
Teaching the Three Rs: Rights, Roles and Responsibilities — a curriculum for pediatric patient rights

by Kathleen G. Davis

Education of pediatric patients, health care professionals, and family members is key to ensuring that children have a voice in the decisions that affect their health and their physical and emotional status.

Historians speak of the *zeitgeist* to explain why certain historical events fail to occur in one decade, yet occur in another. The *zeitgeist* is the spirit of the age, the trend of thought and feeling during a particular time. It is the catalyst for new ideas, inventions or practices to be discovered and then to take hold in a society.

Our societal values and humanistic approach dictate that children should have a voice in the decisions that affect their health and physical and emotional status. To strengthen the movement and ensure the continued growth of pediatric patient rights, one must examine the following areas: 1) the history of patient rights in general and pediatric rights specifically; 2) our current status of incorporating concepts of pediatric patient rights in the daily hospital routine, and 3) the need to continue the process of education of the child, the family, medical professionals, and the community.

The focus of this article will be to explore some of the "growing pains" of the pediatric patient rights movement at one hospital and purport the exigency for continued education of pediatric patients, family members, and health care professionals as we move toward a broader acceptance and practice of the rights of pediatric patients. Techniques of teaching children about their rights as patients will also be discussed. This discussion will pertain to the general concepts of pediatric patient rights while emphasizing the right of informed consent.

A review of the literature concludes that, four decades after the phrase "informed consent" was

coined, problems with the concept of informed consent of adults are similar to those experienced in pediatric patient rights.

However, the process of imparting the necessary and changing information from health care professional to patient is not always readily accomplished. This process necessitates ongoing, open communication between care giver and patient, as well as continuous assessment by the health care provider of the level of patient understanding. Health care providers often see informed consent as little more than a housekeeping chore (Skelly 1994). The view is sometimes held that if a patient wants to know more, he simply needs to ask. However, for a variety of reasons, the patient might not ask questions. For example, he may not have enough information to formulate the question; he may feel that if he needed to know the answer, the doctor surely would have told him; or he may be afraid to hear the response to his concerns.

Implementation of pediatric patient rights shows many of the same characteristics. The situation may become even more complex, however, due to the involvement of additional key players, namely the child's family and members of the religious, social, and ethnic communities. Issues such as parental permission, expectations of health care professionals, influences of family

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members and unrealistic expectations of the child's ability and competency in handling challenges of the diagnosis may surface. At no other time may one be more cognizant of the reality of the statement, "No child is an island," than when dealing with pediatric patient rights, and especially with informed consent and assent.

We are experiencing the infancy of patient rights for children. The movement has taken its first step; it is time to examine the successes and to determine what needs to occur next.

Philosophically and in practice, several perspectives exist. The first is held by those who openly embrace the concept of children's rights. These professionals are characteristically on the children's unit offering choices, lending support, educating, and supporting young patients. These individuals have supported pediatric patients' rights since long before the movement began. One recent example took place as a nurse prepared to do a venipuncture on a six-year-old child with a history of hospitalizations and many sticks. The child was unusually anxious; the unit nurse asked her what would make the procedure more tolerable. The child requested that the school teacher come to help support her through the procedure. Throughout the procedure, the nurse offered choices such as which hand should be tried first, if the child wanted to sit or lie down, if she wanted to count out loud or would rather the teacher do it, and so on. The dialogue was interspersed with supportive comments. When the procedure was over, the child hugged the nurse and proclaimed her a good "sticker."

Still other groups do not support the concept of pediatric patient rights. Illustrative of that attitude is the health care professional who instructed a fourteen-year-old youngster to drink a laxative. When the young lady exercised her right to dissent, the health care professional informed her that she would have to have an enema if the laxative was not gone in five minutes.

Often, the lack of support may be attributed to ignorance and substandard education. As with any program in its infancy, we must be vigilant

in our efforts to ensure that all persons have the knowledge base to understand the program, as well as the experiential base to recognize the importance and effectiveness of the results of implementation of the program. Observation suggests that the following issues may make it difficult or impossible for health care professionals to effectively support young patients in their attempts to exercise their rights:

- lack of basic knowledge or information
- real or perceived lack of time to communicate/interact/support the patient
- equating negotiations with giving in to the child
- inadequate understanding of cognitive levels of functioning or belief that young people aren't capable of autonomous decision making
- paternalistic belief system that does not embrace the basic concept of patient rights or belief that the health care professional knows more about disease and treatment and therefore knows what is best for the patient
- view of pediatric patient rights as an issue dealing exclusively with matters of life and death, thus not seeing need to incorporate the concept in small increments along the continuum of care
- substandard communication or the definition of communication as talking only, rather than the inclusion of effective listening skills

To ensure successful implementation of pediatric patient rights, health care professionals must have the opportunity for sufficient education. The goal should be to have "the feel," as well as the facts in establishing an understanding of the needs of young patients. Regular inservices; modeling of appropriate interactions and discussions with patients; involvement of the psychologist, teacher, child life worker, or others who can provide input on the child's cognitive level of functioning; and the opportunity for discussion about children's rights with colleagues are some of the ways to better prepare health care professionals to support children in the hospital.

