importance of confidential care for many adolescents. The increasing computerization of medical records and information has increased the challenges to and opportunities for protecting adolescent patients' privacy. New federal medical privacy regulations, known as the "Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule," have been issued and will have a major impact on the delivery of health services to both minors and adults.

With this revised position paper, the Society for Adolescent Medicine reaffirms the importance of confidentiality in adolescent health care and explains the support for confidentiality that is found in clinical practice, research, ethics, and law.

Clinical Practice

The overall goal in clinical practice is to deliver appropriate high-quality health care to adolescent patients, while encouraging communication between adolescents and their parents or other trusted adults without betraying the adolescents trust in the health care professional. When deciding how best to provide confidential health care to adolescents in specific clinical situations, health care providers need to take into account the following factors:

- The patient's chronological age, cognitive and psychosocial development, other health-related behaviors, and prior family communication.
- Policies of professional organizations that often support the provision of confidential health care to minors who request privacy for a broad range of health services, including treatment of STIs, contraceptive care, outpatient mental health services and outpatient substance abuse services [10,11].
- Laws that define emancipation determine when a minor can consent to health care (e.g., state minor consent statutes), specify when parental consent or notification is required or permitted (e.g., often for abortion services), clarify the discretion of health care professionals to disclose information, and provide guidance on access to health care information and medical records [12].
- The implications of the HIPAA Privacy Rule for the provision of adolescent health services [13].
- The limits of confidentiality (in situations of suspected physical or sexual abuse, suspected risk of suicide or homicide, and when public health laws require reporting certain diseases, e.g., Chlamydia, gonorrhea, TB, HIV), and strategies to involve the adolescent in appropriate plans for engaging parents or other trusted adults to assist with management of these situations.

Health care professionals must also consider a variety of practical issues. First, experienced clinicians recognize that candid and complete information can be gathered only by speaking with the adolescent patient alone, and by clarifying with whom the information will be shared. Beginning in early adolescence, routinely spending at least part of each visit alone with a patient conveys to the young patients and their parents that this is a standard part of adolescent health care. This also provides regular opportunities to develop a confidential relationship with adolescent patients and to discuss sensitive health topics in an open manner, and it can reassure parents that the health care professional is available to help address topics that they may have a difficult time discussing. Experiences of seasoned clinicians suggest that most parents, who are often very trusting of physicians with whom they have an established relationship, support this arrangement.

Second, routine discussions with adolescents and their parents about both the protections and the limitations of confidentiality are important. This conveys that a clinician is aware and respectful of privacy issues, educates adolescent patients and their parents about the guidelines for this aspect of care, and has beneficial effects on the patient-clinician relationship. It encourages open patient-clinician communication [14–16], which is essential for effective screening, accurate diagnosis, and risk-reduction counseling. This also increases the chance that adolescents will seek future health care for sensitive health concerns [16]. It is important to recognize that adolescent patients are attentive to the specific content of messages [16,17]. Clinicians should be as clear as possible about what can and cannot be managed privately and convey messages that adolescents both understand and can trust.

Third, clinicians need to be aware of system-level

issues that may inadvertently break confidentiality and betray an adolescents' trust. Common problems are related to billing and reimbursement procedures, scheduling notification, and privacy of medical records [18–20]. Strategies to provide appropriate confidential care within this context need to be developed where feasible [20]. Alternatively, clinicians must be knowledgeable and prepared to refer patients who need confidential services to other sites where privacy can be assured. Attention to this issue at the level of health care systems, and within the context of wide-spread use of electronic medical records, is clearly needed.

Fourth, clinicians need to learn the skills to provide appropriate confidential adolescent health care while also encouraging communication with parents. This may involve strategies such as discussing with adolescent patients their perceptions of the pros and cons of communication with parents, helping adolescents to see the potential advantages of increased communication with parents, and offering to facilitate communication with parents in a way that is helpful to the adolescent patient. Giving consistent messages to parents that health care professionals expect parents to discuss a wide range of issues related to health with their adolescent children may be helpful, and parent questionnaires may be an efficient way to regularly reinforce this message [21,22]. At the end of an adolescent visit, when "wrapping up" with the adolescent patient and the parent, it may be very useful to provide general anticipatory guidance counseling that, in fact, is tailored to needs identified during private discussion with an adolescent patient.

