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FROM THE EDITOR

Our Children, Our Future

Audiey Kao, MD, PhD

According to the drug company, Eli Lilly, about 400,000 children, ages 7 to 15, are "abnormally" short and could benefit from growth hormone treatment. The Food and Drug Administration (FDA) agrees and has just approved growth hormone to treat children who are healthy but short—boys predicted to be shorter than 5-foot-3 as adults and girls predicted to be shorter than 4-foot-11. Given our social norms and values, many parents, concerned about their short children, believe the FDA decision will contribute to a brighter, more promising future for their children.

Parents worldwide are concerned with their children's futures. But sadly, in many parts of the world, parental anxiety is often centered on providing the simple, basic needs of life to their children such as adequate nutrition, a good education, and access to medical care. For these parents, their child's height is the least of concerns.

Pediatricians are regularly confronted with parents who believe they are acting in their child's best interest. Since most pediatric patients are unable to fully understand their medical conditions and cannot make informed decisions for themselves, pediatricians must deal with the parental decision makers. The resulting decisions usually end up being in the child's best interest. With advancing medical technology, parents are confronted with increasingly more options for tests and procedures, some of which may be unnecessary and perhaps not even in the child's best interest. At the same time, more pediatric patients are surviving illnesses that were once fatal. As a result, there are minors with chronic illnesses who are, as they become adolescents, increasingly competent to make health care decisions. Because medicine in particular and our society in general value the development of and respect for moral agency, we encourage the increasing participation of adolescents in their health care treatment decisions. Sometimes a child's decisions are contrary to what the parents consider to be in the child's best interest and differ from decisions the parents would make and have made up to that point in the child's care. These clinical situations pose enormous challenges to pediatricians as they strive to do what they think is in their patients' clinical, psychological, emotional, and future best interests.

In this issue of *Virtual Mentor*, we examine the ethical and professional challenges in the specialty of pediatrics. This month's learning objectives are:

1. Understand the ethical issues associated with the fact that the patient is generally not the decision maker.
2. Understand what physicians can do when parents decisions appear not to be in the patient's best interest.
3. Learn methods for involving pediatric patients in decision making/assenting.
4. Understand the guidelines concerning treatment of seriously ill newborns.
5. Understand the pitfalls of prescribing for behavior on the basis of symptoms alone.
6. Learn the federal guidelines for using children as research subjects.
7. Understand methods for assessing whether minors should serve as live kidney donors.

Audiey Kao, MD, PhD is the editor in chief of *Virtual Mentor*.

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CASE AND COMMENTARY

Faith-Based Decisions: Parents Who Refuse Appropriate Care for Their Children, Commentary 1

Commentary by Robert Orr, MD

Case

Adam Lovell, an active 2 ½ -year-old boy, was healthy until the day his parents took him to the local emergency department for vomiting and a suspected case of acute gastroenteritis. To the physicians, Adam appeared lethargic and was responsive only to painful stimulus. A blood culture was obtained, and other laboratory tests were performed. The blood culture later grew a meningococcus. Within hours "purple splotches" appeared on his face, legs, and trunk. Adam was diagnosed with meningococemia and was started on appropriate antibiotics and steroids administered intravenously. Adam was intubated to stabilize his airway and transported to the County Memorial Hospital. On arrival, his perfusion was poor and blood pressure low. The tips of all his digits were dark blue; purpura (purple splotches) were present over most of his trunk, feet, and hands in a "stocking-glove" distribution. Intravenous fluid boluses and vasoactive drug infusions were administered. Adam's parents consented to multiple blood component therapy to treat a coagulopathy. Adam was also treated for respiratory failure related to meningococcal sepsis with both conventional and high frequency mechanical ventilation for the first 11 days of hospitalization.

At 10 days, Adam had well demarcated patches of dry, devitalized tissue (dry gangrene) on both of his feet, his left hand, and the fingers of his right hand. An eschar was present on the posterior surface of his right thigh. Ulcerated areas of skin were present in the perineal region. Consulting surgeons talked to his parents about the risks, benefits, and alternatives of amputation and debridement of portions of both of Adam's feet, his left hand, and the fingers of his right hand. The Lovells consented to the debridement and surgical treatment and signed the consent form. Shortly thereafter the family's minister came to the hospital and prayed with Adam's parents for God to restore life to the devitalized tissues. Soon afterward, the Lovells rescinded consent to surgical treatment and communicated that they wished to allow time to elapse so that God could heal Adam's dead and injured tissues. When the physician and the surgeon told Adam's parents that infection and sepsis would be inevitable without treatment, they agreed verbally that, in the event of sepsis, amputation should be performed.

Over the ensuing 2 ½ weeks, physicians met with the Lovells and vigorously attempted to persuade them to proceed with Adam's amputation and debridement

of dead tissues. Mr. and Mrs. Lovell remained adamant that an expectant approach be maintained. During this time neither sepsis nor wet gangrene, which would have offered absolute indication for surgical intervention, occurred. Despite the best efforts of the family and staff, many hours elapsed where Adam remained quiet and alone in his bed. He would cry and appeared to be sad. At times he cried out "hand" while gazing at his outstretched and mummified hands. During visits, the Lovells read the Bible to Adam and assured him that God would direct his hands and feet to re-grow. The Lovells asserted to the staff that Jesus had arisen from the dead and shown himself to believers, and that God would revitalize Adam's dead tissues. Both family-associated and hospital-based clergy were regularly present to expand opportunities for mutual understanding of religious and medical issues. Adam's parents were repeatedly confronted with the ever-present and increasingly imminent reality that Adam needed amputations to prevent new onset of sepsis and to avoid possible death from sepsis.

After almost a month in the pediatric intensive care unit, Adam began to experience fevers and his white blood cell counts increased; both signs were indicative of developing infection. Therapy with topical and systemic antibiotics was continued and modified. His parents were informed of the changes and of the increasing need to consent to surgical therapy. In an effort to reinforce the inescapable need for surgical therapy, the physicians consulted with a burn surgeon at a neighboring institution by telemedicine. The surgeon confirmed that amputation was unavoidable. These communications were shared with the Lovells, who nevertheless, were not dissuaded from insisting upon further observation. Despite considerable effort to understand and support the parents by their own family members, by the medical staff, by social service, by psychology and by clergy (hospital and family), a clear impasse had been reached. The Division of Social Services (DSS) was engaged to evaluate the case for a possible claim of medical neglect against Adam's parents. With the possibility of the child's custody being assumed by DSS, the parents signed consent for amputation and debridement. The mother signed consent because "only death would take my baby from me." The family requested that a "hands-on" surgical evaluation be performed at another medical facility. This request was granted. Expedited transfer was made, surgical intervention was deemed necessary by the receiving surgeon and amputation and debridement followed within 2 days.

Commentary 1

This case involves parental refusal/postponement of medically needed therapy based on a religious belief in miracles. The postponement resulted in increased patient suffering, prolonged hospital stay, and increased expense.

This case highlights potential tensions between 3 very important societal values: (a) parental responsibility and discretion; (b) professional and societal protection of vulnerable children; and (c) freedom of religion. Sometimes the outworking of such tensions leads to trade-offs, frustration, and the transition from a professional relationship that is collegial to one that is adversarial.