Parents and family members or members of the religious, cultural or ethnic communities may also need opportunities for education regarding children's rights. Some cultures may not be comfortable with the doctrine or with the concept of enabling children to exercise choices. Often

opportunities for education of these people may be shortened by lack of time or the need to administer emergency medical care (Skelly 1994). Parents may be emotionally unable to deal with stressful situations. The family belief system may be that adult family members or the doctors know what is best for the child. Parents may be better equipped to support their child if they are considered team members with valid questions, concerns, and important information to contribute regarding their child. To improve interactions with the parents, the health care professional must *truly* listen and should discuss key issues prior to a crisis, rather than after the fact (Skelly 1994). Effective communication may be the single most important factor in ensuring that a child's rights are preserved and respected.

In some cases, the child himself may choose *not* to choose, being more comfortable with parents making the decisions. A fourteen-year-old boy with high verbal abilities but limited cognitive functioning was considered by many to be above average intelligence. The physician set up a meeting with the parents, the young man, and their pastor to discuss options for experimental treatment vs. no further medical treatment for a malignant tumor that had not responded to previous treatment. As the physician explained the options available, the youngster became withdrawn, hiding his face throughout the meeting. Afterward, he expressed anger at his parents for being "forced" to attend the meeting. He explained that he didn't understand what the physician was saying and would prefer to hear that kind of information from his parents. It is imperative that young people have the right to choose not to be involved, as well as the right to choose to be involved in such decisions.

Obviously, the rights of the hospitalized child are central to this discussion, and this is the population about whom the remainder of the paper will focus. Prior to asking young people to be involved in informed consent, we must assess what "informed" means in this context. Three domains have been identified that must be addressed in order for the young person to be appropriately

involved in exercising his rights. The areas include: knowledge and understanding of the disease and treatment, experience with previous decision-making opportunities (not necessarily relating to health care), and the child's foundation of emotional support. Imparting information regarding the disease and treatment is only one component of adequate education. Alone, it will not necessarily enable the child to participate in *informed* consent.

Regarding knowledge and understanding, we have the following key concepts:

- the concept of rights and what constitutes a right
- the difference between wants and needs
- cause and effect relationships
- basic anatomy, specifically as it relates to the child's disease and treatment
- disease and treatment facts
- differentiation between "good" and "bad" items in similar categories (that is, good touch/bad touch as taught at home and in school versus types of touch necessary in the hospital; illegal versus legitimate drugs, etc.

When asked to define or give an example of a right, most children between the ages of nine and thirteen were able to give some sort of definition. Responses included, "It's what the constitution says we've got"; "It means people can't do bad things to you"; and "Rights are what God gives you and people can't take away." When asked, "What rights do kids have in the hospital," no children in our study were able to give spontaneous responses. When asked further, "Do you have the right to choose between morning and night to take a bath?" an eleven-year-old girl responded, "No, you have to take it when the nurse wants you to." Although most children were familiar with the term "patient rights," they did not seem to recognize the significance of their personal rights.

The students also had difficulty differentiating between rights and wants. Cause and effect relationships must also be included in effective education. A child may be capable of assenting to a lumbar puncture, for example, if she understands that the results will indicate what medications are

needed next. Knowing that a procedure will tell doctors "How you are doing" is meaningless to a child who feels fine and knows the procedure will hurt.

It is not uncommon to hear technical explanations given to young people about their bodies focusing on things they have never learned. A seventeen year old with pancreatitis, for example, thought the pancreas was inside the stomach. Using models of organ systems or dolls with internal organs is an effective method of illustrating anatomy and informing a young person.

Obviously, an understanding of the disease, the treatment and possible side effects, necessary procedures, expected outcomes, and alternatives to treatment is essential. The child's learning style must be assessed prior to offering information. How often the child with a reading disability has been given a myriad of pamphlets and informational booklets to read!

Children today are inundated with information regarding good touch and bad touch, and their right to respond to any kind of touching that they do not like. It may be difficult, then, for a child to assume a comfortable posture with some of the necessary types of touching in a hospital. The child must be given clear explanations about what kind of touching is going to occur and why it is necessary. Specific information about the differences in types of touch is recommended.

