
Youth, Health Care Decisions, and Confidentiality — A Survey Report

By Sarah Norris

Confidentiality is a right of children and adolescents as well as adults. This article reports on a medical attitudes survey administered to students at a Kansas high school and discusses the students' responses in light of the recently revised Health Care Treatment Decision-Making Guidelines for Minors, a document published by Midwest Bioethics Center. The article concludes with suggestions for further study.

When I first entered a doctor's office as a small child, I didn't know what to expect at all. I knew that a doctor was supposed to "help you," but I wasn't sure how or why. I entered a brightly colored waiting room filled with children who looked as unhappy to be there as I must have looked. When I finally saw Dr. Siscone, he greeted me with a smile and two trays of medical tools. One held what I later realized to be a thermometer, hypodermic needles, and a stethoscope: the other was filled with tiny cabbage patch figurines and other toys for me to play with. Throughout the exam I played with the toys and paid little attention to the examination that I had been so apprehensive about. When I left, Dr. Siscone gave me a lollipop and assured me that I would soon feel better. From that first visit until now, going to the doctor has always been a positive experience.

First experiences often influence an individual's future attitudes and responses to difficult or personal experiences, especially if that first experience happens during childhood. Dr. Siscone's tray of toys, but more especially his unhurried, calm helped shape my attitude toward doctors. I was fortunate to have a doctor who made the first visit I remember not intimidating, but actually fun. Although all of my experiences within the medical setting have been positive, many other values and experiences can influence how an individual feels about visiting a doctor. These

influences range from having trust in a doctor to feeling informed about the treatment. The emotional tone of the visit and the ability of the doctor to reassure a patient are also major influences.

When I joined Midwest Bioethics Center as an intern, I was the only member of the staff who was still considered legally a minor. At that time, the communications team asked me what I thought members of my age group thought about confidentiality and patient's rights. The topic interested me, and I decided to write about the rights of minors in today's health care system. I wrote about what I thought these rights were, what they should be, and how I felt about them. After assessing my experiences and the theoretical rights that should be given to minors, I decided to ask others in my age group to share their opinions on a set of questions relating to minors' rights in a medical setting. This article is a summary of my views and the views of my peers — first in reference to the *Health Care Treatment Decision-Making Guidelines for Minors*, a document published by the Midwest Bioethics Center Task Force on Health Care Rights for Minors, and second, as self-reported in a survey distributed to students at Shawnee Mission West High School.

The document on decision making for minors stresses the differentiation in decision-making capacity that various minors exhibit. It

distinguishes between those minors who do not have decisional capacity, those who are developing decisional capacity, and those who have decisional capacity. The document asserts that it is difficult to decide which classification best fits an individual minor, and it is impossible to base this classification on age. Deciding what level of decision-making capacity a minor has must be based on several factors, including an assessment of the minors', the parents', and the health-care providers' beliefs.

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The question of decisional capacity can only be decided on an individual basis. No strict rules or guidelines can dictate any particular minor's capacity. In addition, a child may be deemed to have decisional capacity for one medical situation, but not another. For example, decisions at any age are more difficult to make depending on the severity of the treatment needed. The question of whether a child has decisional capacity must be placed under more scrutiny in situations involving treatment that is serious or possibly even life threatening. The students who participated in my survey should be assumed to have decisional capacity in most situations.

Surveying Medical Attitudes

Sixty-four Biology II students at Shawnee Mission West High School in Shawnee Mission, Kansas, completed a Medical Attitudes Survey (Fig. 1). The survey asked five questions related to their feelings about past experiences with doctors and what they believed should be private or confidential in a

medical setting. These results should not be generalized to the larger population of minors, but still provide an insight into the beliefs and values of the respondents. The majority of students polled had positive feelings about their experiences with doctors. The students who had a neutral feeling toward doctors comprised the next largest group of respondents. Only a few respondents had a negative feelings about their past experiences with doctors.

Most of the students believed that nothing should be kept private in a medical setting if it pertains to the health of the patient. However, many respondents felt that there were specific items that should be kept private if the patient (in this case, the minor) felt that confidentiality was necessary. Examples of information that should be handled confidentially included sexual activity or preference, certain personal habits or social behaviors, and religion. Several students felt that any information that made the patient uncomfortable or was hard to talk about should be kept confidential.

The majority of respondents, in fact, believed that all information shared with a doctor in a medical setting should be strictly confidential, and many respondents also emphasized specific items that should not be shared further once they had been revealed to a doctor. AIDS status, sexual activity, birth control, pregnancy, sexually transmitted diseases, alcohol, tobacco or drug use were in this category, but so was information about current and past illnesses. Some students also believed that there are specific instances in which information should not be kept confidential, particularly if that information could hurt someone else or if the patient was suicidal. Several respondents believed that information should be shared with all other doctors who would be involved in treatment.