Parents are the natural guardians and stewards of their children. That stewardship entails a responsibility to seek the best interests of those children. Society allows parents rather wide latitude in raising and caring for their children, including societal nonintervention in situations which are potentially detrimental to those children (eg, matters of diet, lifestyle, activities, discipline). Our society is willing to step in and override parental authority, via child protective agencies, only when parental decisions involve abuse or neglect, including medical neglect.

Health care professionals shoulder a large part of the societal obligation to protect vulnerable children from medical neglect. When professionals identify a child who faces danger of death or disability because of parents' decisions, actions, or inactions, they are obligated by professional standards and mandated by state law to report the situation to the proper authorities. Those authorities will investigate and will often petition a court to determine whether the situation warrants removal of parental custody. In rare situations of imminent danger to the child, it is ethically justified for health care professionals to proceed with life-saving procedures over parental objections as the report is being made.

While making such reports is never pleasant, professionals are almost always willing to do so when a child is endangered because his or her parents demonstrate lack of understanding or lack of caring. It is distinctly more uncomfortable for them to report parents who clearly care for their children but hold personal, cultural or religious values that are at odds with those of the medical community.^{1, 2} There is a wide consensus in the medical profession and in the courts that even caring parents should not be allowed to refuse life- or limb-saving medications, transfusions, or procedures. Major difficulty often arises, however, in determining when the prognosis is sufficiently grave to warrant judicial intervention.

When parents hold a religious belief that leads them to refuse treatment for a child, at least 2 levels of understanding are needed in an effort to reach agreement. The parents need to understand the clinical situation as clearly as possible. This may sometimes be facilitated or augmented by obtaining a second (or third) opinion. It is ethically permissible to try to persuade the parents using honest facts and clear opinions, though it could be perceived as harassment if attempts at persuasion are frequent or authoritarian.

In addition, the health care professionals need to understand the religious belief as clearly as possible. These beliefs may sometimes be well understood and clearly articulated by the parents. It is often helpful, however, to involve a "religious translator" in the conversation, ie, a chaplain or perhaps another person from the parents' own faith tradition, and preferably a person with some depth of education and position of authority. One reason for utilizing such a resource person is that parents (or anyone) may sometimes focus on one religious tenet while ignoring a balancing tenet; eg, waiting for a miracle versus an obligation to preserve life and relieve suffering. A more objective look at the entire faith tradition may sometimes allow parents the freedom to consent to procedures without feeling they have

abandoned the teachings of their faith.

In this case, the parents seem to have been influenced in their refusal of surgery by their minister. The medical professionals honored their request and negotiated an agreement that specific signs would trigger surgery. Over the next 2 1/2 weeks, while the child was stable, they attempted to persuade the parents. Clergy from the hospital and from the family were "regularly present to expand opportunities for mutual understanding of religious and medical issues." The narrative does not indicate the tone or content of these conversations. Neither does it mention the denominational affiliation of this family. Consultation could have been sought with other ministers from that tradition, or other persons of religious authority, to see if this family, and especially this minister, were following all the tenets of the faith or whether they held disproportionately to one tenet over another.

In the face of an insurmountable impasse and signs of clinical deterioration, the professionals correctly sought another clinical opinion. It was probably wise to seek that opinion from outside the institution because families sometimes feel "everybody here is against us" in these situations. When the urgency of the need for surgery was confirmed, they very appropriately involved the child protective agency. This threat convinced the parents to consent to life-saving surgery after involvement of yet another consultant.

From a purely medical perspective, this child's best interests could have been better served if the parents' original consent had not been withdrawn and the subsequent 2-3 week wait in the pediatric ICU and concomitant additional suffering had been avoided. From a purely religious perspective, the best interests of this family were better served by honoring parental beliefs and waiting for clarity about medical urgency. The professionals involved are to be commended for seeking compromise, and in ultimately doing their best to honor both of their obligations: to protect human life and to respect persons with differing beliefs.

Post-Script: It is easy to look back on this case critically and say "Miracles don't happen. Belief in miracles is irrational and should not be honored." Miraculous events in medicine are exceedingly rare, and are, by definition, unexplainable. However, we should not write off individuals merely because they profess belief in miracles. At the same time, medical professionals (and hospital public relations staff) should avoid using such terms as "miracle drug," miraculous outcomes, etc. Such incorrect usage trivializes an important element found in many faith traditions.

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CASE AND COMMENTARY

Faith-Based Decisions: Parents Who Refuse Appropriate Care for Their Children, Commentary 2

Commentary by William E. Novotny, MD and Ronald M. Perkin, MD, MA

Case

Adam Lovell, an active 2 ½ -year-old boy, was healthy until the day his parents took him to the local emergency department for vomiting and a suspected case of acute gastroenteritis. To the physicians, Adam appeared lethargic and was responsive only to painful stimulus. A blood culture was obtained, and other laboratory tests were performed. The blood culture later grew a meningococcus. Within hours "purple splotches" appeared on his face, legs, and trunk. Adam was diagnosed with meningococemia and was started on appropriate antibiotics and steroids administered intravenously. Adam was intubated to stabilize his airway and transported to the County Memorial Hospital. On arrival, his perfusion was poor and blood pressure low. The tips of all his digits were dark blue; purpura (purple splotches) were present over most of his trunk, feet, and hands in a "stocking-glove" distribution. Intravenous fluid boluses and vasoactive drug infusions were administered. Adam's parents consented to multiple blood component therapy to treat a coagulopathy. Adam was also treated for respiratory failure related to meningococcal sepsis with both conventional and high frequency mechanical ventilation for the first 11 days of hospitalization.

At 10 days, Adam had well demarcated patches of dry, devitalized tissue (dry gangrene) on both of his feet, his left hand, and the fingers of his right hand. An eschar was present on the posterior surface of his right thigh. Ulcerated areas of skin were present in the perineal region. Consulting surgeons talked to his parents about the risks, benefits, and alternatives of amputation and debridement of portions of both of Adam's feet, his left hand, and the fingers of his right hand. The Lovells consented to the debridement and surgical treatment and signed the consent form. Shortly thereafter the family's minister came to the hospital and prayed with Adam's parents for God to restore life to the devitalized tissues. Soon afterward, the Lovells rescinded consent to surgical treatment and communicated that they wished to allow time to elapse so that God could heal Adam's dead and injured tissues. When the physician and the surgeon told Adam's parents that infection and sepsis would be inevitable without treatment, they agreed verbally that, in the event of sepsis, amputation should be performed.

Over the ensuing 2 ½ weeks, physicians met with the Lovells and vigorously attempted to persuade them to proceed with Adam's amputation and debridement of

dead tissues. Mr. and Mrs. Lovell remained adamant that an expectant approach be maintained. During this time neither sepsis nor wet gangrene, which would have offered absolute indication for surgical intervention, occurred. Despite the best efforts of the family and staff, many hours elapsed where Adam remained quiet and alone in his bed. He would cry and appeared to be sad. At times he cried out "hand" while gazing at his outstretched and mummified hands. During visits, the Lovells read the Bible to Adam and assured him that God would direct his hands and feet to re-grow. The Lovells asserted to the staff that Jesus had arisen from the dead and shown himself to believers, and that God would revitalize Adam's dead tissues. Both family-associated and hospital-based clergy were regularly present to expand opportunities for mutual understanding of religious and medical issues. Adam's parents were repeatedly confronted with the ever-present and increasingly imminent reality that Adam needed amputations to prevent new onset of sepsis and to avoid possible death from sepsis.