Similarly, information about illegal drugs is prevalent in our schools. A review of the health curriculum for a Montana school district suggests that for children in kindergarten through fifth grade, a disproportionately small amount of time is devoted to appropriate use of legitimate drugs compared with drugs of abuse (Skelly 1994). It follows that a young person may be hesitant to take drugs that are unfamiliar. Again, communication and explanation are essential.

In addition to the child's knowledge base, past experiences relating to decision making and exercising of independence are of critical importance. If a child has never been allowed to make important decisions or has not been encouraged

to seek independence, it is not responsible to assume that the child will be able to do so at the time of a serious illness. The patient may need multiple opportunities for personal decision making, including support and encouragement when those attempts are not comfortable for her.

The emotional support that the child receives may also affect the ability to make decisions. The larger the circle of support, the more likely that the youngster will be able to exercise her rights. Parents, too, may benefit from support as they make the transition from making difficult decisions themselves, to allowing the young person to make her own decisions.

Through trial and error, the thrill of victory and the agony of defeat, specific components needed in an effective curriculum to teach young people about their rights as patients have surfaced. There is no one magical method to ensure that a young person has the knowledge, experiences, and emotional support to be successful in exercising her rights as a patient. Every child comes to the health care arena with a unique set of needs as well as strengths. Individualization is essential. Certain specific methods, however, when used alone or in combination, have proven effective with different children at various stages of development. For ease of discussion, the methods have been divided into three groups, based on age and developmental levels: preschool, school-aged, and adolescent. These malleable methods work effectively from one age category to the next. The needs of the specific child must be the determining factor in choosing activities. The tendency of young people to exhibit regressive behavior in the hospital is a consideration when choosing methods of instruction.

Play is an effective method of teaching young children (generally three to five-years-of-age) about themselves, their bodies, diseases and decision making. Play also affords the opportunity to increase self-confidence and establish a stronger sense of self. Medical play and manipulation of medical equipment enable the young child to achieve mastery and familiarity with previously frightening items. Primary goals for preschoolers

include establishing a sense of self as a beginning to recognition that children own their bodies, identification of previously unknown body parts, increasing responsibility and decision making. The child should be encouraged to make decisions whenever possible in the hospital (Do you want to color or paint? Which outfit do you choose to wear?). These decisions are the foundation for making health-related decisions in the future.

It may be difficult for the school-aged child to discuss feelings regarding illness and treatment. An effective alternative are "Me" dolls, fabric dolls with no face or clothing. With magic markers, the child creates a doll that conveys her own feelings; adding facial features, showing areas of pain with red or black markers, or writing feelings on the body of the doll. A nine-year-old boy recently covered his "Me" doll with broad, black streaks saying that he felt angry all over, "even in my elbows." Journals are also be effective tools.

Some of the greatest challenges in regard to practicing patient rights are experienced in the adolescent population. Adolescents are often expected to act like grown ups while being treated like children. Expectations of parents, health care professionals, and the adolescent herself are often ambiguous.

Several of the same methods — anatomy education, journals, posters, writing, "Me" dolls — are appropriate for adolescents as long as they are tailored to their developmental level. For some teens writing their autobiography gives them a forum in which they can identify and acknowledge issues of importance to them.

Computer technology affords effective techniques for teens to learn about their disease. Self-directed or teacher-directed study are possible on the Internet as well as through specific software programs. The adolescent, upon completing the research, may want to interview a physician, nurse, resident, or medical student. This technique allows the young person to increase communication, as well as knowledge. It also enables the interviewee to be more cognizant of the patient's knowledge and perspectives.

Regardless of a patient's age, it is important that a primary goal is to increase knowledge and understanding; provide opportunities to experience and practice decision-making skills; and ensure that adequate emotional support is in place. All young people benefit from decision-making opportunities in the hospital and at home. The child's choices and concerns are of primary importance.

The zeitgeist has arrived for pediatric patient rights. It is now up to us to embrace that spirit, fueling the movement to progress and grow. The voice of small people is very soft, often inaudible. Therefore, we must lend them our ears and our voices. We must encourage the children who are the driving force, parents, peers, the government, and society as a whole to support what is ethically right for children. The term ethics conjures up feelings of what is right and good. Although what is right and good is the ultimate destination in ethical issues, the route may be unfamiliar and, at times, unpleasant. Despite the journey's perils, we must keep sight of the ultimate goal: to support, empower and enable all children to have access to what is rightfully theirs. As stated by John, age six, "I don't always know what's right, but sometimes some people might help me figure it out."

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