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Medical Attitudes Survey

1. My overall experience of visiting a doctor (dentist, eye doctor, or medical doctor) has been positive. Circle one.

Strongly Agree

Agree

Neutral

Disagree

Strongly Disagree

2. Briefly describe an experience that shaped your opinion about the above question.

3. If privacy is defined as the right not to share information with a doctor, what information, (if any) do you believe should be private in a medical setting?

4. If confidentiality is defined as the right to share information with a doctor without the fear that it will be shared with others, what information do you believe should be confidential in a medical setting?

5. Is there a time when you felt either your privacy or confidentiality were had been violated by a doctor or his staff? If so briefly describe that time.

Figure 1. — Medical Attitudes Survey (Norris 1998).

my opinion, this clearly violates the guidelines outlined in the minors' rights document. In addition, it complicates the provider-patient or trusting relationship between the patient and doctor. If persons do not know what their records contain, they cannot accurately judge if their confidences have been kept. Their trust in doctors will diminish because of this lack of information.

My survey shows that these students are sensitive to issues of confidentiality and capable of participating in decisions related to their own health care. Many of them know how to keep confidences and yet also know how *not* to treat confidentiality as an absolute value (i.e., in cases of potential harm to oneself or others, it may be necessary to reveal otherwise confidential information).

Many values are involved in the formation of these opinions. One value that is particularly common in the American mindset is individuality, and Americans bring their belief in this value into the medical setting. Patients often believe that it is their right as individuals to decide who should be privy to their medical information. This value is reflected in the responses of those who participated in the survey. Another underlying principle involved is trust. Do students feel that they can trust their doctors with information that they deem

private? Most of the students surveyed believed that a doctor should be trusted on the basis that providing as much information as possible benefits their treatment, and that the doctor needs as much information as possible to provide a full diagnosis.

So, then, do our values or the consequences of our actions motivate our behavior? For instance, a minor who has become pregnant may wish to keep this information confidential for fear of the consequences that it will bring. Her motivation to keep the information confidential is not necessarily based on an underlying value, but on the unpleasant circumstances that might follow from the disclosure or breach of confidence. The notion of consequences was evident in many of the students' comments; those who believed information should be private or confidential because it made them uncomfortable or embarrassed were clearly responding to their perception of the consequences involved in making this information public. However, in the case of the pregnant student, her doctor's breach of confidence would have its own repercussions. It might cause the young woman to change the basic way that she feels about her health care in general. Following that incident, she might always question the confidentiality of anything that she discussed with her doctor. She would lose the basic value of trust, a value vital to the medical setting.

Parental Access and Children's Rights

The *Decision-Making Guidelines for Minors* contains lists of rights for minors who are placed in a medical facility. These lists are written in a style to promote the comprehension of children of several different age groups. The document also contains a list of rights for parents of children who have been placed in medical facilities. It is in this part of the document that respondents to my survey expressed conflicting views. Their disagreement concerns the rights of parents to access a student's medical records.

Several respondents stated in their answers that they do not want their records disclosed to anyone without their consent. The guidelines agree that minors with decisional capacity should be consulted; it states that patients have "personal privacy" and that all records should be kept "as confidential as possible." But the guidelines for parents state that parents have a right to access the student's medical files. According to the document, if a child wishes to stop the opening of the records to his or her parents, but the parents insist, the resulting conflict should be mediated. However, the document is unclear about whose side would be taken if the conflict cannot be resolved.

If parents are, in the end, allowed to see their child's records without the child's permission, how are the rights of minors with decisional capacity *not* violated? The document does, however, offer some options in an effort to protect confidentiality. One of these options allows the parents to see only the financial information involved in a minor's record. The document also advises that doctors should use caution when placing confidential information in a minor's medical records. Finally, the document states that a minor should always be informed when a breach of confidentiality is unavoidable. (I have not made any study of state laws related to this issue.)

Both the survey and the guidelines document bring up issues that I believe would be helpful and interesting to investigate. The first issue is to what extent students believe that parents should be involved in their health care decisions. Even if they feel comfortable sharing medical information with their parents, they may want a more active role in actual decisions. The second question is whether society has become too medicalized. Are a minor's social behaviors relevant to the doctor's diagnosis? And finally, the third question that we could pursue is what type of information students believe should be kept from them by their doctors.

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