After almost a month in the pediatric intensive care unit, Adam began to experience fevers and his white blood cell counts increased; both signs were indicative of developing infection. Therapy with topical and systemic antibiotics was continued and modified. His parents were informed of the changes and of the increasing need to consent to surgical therapy. In an effort to reinforce the inescapable need for surgical therapy, the physicians consulted with a burn surgeon at a neighboring institution by telemedicine. The surgeon confirmed that amputation was unavoidable. These communications were shared with the Lovells, who nevertheless, were not dissuaded from insisting upon further observation. Despite considerable effort to understand and support the parents by their own family members, by the medical staff, by social service, by psychology and by clergy (hospital and family), a clear impasse had been reached. The Division of Social Services (DSS) was engaged to evaluate the case for a possible claim of medical neglect against Adam's parents. With the possibility of the child's custody being assumed by DSS, the parents signed consent for amputation and debridement. The mother signed consent because "only death would take my baby from me." The family requested that a "hands-on" surgical evaluation be performed at another medical facility. This request was granted. Expedited transfer was made, surgical intervention was deemed necessary by the receiving surgeon and amputation and debridement followed within 2 days.

Commentary 2

The validity of parental consent for children has been taken for granted even though the presumption that parents invariably choose in their child's best interest may at times be inaccurate. Rights are virtually never absolute and parents are not at liberty to destroy, maim, or neglect their children. Similarly, by societal convention, health care choices available to parents are not unlimited. Parents are restricted to choices that conform to societal norms. It has been suggested that parents might refuse a medical recommendation for at least 3 categories of reasons: neglect, disagreement based upon religious or other values, or inability to comply.¹ By this categorization the parents of the child discussed in the case report were neither neglectful nor

unable to comply. Clearly there was disagreement based upon religious beliefs. In 1977 Ruth Macklin wrote "Freedom of religion does not include the right to act in a manner that will result in harm or death to another."²

Another view, voiced by Peter Rosen, is that "whether...(the guardians)...are sincere, sane, and in every other capacity model parents, their insistence upon treatment that is scientifically inferior to conventionally accepted treatment is abusive, even if their intent is not."³ The *American Academy of Pediatrics* recognizes the "important role of religion in the personal, spiritual, and social lives of many individuals and cautions physicians and other health care professionals to avoid unnecessary polarization when conflict over religious practices arise. Nevertheless, physicians who believe that parental religious convictions interfere with appropriate medical care that is likely to prevent substantial harm or suffering or death should request court authorization to override parental authority or, under circumstances involving an imminent threat or a child's life, intervene over parental objections."⁴ In the case at hand, the health care team had unanimity of opinion regarding the fact that delaying surgical intervention was scientifically inferior and inadequate. The question that ultimately proved most challenging to answer was the point in time when the parental choice became unacceptable.

Surgical recommendation to perform amputation was initially made at 10 days into the hospitalization. The parents were repeatedly and vigorously apprised that delay in surgery might result in the need for more extensive amputations, other organ system morbidity, or even death secondary to sepsis. Surgical therapy was provisionally refused, and this refusal was accepted by the health care team. This refusal of surgical intervention was followed by efforts to further discuss and understand religious issues, provide parents with surgical opinion from another health care center, and continue to meet the daily health care needs of the child. In the absence of "hard-data" in the literature that addressed the medical/surgical/rehabilitative outcomes of children with gangrenous extremities treated in an expectant manner, "common-sense health care assessment" by the health care team did weigh progressively toward limiting further procrastination for the performance of surgical therapy. The hope that further discussion might persuade the parents of the need for surgical intervention faded with time. The increasing threat of sepsis mandated that child protective services be involved to evaluate for "medical neglect" or that the court be directly petitioned to hold a hearing to evaluate the need for surgery. The US Supreme Court in *Prince vs Commonwealth of Massachusetts* has determined that parents do not have the right to expose children to ill health or death in the course of their own expression of religion.⁵

The proposition that it is inappropriate for strangers (nonfamily) to be part of the agonizing treat-or-let-be decisions ignores the reality that a diligent and skillful health care team is initially more objective and later more intimately acquainted with the health care needs of the child. Particularly in the critical care environment, though the health care team begins as only a team of objective strangers, its members evolve into loving and informed allies who act from a sense of both duty

and beneficence. The perspective of the health care team is unique, intimate and important. The voice of its members needs to be heard in a court of law after concerted effort over time to understand and educate both the parents and the health care team has failed to resolve fundamental issues regarding care.

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CASE AND COMMENTARY

Spare the Rod and Save the Child, Commentary 1

Commentary by Elvira Isganaitis, MD, MPH and Robert Kamei, MD

Case

Dr. Kennedy is a family medicine physician in a mid-sized southern town. Most of the kids he treats belong to the traditional type family that is increasingly rare in urban centers but still prevalent in Dr. Kennedy's town. Of course, the town has its share of unwed teenaged mothers and kids who get into drugs and trouble, but town and church support for those in trouble is strong.

Dr. Kennedy knows that most of the families he treats discipline their kids by "not sparing the rod." That is, kids who are found out skipping school, getting failing grades, or hanging out where or with whom they should not be, get whipped with the belt. He has talked with these parents for years about this form of discipline, but they all grew up with physical discipline and they believe their own whippings are what made them into productive, law-abiding, church-going people. Dr. Kennedy keeps up his education campaign, but he hasn't convinced many parents. What they are doing works, as they see it. That's why their town doesn't have the crime and street gangs of the nearest big city.

Dr. Kennedy has never seen a kid in the ER that he suspected had broken bones or a concussion brought on by intentional beating. One day, however, Mrs. Harris brought 11-year-old Derek in for a pre-sports exam. Derek was entering middle school and was going to play soccer. The school wanted each student player to have a physical to guard against incidences of severe asthma attacks or other foreseeable reactions to strenuous work-outs. It was the last possible day before the physicians' reports were due to the school, and Dr. Kennedy fit Derek into his schedule.

During the physical, Dr. Kennedy noticed fading "stripes" on Derek's buttocks and, when he asked Mrs. Harris whether she knew how Derek got them, she said she had put them there and she'd put more there if he didn't straighten up and stop skipping school. Strangely, this was the first time Dr. Kennedy had been faced with physical evidence of the "discipline." He had known the Harrises for a long time. They were loving parents. Yet he felt as though he had to do more than just talk to Mrs. Harris once again about disciplining her kids.

Commentary 1

Does a minor physical injury inflicted with a child's best interests at heart count as

child abuse? What are a physician's ethical and legal responsibilities in such instances?