Finally, it is important to acknowledge that some adolescents do not have parents, parental support, or any meaningful connection with parents. Some adolescents have experienced abuse or neglect by parents, and have legitimate fears about future parental abuse, which may include being asked to leave one's home by parents [23]. When clinicians encourage adolescents to communicate openly with their parents, it is important to ask about reasons for any reluctance to do so. There are times when it may be appropriate to identify and engage other trusted adults into management plans.

Research

Over the past decade, research has confirmed that concerns about privacy can prevent many adolescents from seeking health care [16,24–28]. In two large national surveys, approximately one-quarter of middle and high school students reported that they did not seek health care they needed [26,27]. One of these studies found that 35% of students who did not seek care reported one reason was "*not wanting to tell their parents*" [26]. The impact of privacy concerns on care-seeking for specific sensitive health services is likely much higher. Essentially one-half of single, sexually active girls under 18 years of age recently surveyed in family planning clinics in one state reported that they would stop using the clinics under conditions of mandatory parental notification for prescription contraceptives. An additional 12% reported that they would delay or discontinue use of specific services such as services for STIs [28]. Subsample analyses provided an indication of the potential magnitude of negative outcomes associated with decisions to forgo care: only 1% of adolescent girls who indicated they would stop using family planning services indicated that they would also stop having sexual intercourse, instead, they would continue to have sex, but use less effective or no contraceptive methods [28]. Recent research has also confirmed that privacy concerns influence where many adolescents go for health care, and that often this is not to see their regular health care provider [24,29–31].

When adolescents do seek health care, privacy concerns likely affect the quality of health care received. A substantial proportion of primary care physicians do not provide confidential adolescent health services [32], discuss confidentiality with patients [33], or train their office staff to give accurate information about confidential services available in their practice [32]. Adolescents who are concerned about privacy are less likely to openly communicate with health care providers particularly about issues related to substance use, mental health, and sexual behaviors [16,34], which influences information exchange about key health issues for this age group [21]. Privacy concerns also influence adolescents willingness to receive services such as pelvic examinations and testing for STIs or HIV [34–37], which should be a part of routine care for many youth.

Research is beginning to document the difficulty many health care professionals face when trying to provide confidential services to adolescent patients. For example, the majority of clinician members of the Society for Adolescent Medicine note barriers to providing confidential testing for chlamydial infection in their main clinic settings, primarily related to system-level issues such as billing and reimbursement [19].

Future research related to confidentiality and ad-

olescent health care should be placed within a broad research agenda focused on finding ways to increase the numbers of adolescents who receive high quality health care for the wide range of health issues important in this age group. This should include investigating the impact of providing or limiting confidential adolescent health services on specific health outcomes, and informing strategies to address system-level barriers to provision of confidential adolescent services.

Finally, it is important to note that although research confirms the importance of confidentiality to many young people, concerns about confidentiality and disclosure of information regarding sensitive issues to parents is not universal. In the survey conducted in family planning clinics noted above [28], approximately one-third of adolescents would continue to use family planning services under conditions of mandatory parental notification for prescription contraceptive use. Previous reviews of the literature have found that most pregnant minors willingly discuss abortions with their parents [38]. Further research is needed to better understand variations in the importance of confidential health care among adolescents, and how health care professionals can facilitate improved communication between adolescents and their parents or other trusted adults in a way that benefits adolescent health and well-being [39,40].

Ethics

Protecting the confidentiality of adolescents' health information is a professional duty that derives from the moral tradition of physicians and the goals of medicine. The goals of medicine include curing disease, prolonging life, relieving suffering, and preventing illness. Basic moral principles can help guide health care professionals in their pursuit of these goals: respect for autonomy, beneficence, nonmaleficence and justice [41]. Each of these principles also has specific relevance to confidentiality protection in adolescent health care.

Respect for *autonomy* means that patients' own wishes, ideas, and choices are to be supported during the process of helping them. When a relationship exists between a health care professional and a patient that protects the patient's privacy, the patient's autonomy is supported. Protection of confidentiality in a health care setting is derived from this principle. It represents an agreement between the patient and the health care professional that information discussed with and discovered about the patient during encounters between them will not be shared with other parties without the patient's permission.

Nonmaleficence means that health care professionals avoid doing harm to the patient. In some circumstances, failing to respect an adolescent's privacy or to honor an express or implied agreement of confidentiality might cause harm. This might occur through disclosure of information to a parent or guardian, even though including parents in an adolescent's care might generally be helpful to the adolescent. Determining what may be harmful can be challenging because adolescents demonstrate different levels of maturity, engage in different behaviors, and have different family relationships. Avoiding harm, in conformity with the principle of nonmaleficence, must be viewed within the context of other moral principles such as autonomy and beneficence.

