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Original article

Understanding Confidentiality: Perspectives of African American Adolescents and Their Parents

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Abstract:

Purpose: To identify adolescents' and parents' understanding of confidentiality in the patient/doctor relationship.

Methods: In the teen clinic of an academic hospital, questionnaires were administered separately to 50 accompanying parents and 50 adolescents aged 13 to 17 years. The true/false questions were designed to identify both adolescents' and parents' perceptions of the general breadth and limitations of confidentiality and specifically related to selected high-risk behaviors.

Results: Most adolescents and parents understood confidentiality to mean that conversations, testing and treatments about certain aspects of health care could be kept private between a doctor and patient. However, most parents felt that confidentiality guidelines did not apply to patients under 18 years. In contrast to 36% of adolescents, 96% of parents believe that the doctor would discuss any conversation the doctor had with the patient that might be important to the parent in spite of adolescents' wish for them not to be told. Parent/adolescent dyads agreed regarding the general value of a confidential adolescent/doctor relationship and the application of confidentiality to certain topics but disagreed with respect to others.

Conclusions: The adolescents and parents in this study have a good understanding of the meaning of confidentiality but are less clear on its application to the adolescent patient/doctor relationship. Nearly all adolescents and their parents appreciate the circumstances under which confidentiality will be breached. The protections confidentiality offers adolescents are understood less well by both parties, but parents seem to have a greater degree of misunderstanding. Parents believe that the doctor will inform them about many of their adolescents' high-risk behaviors. These false impressions may lead to assumptions, miscommunication, and conflict in the adolescent patient/doctor/parent triad.

Keywords: Confidentiality; Adolescent; Parent

Confidentiality in the doctor/patient relationship broadly means that the doctor will not reveal information about the patient without the permission of the person who consented to the health care. Both federal and state laws exist that protect confidentiality in adolescent health care with regard to issues such as outpatient mental health, drug and alcohol abuse treatment, human immunodeficiency virus (HIV) testing, birth control, and treatment of sexually transmitted infections. Nonetheless, the protections and limits of many of these laws are variable and are not always well understood [1]. Disparate perceptions of confidentiality can create tension in the adolescent patient/doctor/parent relationship. Designing pertinent and effective interventions to avoid misunderstanding requires a thorough understanding of the adolescents' as well as parents' perspective of confidentiality in the doctor/patient relationship. Previous studies have recognized that the adolescent's understanding of con-

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fidentiality is limited but have not identified specific areas of misunderstanding [2,3]. Furthermore, their parents may not be aware of the scope of confidentiality within the adolescent patient/doctor relationship, as is suggested by a Minnesota study revealing that parents have a poor understanding of the legal aspects of adolescent confidentiality [4]. Little additional information is available regarding parental understanding of confidentiality in the adolescent patient/doctor relationship. This study seeks to identify and describe adolescents' and parents' degree of understanding regarding disclosure and confidentiality in the doctor/patient relationship as a first step to designing effective educational interventions.

Methods

This study was conducted in the Pediatric and Adolescent Outpatient Clinic of a large urban academic medical center. The clinic is subdivided into an adolescent medicine area where teens receive their care. Each of the patients identifies the attending adolescent medicine physician as his or her primary provider; however, pediatric residents first see the patients under the attending's supervision. In this setting, standard practice is for the physician to interview the patient alone and to verbally instruct the patient on the clinic's confidentiality policies. These policies are consistent with the recommendations of professional medical organizations such as the Society for Adolescent Medicine and the American Medical Association, which reflect scientific evidence and ethical principles as well as federal and state law [5,6].

From this patient population we randomly selected 60 accompanying parents or legal caregivers and 60 adolescent patients aged 13 to 17 years who presented for medical care, including both illness visits and routine care. After obtaining informed consent from the parent and assent from the patient, we administered a 28-item questionnaire to the adolescent patients and a separate but parallel questionnaire to their parents before the appointment. Institutional Review Board approval was obtained before initiating the study.

The questionnaire items were predominantly true/false, written at approximately the fourth grade level, and reviewed by grade school teachers to assure comprehensibility and readability. After 10 sets of adolescents and parents completed questionnaires, we performed iterative revisions and solicited verbal feedback from participants to optimize clarity and improve presentation of the questionnaire. These results from the first 10 sets of participants were not included in the data analysis, leaving a total of 50 parents or legal caregivers and 50 adolescents for the final analysis. The overall purpose of the questionnaires was to ascertain the adolescent and parental understanding of both the limits and breadth of confidentiality. The items on the questionnaire fell into two broad categories: (1) items designed to determine understanding of confidentiality principles in the doctor/patient relationship in general; and (2) items designed to assess understanding of confidentiality principles with respect to sensitive adolescent health concerns, including substance use (marijuana, tobacco), sexuality (sexual activity, sexually transmitted infections, birth control, pregnancy), abuse, suicidality and homicidality. Regarding the second category, the adolescent or parent was asked to evaluate a statement about each topic. These statements asked whether the doctor would inform the parent if the adolescent patient received counseling, evaluation or treatment for that particular topic while the parent was not present. A Research Assistant was available to answer questions during completion of the questionnaire.

Table 1
Demographic information

	Adolescents	Parents
Gender		
Female	72%	98%
Male	28%	2%
Race		
African American	100%	100%

The results are reported as percentage, with 95% confidence intervals (CI). CIs were calculated according to the following formula: $p \pm 1.96 \times$ square root of $p(1 - p)/n$, where p = percent answering true, and n = total sample size, or 50. Parent and adolescent questionnaire responses were cross-classified for each question to determine the percentage of adolescent/parent dyads that gave an equivalent response. Percent concordance was calculated as the sum of those dyads where both responses were "true" and those dyads where both responses were "false," divided by 50, and expressed as a percent.

Results

Fifty patients and fifty accompanying parents completed the questionnaires. Demographic characteristics are shown in Table 1. The mean age of the adolescents was 14.9 years. No one declined to participate or withdrew from the study.

The first group of questions addressed general understanding of confidentiality. The results are shown in Table 2. In general, most parents (88%) and adolescents (90%) understand the definition of confidentiality and believe that the concept of a confidential relationship is valuable. Both parents (88%) and adolescents (90%) believe that doctors can provide useful information and that having access to a physician is beneficial for adolescents to discuss subjects they don't feel comfortable discussing with their parents. In addition, adolescent/parent dyads showed a high degree of concordance on these general issues (76–90%).

Despite these findings, several apparent misconceptions are evident. Most (60%) of the parents believe that the principle of confidentiality does not apply to their teenagers