The American Academy of Pediatrics (AAP), in its 1998 Policy Statement on "Guidance For Effective Discipline,"¹ sets forth working definitions to help physicians distinguish between appropriate forms of discipline and physical abuse. The term discipline (from the Latin "disciplinare" = to instruct) refers to the "teaching and nurturing that children receive to achieve competence, self-control, self-direction, and caring for others."² Punishment is defined as the application of a negative stimulus to reduce or eliminate a behavior. Two types of punishment are typically used with children: verbal punishment, which may consist of reprimands and disapproval, and punishment involving physical pain, as in corporal punishment.

Corporal punishment—which may range from slapping and spanking to beatings and burnings—is a controversial discipline strategy. While some argue that corporal punishment is never acceptable in any of its forms, others view spanking as a useful disciplinary tool provided it is used infrequently and in children of the appropriate age. Spanking (ie, striking with an open hand) may be an effective negative reinforcement in a school-aged child, but carries an unacceptable risk of serious injury when used in children less than 18 months.¹ Appropriate discipline should not leave a child with a lasting injury.

Physical abuse refers to any inflicted, non-accidental injury;³ this includes any injury inflicted with an object as well as any injury not in keeping with the history given or with the child's development.¹ Corporal punishment constitutes physical abuse if it leaves a skin injury that lasts more than a few minutes.⁴ Child abuse remains common in North American society, resulting in 1000 deaths per year in the US alone.³ Corporal punishment severe enough to qualify as physical abuse, including beatings with rods and belts, occurs in up to 35 percent of middle class American households.⁵

Spanking is no more effective than non-violent discipline methods such as time-out or removal of privileges for reducing undesired behavior in children.⁶ In addition, its use carries a risk of physical injury and models violent behavior.⁷ For these reasons, the AAP recommends that parents be "encouraged and assisted in developing methods other than spanking" when disciplining their child.¹

When faced with instances of physical punishment that meet criteria for child abuse, physicians are posed an ethical dilemma. The central ethical conflict lies in reconciling, on the one hand, parents' rights to raise their child according to whatever personal or religious principles they choose, with on the other hand, the child's right to freedom from physical harm and violence. In addition, physicians are bound by legal obligations to report any suspected incidences of child abuse.

In general, a physician's role in negotiating ethical dilemmas is threefold. First, they must promote informed decision making by parents and children; second, the

physician should act as a children's advocate; and finally, they should override parents only as a last resort.³ These ethical principles will serve as a framework for the remainder of our discussion.

Promote informed decision making by parents and children

Primary care providers must be approachable, non-judgmental, and comfortable when broaching issues of discipline during health maintenance visits. While over 90 percent of pediatricians report discussing discipline in general with their patients,¹ only 53 percent report discussing the pros and cons of corporal punishment in particular.⁸ This lack of communication may in part explain the widespread use of corporal punishment among North American families, over 90 percent of which use spanking.⁹ While spanking was formerly accepted and even promoted as an effective disciplinary method, more recent studies have cast doubts on its usefulness. When educating families about discipline, physicians can draw on an extensive body of research documenting the adverse effects of corporal punishment.¹⁰ Parents must often escalate the intensity of the punishment, which risks leading to physical abuse. Spanking is associated with higher rates of substance abuse, depression, and discipline problems.¹¹ Moreover, spanking models the use of violence in conflict resolution, which may explain why children subjected to corporal punishment are more likely to be involved in violent crimes and intimate partner violence as adults.¹² It may also be appropriate for physicians to provide information about local laws surrounding child abuse and mandatory reporting statutes. For more information on these, physicians may refer to the following helpful website: http://www.smith-lawfirm.com/mandatory_reporting.htm.

Act as a children's advocate

A physician's role in preventing physical abuse and encouraging appropriate forms of discipline is not limited to the confines of their office. Physicians can play an active role in changing community attitudes toward corporal punishment by enlisting the help of other community leaders (eg, teachers, priests or ministers, police officers). Physicians caring for children must realize that they are authorities in appropriate child-rearing practices. They may be called upon to deliver their educational message in many venues, ranging from op-ed pieces for local newspapers to testifying for various levels of government.

Override parents only as a last resort

When a provider is presented with clinical evidence of physical abuse, reporting to local authorities is not only clinically indicated but also mandated by law. All 50 states have passed legislation requiring that professionals, including health care workers, who come into contact with children report any suspected abuse.¹³ Contacting Child Protective Services (CPS) is appropriate when the clinician has grounds to suspect that physical, sexual or emotional abuse has occurred. Providers should assess the potential for irreversible injury or fatality. Risk factors for violence (eg, marital conflict, alcohol abuse, drug use, financial instability) should also be taken into account in raising or lowering thresholds for reporting.

In the case scenario presented above, interventions such as office-based parental education have failed. Even though the mother's has good intention in disciplining her son, the bruises on his buttocks are a physical injury that mandates reporting. However, CPS referral should be done with a realization that it is a therapeutic and not punitive measure. An initial discussion with CPS may help the physician work out the best course of action to help this family. In addition, CPS may provide resources such as counseling and respite daycare to families, thereby remedying dangerous patterns of interaction and preventing the devastating consequences of child abuse. Because the potential harm to a child in cases of abuse is so great, false positive reports to CPS are acceptable. Moreover, the provider is immune from civil or criminal liability should an abuse report made in good faith later prove to be unfounded.¹⁴

While there are clinical definitions to help physicians determine whether child abuse has taken place, these criteria are guidelines and cannot replace sound judgment. If the provider in the case had been faced with only a history of corporal punishment rather than physical injury (ie bruises), it might be acceptable to proceed with education, counseling, and close follow-up. Yet the intentional nature of the injury in this case scenario and the possibility for escalating injury in the future mandates that the provider mobilize resources to protect this child.

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CASE AND COMMENTARY

Spare the Rod and Save the Child, Commentary 2

Commentary by Arthur F. Kohrman, MD

Dr. Kennedy is a family medicine physician in a mid-sized southern town. Most of the kids he treats belong to the traditional type family that is increasingly rare in urban centers but still prevalent in Dr. Kennedy's town. Of course, the town has its share of unwed teenaged mothers and kids who get into drugs and trouble, but town and church support for those in trouble is strong.

Dr. Kennedy knows that most of the families he treats discipline their kids by "not sparing the rod." That is, kids who are found out skipping school, getting failing grades, or hanging out where or with whom they should not be, get whipped with the belt. He has talked with these parents for years about this form of discipline, but they all grew up with physical discipline and they believe their own whippings are what made them into productive, law-abiding, church-going people. Dr. Kennedy keeps up his education campaign, but he hasn't convinced many parents. What they are doing works, as they see it. That's why their town doesn't have the crime and street gangs of the nearest big city.

Dr. Kennedy has never seen a kid in the ER that he suspected had broken bones or a concussion brought on by intentional beating. One day, however, Mrs. Harris brought 11-year-old Derek in for a pre-sports exam. Derek was entering middle school and was going to play soccer. The school wanted each student player to have a physical to guard against incidences of severe asthma attacks or other foreseeable reactions to strenuous work-outs. It was the last possible day before the physicians' reports were due to the school, and Dr. Kennedy fit Derek into his schedule.