Beneficence is the principle that requires action to further a patient's welfare; doing good for the patient. Protecting confidentiality often enables a health care professional to benefit a patient. Offering confidential care to adolescent patients encourages them to disclose their symptoms and life circumstances fully and completely, thereby increasing the likelihood that they will receive appropriate care and enhancing the clinician's capacity to help them.

Justice requires health care professionals to give adolescents a fair and reasonable opportunity to receive appropriate health care on the same basis as other groups in society. To the extent that the lack of confidentiality protection impedes adolescents' access to health care they need, protection of confidentiality may be necessary to further the principle of justice.

Individual adolescents vary in their levels of psychosocial maturity and economic independence, as well as in their behaviors and family situations. Therefore, it is inappropriate to apply a single moral prescription in all cases. The protection of confidentiality in adolescent health care should be grounded in the moral principle of respect for autonomy, but must recognize that in specific circumstances it may be permissible or even necessary to breach confidentiality to further other important moral principles, such as beneficence or nonmalificence.

Both the disclosure of confidential information and the failure to disclose may constitute a clear moral breach in specific circumstances. A professional who fails to disclose confidential information, despite a likely benefit to the patient, merely because it would be inconvenient or difficult, puts his or her own needs above those of the patient. Similarly, a

professional who breaks confidentiality merely because it is "good for the patient," without a strong and persuasive reason, engages in inappropriate paternalism (i.e., interference with a person's freedom of action based on a wish to benefit them). Neither of these is morally defensible.

A breach of confidentiality, even one that is motivated by paternalism, may damage an adolescent's trust in the health care professional. Therefore, it should be avoided unless a greater good can be achieved by breaching confidentiality. There are circumstances in which breaching confidentiality by disclosing information to an adolescent's parents, caretakers, or others may lead to a greater benefit (for the patient or society). These circumstances might include cases of suicidal or homicidal ideation or acts, serious chemical dependence, and life-threatening eating disorders. "Justified paternalism" in the care of adolescents could be appropriate under these circumstances, provided there is reasonable evidence that an adolescent's capacity for exercising autonomous choice is impaired and protecting the adolescent's life is the central goal [42]. In this view, protecting life outweighs the principle of autonomy.

Even when a health care professional encounters a circumstance in which "justified paternalism" and disclosure better serves the adolescent, there is still a moral duty to respect the adolescent. This can be accomplished by explaining to the adolescent beforehand the basis of any decision to breach confidentiality and involving the adolescent in the process of identifying how and to whom the information will be disclosed.

Law

Numerous laws protect the confidentiality of health care information. Many of these laws apply to adolescents who are minors as well as to adults. Nevertheless, there are some important differences based on the legal status of adolescents. Adolescents who are under the age of majority (usually age 18) are minors and generally cannot expect the same level of confidentiality protection under the law as adults. Adolescents who are age 18 or older are adults and should expect the same confidentiality protection as other adults.

Confidentiality and consent. The concepts of consent and confidentiality are inextricably intertwined. First, when a minor's own consent for health care is not legally sufficient, the process of obtaining consent from someone else compromises confidentiality. Second, even when minors are legally authorized to consent, the law may also permit (or require) that a parent or another person or entity be informed. Third, some medical privacy laws explicitly rely on the minor consent laws in delineating who controls the confidentiality of health care information for minors.

The law generally requires the consent of a parent when health care is provided to a minor child, but includes numerous exceptions [43]. The exceptions include medical emergencies, care for the "mature minor," and laws authorizing minors to consent to their own care [12,43,44]. Consent may also be required from a legal guardian or conservator for a person who is an adult but severely mentally incapacitated.

A legal basis for minors to consent to their own care also provides a strong foundation for protecting the confidentiality of the care. Every state has statutes that authorize minors to consent to medical care under a variety of circumstances [12]. In some statutes, the authorization is based on the minor's status, such as when the minor is emancipated, married, serving in the armed forces, pregnant, a parent, or a high school graduate; is living apart from parents; has attained a certain age; or has qualified as a mature minor. In other statutes, the authorization to consent to health care is based on the type of care needed, such as contraceptive services; pregnancy related care; diagnosis and treatment of STIs, HIV, or reportable diseases; treatment for drug or alcohol problems; care related to a sexual assault; or mental health services. Although not every state has statutes covering minors in each of the above status categories or all types of "sensitive" services, every state does have some of these provisions [12]. These minor consent laws reflect policy judgments that certain minors have attained a level of maturity or autonomy that makes it appropriate for them to make their own medical decisions or that adolescents generally are unlikely to seek certain "sensitive" but essential services unless they are able to do so independently of their parents.