During the physical, Dr. Kennedy noticed fading "stripes" on Derek's buttocks and, when he asked Mrs. Harris whether she knew how Derek got them, she said she had put them there and she'd put more there if he didn't straighten up and stop skipping school. Strangely, this was the first time Dr. Kennedy had been faced with physical evidence of the "discipline." He had known the Harrises for a long time. They were loving parents. Yet he felt as though he had to do more than just talk to Mrs. Harris once again about disciplining her kids.

Commentary 2

First of all, Dr. Kennedy must recognize his status as a "mandated Reporter" (at least in most states) ie, once he recognizes evidence of possible or evident abuse, he is required to report his observations to the State Child Protection Agency.

However, we know that many physicians, particularly those in positions like Dr. Kennedy, do not report as mandated.

The family pediatrician, who knows (or thinks he or she knows) the patients very well is appropriately conflicted between the duty to report and the very real risk of rupturing a long-term, mutually respectful and productive relationship by the act of confronting parents with what appears to be real physical assault on the child. As is pointed out in the case presentation, local cultural mores may permit or even encourage physical punishment (most of which goes undetected) as an important part of child-rearing; nonetheless, the potential or actual damage to the child must be acknowledged and stopped. Unfortunately, we know of many cases of culturally or religiously justified punishment has led to the serious injury and even the death of the child victims.

There are a variety of ways in which Dr. Kennedy might both fulfill his obligation to the law and the child and, at the same time, try to make the family understand his position and reasoning—these may not be successful, and the physician-family relationship may deteriorate; that outcome (if it occurs) must be accepted as a risk by the physician.

In this case, it may be useful for the physician to probe with Derek (alone) his reasons for skipping school and the other behaviors which lead to physical punishment—Dr. Kennedy might then be armed to help the family understand how their actions were worsening the situation, and bringing on the errant behavior of their son.

This physician's obligation to the child cannot be compromised; he should report the child's situation to the Child Protective Agency, after meeting with the child and the parents, and disclosing to them his mandate to report his observations. At the same time, he could offer to follow closely with the family during the investigation and to discuss alternative (non-physical) methods of punishment, at the same time counseling with Derek about his behaviors and their causes.

This is a tough problem for Dr. Kennedy, but his first responsibility is to the child; his efforts to change the community's understanding of the consequences of physical punishment is laudable and should continue; it is an important form of child advocacy.

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CASE AND COMMENTARY

Obesity as Medical Neglect: Should Doctors Report?

Commentary by David Collier, MD, PhD, Ronald M. Perkin, MD, MA, and Joseph R. Zanga, MD

Case

MD is a 15-year-old Hispanic boy with a medical history of chronic renal failure (CRF) and morbid obesity. As an infant, MD was taken from a migrant worker camp into the custody of the Department of Social Services because his biological mother failed to provide adequate nutrition and care. He was later adopted by a family that attended more closely to his needs and care. At age 2 he was diagnosed with renal failure secondary to focal segmental glomerular sclerosis (FSGS) and required peritoneal dialysis until age 3, when he received a cadaveric kidney transplant.

Over time MD's linear growth decelerated, crossing from about the 25th percentile at age 6 to less than the 5th percentile by age 8. At 11, he had an acute rejection event, and he has remained in chronic renal failure. MD has experienced other problems related to his renal failure such as hypertension and renal osteodystrophy.

MD suffers from excessive weight gain; at his current height of 134 cm (5th percentile) and weight of 130 kg (>95th percentile) his body mass index is 72 kg/m², which greatly exceeds the 95th percentile for his age and sex. He suffers from many of the morbidities associated with obesity, including obstructive sleep apnea, and requires continuous positive airway pressure (CPAP) while sleeping. He has dyspnea on exertion and severe exercise intolerance resulting in both his inability and unwillingness even to take walks around the neighborhood. MD does not attend high school because he cannot tolerate moving from class to class. The hypertension associated with CRF is exacerbated by his obesity, and he has developed left ventricular hypertrophy. His excessive weight stresses his musculoskeletal system, and in concert with renal osteodystrophy, has resulted in genu valgum (deformity of the legs that produces "knock knees") requiring surgical repair. He has poor self-esteem and periods of depression and has developed ADD secondary to sleep apnea (no longer requiring medication because of CPAP treatment). MD's elevated insulin levels (fasting c-peptide level of 7.4, normal range 0.4-2.2) suggest that he has developed insulin resistance that will likely progress to type II diabetes. MD needs treatment for the chronic renal failure but his obesity makes him a very poor candidate for either dialysis or a repeat transplant. His obesity is, therefore, exacerbating the morbidity and mortality risks associated with his underlying renal disease, may prevent him from getting the definitive life-

preserving treatment he needs (a kidney transplant), and is causing morbidity and mortality risks independent of his renal disease.

MD and his family have been told about the risks associated with his obesity, have received extensive dietary counseling, and have worked with mental health services. Social workers, occupational therapists, and exercise counselors have all visited the family's home. On 2 different occasions, when MD was 12 and again at 13, he was admitted to inpatient rehabilitation facilities to increase his exercise tolerance and weight loss. On both occasions MD lost weight, but his family withdrew him because they felt that he was being "starved" and treated cruelly. He was also enrolled in a hospital-based outpatient wellness/fitness program, from which his parents also withdrew him. MD rarely brings his food diary to appointments with his dietician, and his parents also refused a proffered liquid diet because they felt it would be cruel to him. The patient and his family acknowledge that he is excessively overweight, but blame his medications, including steroids (currently 10 mg prednisone per day), and wish "there was a magic bullet" to solve this problem. With respect to all other aspects of his health care, MD and his family are extremely reliable, and he is apparently compliant with his medications.

Commentary

In the United States, physicians and other health professionals who suspect that a child is being abused or neglected have a legal, and ethical, responsibility to report that suspicion to child protective services. By definition a neglected child is one "who does not receive proper care, supervision, or discipline from the juvenile's parent, guardian, custodian, or caretaker; or who has been abandoned; or who is not provided necessary medical care; or who lives in an environment injurious to the juvenile's welfare; or who has been placed for care or adoption in violation of the law."¹ In light of that definition would a report filed with respect to MD be appropriate?

According to CDC guidelines, children between the ages of 2 and 18 years with a body mass index ($BMI = wt [kg]/ht^2 [m]$) that exceeds the 95th percentile for age and sex norms are overweight (obese). Although not a measure of adiposity, BMI is a simple screening tool for identifying children at risk, is the same measure used for adults, and correlates well with the complications of obesity.

Both adults and children suffer from these complications² to greater or lesser degrees. For children, orthopedic complications include tibia vara and slipped capital femoral epiphysis. Obesity is also the most important preventable risk factor for the development of osteoarthritis. Metabolic and endocrine disorders, including insulin resistance, dyslipidemia, and hypertension (syndrome X/metabolic syndrome), and polycystic ovary disease are associated with obesity. Previously rare in children, the prevalence of non-insulin-dependent diabetes mellitus (NIDDM) has increased approximately 10-fold in concert with the increased prevalence of childhood obesity. Children as young as 4 are known to be affected.³ Obesity can affect neuro-cognitive and behavioral function by causing pseudo-

tumor cerebri or excessive daytime somnolence (or hyperactivity) which can result in impaired school performance. Cardiomyopathies such as cor pulmonale and left ventricular hypertrophy may develop in response to obesity-related sleep apnea, systemic hypertension, and hypopnea/hyperventilation, which may be refractory to treatment with simple nasal CPAP and require BiPAP and high airway pressures, and can result in congestive heart failure and death. At the very least, the problems of poor self-esteem, stigmatization, depression, and severe exercise intolerance can lead to social withdrawal, isolation, and difficulties with activities of daily living.

Many of these problems are illustrated by the child in question. MD's long and short-term health and activities of daily living are clearly compromised by his obesity. Weight loss is considered medically necessary for his well-being, but the process was undermined by his parents who failed to effect the recommended changes. They therefore are, by definition, neglectful.

Clearly there was a *legal* duty to report this child as neglected, but are there rights, duties, values and ethical considerations that might not support such action? While the most important consideration is to determine what is in the best medical interest of the child, health professionals must also consider the confidentiality rights of the patient, and must respect both the patient's and the family's autonomy. The therapeutic alliance with them must also be maintained. Therefore, evaluating the utility of reporting, presuming benefit to the child versus the harm it may cause, gives some health professionals pause.

The following were issues discussed and weighed in MD's case:

Diet and exercise, at least in the short term, had proven successful in helping this patient maintain or lose weight. By undermining his diet and exercise program, his parents neglected his health.

Many other post-transplant patients on the same regimen do not become morbidly obese, therefore MD's BMI cannot be ascribed strictly to his medications (as his parents wish to think).

Weight reduction programs that work for modestly obese patients (140-150 percent of ideal body weight) are ineffective for very obese patients (190 percent of ideal body weight or greater). MD is > than 300 percent of his ideal body weight.⁴

MD is now an adolescent with increasing levels of autonomy and self-determination. At this juncture therefore, his parents cannot be held entirely responsible for his behavioral choices, even those that are self-destructive.

The decision to report is not as straightforward as it seems.

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CASE AND COMMENTARY

Palliative Care for an Infant with Short Bowel Syndrome and Advanced Liver Disease, Commentary 1

Commentary by Mark Sheldon, PhD

Case

After 5 months of routine NICU Care, and treatment for malabsorption and malnutrition, Mary was discharged from the NICU and allowed to go home with her parents. Eight hours after discharge, her parents brought her back to the hospital with fever and vomiting. During this second hospitalization, Mary had bacterial and fungal infections, multiple changes in her vascular access sites, and complications, including advanced liver disease, from the total parenteral nutrition (TPN). Her liver dysfunction was characterized by abnormal coagulation, only partially corrected by blood products and vitamin K, hypoalbuminemia, and hypoproteinemia. She bled from her nose and mouth after crying or sneezing, and extensively from her ostomy site. Mary had multiple episodes of hypovolemic shock that required blood transfusions. Her massive hepatosplenomegaly interfered with respiration.

Early in her NICU stay Mary's physicians discussed with the Janes the possibility of transporting Mary to another medical center for an intestinal transplant. Mary's parents appeared to understand the seriousness of their daughter's condition and wanted the doctors to do "everything possible" for her. Mary's liver dysfunction progressed and she became more edematous, had skin breakdown, and had to be more frequently volume resuscitated and transfused. Her tenuous condition now made it impossible to consider moving her to another location for a transplant. Mary's physicians considered her condition terminal and could see that she was suffering.

Dr. Andrews and her colleagues tried to talk to the Janes about palliative care and the imminent death of their daughter. In one instance Dr. Andrews approached Mrs. Jane, who never left the hospital unless her husband or mother came to relieve her, but Mrs. Jane stopped Dr. Andrews in mid-sentence.

"I see where you're going with this, Dr. Andrews, but my baby is strong. Children are resilient. Mary got well enough to go home once and she'll do it again, we've just got to give her a little time."

*The patient's name has been changed to protect her privacy and that of her parents.

Commentary 1

This is a case where it is important for Dr. Andrews to remember 2 things: who the patient is and the Hippocratic Oath. The patient is Mary Jane and the Hippocratic Oath states, "...I will keep them [patients] from harm."

It is particularly difficult to remember who the patient is when the patient is a child and there are loving parents involved. Psychologists indicate that there is hardly an experience more painful and traumatic than the loss of a child. Parents clearly and reasonably expect to die before their children; a child's death goes against the natural order. The essential role of parent is to protect the child. Furthermore, if the physician is a parent, he or she may identify too strongly with the parents, or may feel guilt in connection with the fact that his or her own child is healthy while the patient is dying. All of this means that the tendency of the physician will be to continue to treat as long as there are treatment alternatives to pursue.

Much has been written about the importance of recognizing that the family is often centrally involved in the treatment of any patient and may be even more involved in the cases of pediatric patients. No one would take issue with a concern to accommodate the wishes of the family to the extent possible. For physicians and staff the hospital world is routine, and they may not always appreciate the challenges families confront when a loved one is hospitalized. Given the extent to which the treatment of illness and disease is so completely institutionalized in our society, however, it is not unusual for families to face, for the first time and all at once, 3 very significant challenges: an exceedingly technologically complex and unfamiliar environment, an experience of great emotional and psychological complexity, and enormous personal responsibility. And it is the task of the physician and staff to educate the family in regard to all 3 and to help the family cope.

The neonatal unit, particularly, is a place of great technological complexity. The case description makes clear that everything has been done for this baby. One imagines that the parents have been engaged in a huge effort to understand the options that the technology has made available for the treatment of their baby, although it is not clear that they have fully appreciated the cost to their baby of such efforts. Considering their baby's pain and suffering, one is not able to imagine the emotional and psychological anguish that the Janes have experienced. It is likely that nothing in their previous lives prepared them for the profound responsibility that they are being asked to shoulder.

Another feature of this case, which Dr. Andrews should take into account, is that the neonatal unit is a place that requires a team effort. Nurses have been involved fundamentally in the care of this infant, probably at great emotional cost to them. As the baby's skin breaks down, they, more than anyone, are aware of what the baby must endure if additional life-saving interventions are undertaken. The physician is accountable to her staff, as well as the parents, and the conscientious staff takes the imperative to do no harm just as seriously as do the physicians.

True, much is remarked about the resilience of children. Pediatricians are often surprised when a child pulls through. But it is clear that there are cases where such an outcome will not be possible, and this is one of those cases. This case has involved the pursuit, by clinicians, of every available heroic intervention that might provide benefit. However, the issue, at every step of the way, has been whether any benefit could be achieved that would outweigh the burden, the discomfort, and the suffering to which the baby was subjected as these interventions were undertaken.

At this point, it is clear that no further benefit can be provided, all options have been exhausted, and the baby stands only to experience more suffering and pain. Furthermore, she will die regardless of what is done. This is the time for Dr. Andrews to bring her professional judgment to bear. This is what being trained to exercise professional judgment is all about. Gently and firmly, she must refuse any interventions that aim at prolonging the baby's life. She must say "no" to the parents and explain that, ultimately, the baby is her patient, her responsibility, and that her professional ethic requires her to refuse to intervene aggressively to prolong this baby's suffering. It is time, she must explain, to shift entirely to palliative care in an effort to keep the baby comfortable and allow her to die. If the parents refuse, she must tell the parents that she can no longer care for this baby, that what they are asking her and her staff to do constitutes a harm that is not acceptable.