The HIPAA Privacy Rule. The most recent legal development affecting the confidentiality of adolescents' health care information is embodied in new federal medical privacy regulations, the HIPAA Privacy Rule, issued under the Health Insurance Portability and Accountability Act of 1996 [45]. The Rule creates new rights for individuals to have access to their protected health information and to control the disclosure of that information in some circum-

stances. It contains specific requirements that affect medical records and information pertaining to the care of minors [13,46]. The HIPAA Privacy Rule provides that, in general, when minors legally consent to health care or can receive it without parental consent, or when a parent has assented to an agreement of confidentiality between the minor and the health care provider, the parent does not necessarily have the right to access the minor's health information. Who may do so depends upon "state or other applicable law."

Thus, a health care provider must look to state or other law to determine whether it specifically addresses the confidentiality of a minor's health information. State or other laws that explicitly require, permit, or prohibit disclosure of information to a parent are controlling [13,46]. If state or other law is silent on the question of parents' access, a health care professional exercising professional judgment has discretion to determine whether or not to grant access [13,46]. The relevant sources of state or other law that a health care provider must consider include the state minor consent laws, state medical privacy laws, the federal confidentiality rules for the federal Title X family planning program, the federal confidentiality rules for drug or alcohol programs, and court cases interpreting both these laws and the constitutional right of privacy.

During the evolution of the HIPAA Privacy Rule, numerous professional health care organizations, including the Society for Adolescent Medicine, strongly supported the confidentiality protections for adolescents [47]. In its final form, the HIPAA Privacy Rule recognizes the importance of confidentiality protection in adolescent health care and allows health care professionals to honor their ethical obligations to maintain confidentiality consistent with other laws [48].

Confidentiality limits. Even when the law protects the confidentiality of adolescents' health information, legal limits apply, in addition to the clinical and ethical limits that exist. The legal limits include, for example, any requirements to notify parents in specific circumstances, laws granting parents explicit access to minors' complete medical records, legal obligations to warn intended victims of homicide and to take protective action in cases of suicidal ideation or attempts [49]. In addition, the obligation to report child abuse acts as an overall limit on the scope of confidential care, although there are ongoing questions of interpretation regarding the application of child abuse reporting laws to some adolescent health situations, such as consensual sexual behavior of adolescents [50]. Also, public health laws that require reporting of communicable diseases, including some STIs, place limits on confidentiality, although the public health reporting and contact tracing system has been structured to minimize breaches of confidentiality and to protect privacy as much as possible [51].

Confidentiality and payment. Adolescents often have difficulty obtaining confidential health care unless there is a clear way to pay for the care. Most often, an adolescent's care is paid for by parents or by health insurance. Alternatively, adolescents may be able to receive certain services without charge or at an affordable cost in a variety of settings such as community or migrant health centers, health departments, school-based and school-linked health clinics, and family planning clinics, among others [1].

A few of these sites operate under laws that provide confidentiality protection for minors as well as adults. For example, since 1970 the federal Title X Family Planning Program has included strong confidentiality protections for adolescents. In Title X clinics there are sliding fee scales based on income, and adolescents are permitted to qualify based on their own (rather than their parents') income. Eligible adolescents are also entitled to receive confidential family planning services through Medicaid and may be able to do so under the State Children' Health Insurance Program (SCHIP) [52].

Reliance on health insurance coverage for confidential care can be problematic for an adolescent. The necessity for a parent to sign the insurance claim (in the case of private insurance), or to furnish the Medicaid or SCHIP card significantly limits the confidentiality of services. Furthermore, the diagnoses on billing statements when mailed to parents can also violate confidentiality. The effect of the HIPAA Privacy Rule on adolescents' ability to obtain confidential care through a family insurance policy is not yet known, but several aspects of the Rule could be helpful [13,46]. First, the Rule gives legal significance to informal agreements of confidentiality between an adolescent and a health care provider to which a parent has given assent. Second, the Rule would permit minors who have such agreements or who have consented to their own care to request specific privacy protections from a health care provider or health plan.

Conclusion

There is a strong basis for protecting the confidentiality of adolescents' health information in the standards of clinical care for this age group. These standards are firmly supported by extensive research findings about the impact of privacy concerns on adolescents' access to care. They are also rooted in basic principles of biomedical ethics and a legal framework that has developed over nearly a half century.

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