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CASE AND COMMENTARY

Palliative Care for an Infant with Short Bowel Syndrome and Advanced Liver Disease, Commentary 2

Commentary by Roytesa Savage, MD, Ronald M. Perkin, MD, MA, and Joseph R. Zanga, MD

Case

After 5 months of routine NICU Care, and treatment for malabsorption and malnutrition, Mary was discharged from the NICU and allowed to go home with her parents. Eight hours after discharge, her parents brought her back to the hospital with fever and vomiting. During this second hospitalization, Mary had bacterial and fungal infections, multiple changes in her vascular access sites, and complications, including advanced liver disease, from the total parenteral nutrition (TPN). Her liver dysfunction was characterized by abnormal coagulation, only partially corrected by blood products and vitamin K, hypoalbuminemia, and hypoproteinemia. She bled from her nose and mouth after crying or sneezing, and extensively from her ostomy site. Mary had multiple episodes of hypovolemic shock that required blood transfusions. Her massive hepatosplenomegaly interfered with respiration.

Early in her NICU stay Mary's physicians discussed with the Janes the possibility of transporting Mary to another medical center for an intestinal transplant. Mary's parents appeared to understand the seriousness of their daughter's condition and wanted the doctors to do "everything possible" for her. Mary's liver dysfunction progressed and she became more edematous, had skin breakdown, and had to be more frequently volume resuscitated and transfused. Her tenuous condition now made it impossible to consider moving her to another location for a transplant. Mary's physicians considered her condition terminal and could see that she was suffering.

Dr. Andrews and her colleagues tried to talk to the Janes about palliative care and the imminent death of their daughter. In one instance Dr. Andrews approached Mrs. Jane, who never left the hospital unless her husband or mother came to relieve her, but Mrs. Jane stopped Dr. Andrews in mid-sentence.

"I see where you're going with this, Dr. Andrews, but my baby is strong. Children are resilient. Mary got well enough to go home once and she'll do it again, we've just got to give her a little time."

*The patient's name has been changed to protect her privacy and that of her parents.

Commentary 2

Mary Jane was indeed a resilient infant, and, over the course of her short life, her parents, particularly her mother, not unexpectedly bonded with her and likely contributed to that resilience. Unfortunately her short bowel syndrome and advanced liver disease made it impossible to nourish her adequately by either parenteral or enteral means. Intestinal transplant was considered but quickly became an unreasonable option in light of the severity of Mary's liver disfunction. Even in the best of circumstances, however, likelihood of 1-year survival after intestinal transplant is only approximately 50 percent,¹ making the decision to operate a difficult choice for parents and a difficult recommendation for physicians to make.

In this infant's case other choices were equally difficult, and ethical discussions began to assume as much of a role in her care as the medical discussions. Nonmaleficence was the first consideration, given that the total parenteral nutrition, initiated to sustain the child's life, was ultimately hastening her death by destroying her liver. Withholding this therapy was therefore ethically permitted if not obligated.²⁻³

The physicians, not the parents, ultimately concluded that the greatest benefit to Mary, and the most appropriate therapy, was to offer comfort care. In this they were supported by the American Academy of Pediatrics' Committee of Bioethics which in 1994 concluded that "continuing non-beneficial treatment harms many patients and may constitute a legal, as well as moral, wrong."⁴

As consideration of the appropriateness of palliative care continued, some members of Mary's health care team wondered whether it might be illegal to withdraw nutrition and hydration, citing the 1984 Department of Health and Human Services amendments to the Child Abuse Prevention and Treatment Act. These regulations, commonly known as the "Baby Doe Regulations," require that, except under certain specified conditions, all newborns receive maximal life-prolonging treatment. While still criticized by some, the Baby Doe Regulations continue to influence decision making for terminally ill newborns.⁵⁻⁶ There is clear consensus, however, that withdrawal of artificial nutrition and hydration when they are more harmful than helpful and when the child's parents or legal guardians are in agreement, is fully acceptable and justifiable both legally and morally.

For a variety of reasons Mary's parents (and others in similar circumstances) were unwilling to consider palliative care. Health professionals are often unwilling to embark on this course due to concern about hastening death. Ethical consideration of aggressive palliation often includes a discussion of the principle of double effect.⁷ This principle, which stems from the moral theology of Thomas Aquinas, states that an action with both a good and bad effect is ethically permissible if the following conditions are met:

1. The action itself is morally good or at least indifferent.
2. Only the good effect is intended (even though the bad or secondary effect may be foreseen).
3. The good effect must not be achieved by way of the bad.
4. The good effect must outweigh the bad.

Often the most difficult aspects of initiating such an approach to care is reluctance on the part of health professionals,⁸ and the lack of understanding by patients, parents, or relatives. It is of course not a decision to be made lightly, and in the case of Mary Jane it is clear that additional discussion was required between Dr. Andrews and the parents before such an approach could be accepted.

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IN THE LITERATURE

Children as Live Kidney Donors for Siblings

Catherine Kim

According to Dr. Aaron Spital, studies suggest that kidney transplantation from living donors offer the best results for pediatric patients with end-stage renal disease. Fortunately, many parents are willing to donate a kidney to improve the health of their child. Not all parents can donate, however, because of tissue incompatibility with their child, and not all patients have such willing parents. Under some circumstances, pediatric patients in need of a renal transplant look to siblings for a kidney donation.¹

Organ transplantation involving living, related minors is ethically complex for several reasons. First, most medical decision-making for minors is based on the therapeutic value of the procedure in question. In the case of live organ transplantation, the minor donor does not receive any physical benefit from the surgery. Second, the legal category of "minor" encompasses a wide age range and varying levels of maturity, posing questions such as how to treat a 7-year-old potential donor versus a 17-year-old potential donor. Third, in cases where the minor donor and recipient are siblings, the conventional models of medical decision-making become more complicated.

Since living donor transplantation is controversial, several cases of sibling-to-sibling kidney transplantations have appeared in US courts. Many of the court rulings have approved such transplantations, even those using minor donors, on the grounds that the donor will receive psychological benefits as a result of the procedure. Robert Crouch and Carl Elliott state that courts claim to base their decisions on the best interests of the donor; however, since organ transplantation provides no physical benefit to the donor, the courts broaden the construct of "best interests" by including psychological benefits.²

Spital believes that basing court decisions solely on psychological effects is problematic. How can a judge determine what degree of psychological benefit is sufficient to justify the risks involved in transplantation?¹ It is also impossible to predict with complete confidence the psychological influence that organ transplantation will have on a child. Even if the courts' identification of positive psychological effects is accurate, Crouch and Elliott believe that it is most likely a young child will not experience those benefits due to his or her mental, emotional, and moral immaturity. But, they argue, an adult sibling donor is mentally developed enough to wish to donate for reasons other than his or her own psychological

benefit. In this context, the authors discuss "self-regarding interests" and "other-regarding interests." "Self-regarding interests are those that relate exclusively to the well-being of the agent himself or herself. Other-regarding interests involve the desires that an agent has for the well-being of another person."² Crouch and Elliott suggest that, although the intertwining of self-regarding interests and other-regarding interests is reasonable in a competent adult, in many cases it is unclear whether a potential child donor has developed an other-regarding interest in the sibling recipient. If the other-regarding interest is weak or does not exist, then many of the psychological benefits identified by the courts are no longer valid.

Although young children may not fully comprehend the implications of undergoing organ removal, older minors may be mature enough to participate in making such an important decision.¹ The Council on Ethical and Judicial Affairs of the American Medical Association has stated: "In general, adolescents 14 and above appear mature enough to make decisions about their medical care, but [capacity] must be evaluated on a case by case basis."³ The council also recommends using the courts to help assess and confirm the minor's competence and maturity. However, Crouch and Elliott strongly critique the grounds on which courts' have allowed sibling kidney transplantation from minor donors. In *Masden v Harrison*, the justice approved of a kidney transplant between 19-year-old twins, legally still minors, since the age of majority in Massachusetts was 21.⁴ The decision was made on the basis that the death of one of the twins would have a profoundly negative psychological impact on the other. This same line of reasoning was used in *Hart v Brown* to support a kidney transplant between a 7-year-old girl and her twin sister.⁵ Crouch and Elliott criticize the courts' use of the same psychological benefits argument in 2 cases dealing with minor donors of vastly different maturity levels.

Several court decisions regarding live organ donation from children have been based upon the formal constructs of the "best interests" standard and the sovereign, independent, and self-interested human agent. However, according to Crouch and Elliott, this is an inaccurate description of the human agent among siblings, which is often the relationship between a minor donor and recipient. Family members love each other and are of priceless importance in each other's lives. "To attempt to cram a formal relation into an intimate context does violence to the morally significant aspects of the family relationship," the authors say.² Crouch and Elliott believe that a more accurate representation of the human agent within the family recognizes that the best interests of family members are not independent and self-interested but rather strongly entwined.

Crouch and Elliott do not imply that kidney transplantations between living, related minors should never occur. Rather, they argue that justification for the transplantation must recognize that it is not the child donor's best interests as an individual that are being served, but instead the interests of the family as a whole. They also caution against children being unduly influenced by parents who must balance the best interests of the child donor with those of the related recipient. In short, they question the grounds on which previous court decisions regarding child

donors have been made and urge that courts consider the potential risks and benefits to the donor, the probability of a successful outcome, and possible alternatives.

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IN THE LITERATURE

The Pediatrician's Role in Family Decision Making

Susanna Smith

The bounds of the patient-physician relationship are difficult to define in pediatrics because of the necessary involvement of the child's surrogate decision maker usually, the parent. The triadic relationship, patient-parent-physician, adds complexity because it often means considering both the child's best interests and what his or her parents see as the family's best interests. The literature has raised questions about the appropriate role of parental and family interests in clinical decision making for children.

In a recent report, the Task Force on Family of the American Academy of Pediatrics (AAP) has taken an interesting look at the patient-parent-physician relationship by examining the appropriate role for pediatricians in family decision making.¹ For example, what is the physician's role when parents divorce and a custody battle ensues? Is it appropriate for a pediatrician to speak to a patient's parent about healthy parent-to-parent communication? A quarter of all pediatric office visits are associated with children's psychosomatic, social, or behavioral problems,² a fact which suggests that parents often turn to pediatricians to treat problems other than childhood illness and for assistance in raising socially integrated, well-adjusted children.

The AAP task force points out that the primary role of pediatricians is to treat illness and maintain child well-being, but it emphasizes that this must be done within the context of the family. This expansion on the traditional role of the pediatrician requires an understanding of the family's strengths and weaknesses and a push from the physician to promote the coherence and healthiness of the family structure because it is so closely linked to the child's well-being.

The task force suggests that it is necessary for pediatricians and family researchers to work together towards a greater understanding of how successful families function and of how to improve weaker families and teach them to be more supportive. The report stresses the need for physicians to recognize the diversity among families and to encourage resilience within families. The report calls for closer alliance not only between family researchers and pediatricians but also between pediatricians and parents, by suggesting it is appropriate for pediatricians to take on the role of the parents' coach in learning how to be better caregivers.

In formulating its policy recommendations, the task forces considered both

pragmatic and philosophical issues. For example, are current reimbursement practices sufficient for pediatricians to extend clinical encounter time to family concerns? What does society see as an appropriate role for nonfamily members, such as physicians, in child rearing?

Despite pragmatic challenges and perhaps some societal objections, the task force believes that the importance of families to children's well-being makes it imperative that pediatricians take a more active role in encouraging healthy families. Although the AAP has acknowledged in the past the role of families in the practice of pediatrics, this report calls for pediatricians as a group, as well as individual physicians, to more diligently and consistently advocate for the promotion of child health by supporting their patients' families.

The report offers 80 recommendations, which can be grouped into 4 categories. The first category covers educational recommendations for both residency programs and continuing medical education, such as requiring residents to be able to explain the value of a father's involvement in the home and assist families in understanding the problems and risks associated with stepfamilies and live-in partners. The AAP also advocates that continuing medical education for pediatricians should include, for example, a course that examines both the impact of a child's health problem on the family and the impact of the family's problems on the child's health. Second, the task force recommends that the AAP advocate both publicly and internally for policies and education programs that "encourage, support, promote, and help to sustain healthy marriages."³ While the report finds value in the traditional 2-parent family, it also stresses the need for pediatricians to help families of all varieties to understand and meet the needs of the family's children.

The third category encompasses practice-directed recommendations such as pediatricians helping parents understand and fulfill their roles as the primary caregivers to their children's physical, emotional, and social well-being. For example, it is appropriate, according to the report, for pediatricians to discuss such issues with parents as daily child care arrangements, parental choices concerning work schedules, and how much time they choose to allocate to their children, as well as other family members' tobacco or alcohol use and how it may affect the children in the home. Finally, the report makes a number of recommendations for future research such as studying how best to support single-parent families and how best to involve absentee or adolescent fathers in the lives of their children.

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HEALTH LAW

Overriding Parental Decision to Withhold Treatment

Michael Woods, MPH

Jennifer Moore was admitted to the hospital with symptoms of premature labor. An ultrasound revealed that her fetus weighed approximately 629 g and had an estimated gestational age of 24 weeks, a full 14 weeks before term. Doctors also feared that Mrs. Moore might have a life-endangering infection. Dr. Black, Jennifer's attending obstetrician, and Dr. Hudson, a neonatologist, informed Mrs. Moore and her husband that if the baby were born alive and survived, she would suffer severe impairments. The Moores were also told that the hospital had never been able to save a child born this prematurely and that, although every year for the past 5 years, the birth-weights of children who survived had gotten lower, anything they did to sustain life would be guesswork. Dr. Black indicated that, due to Mrs. Moore's life-threatening infection, an abortion was not an option. Finally, the physicians informed the Moores that the baby would be born within 24 hours.

Considering all their options, the Moores orally requested that if the baby were born alive, no heroic measures be used to keep her alive. Dr. Hudson recorded the Moores' oral request in the medical records, and Dr. Black informed the nursing staff that no neonatologist would be needed at delivery.

After further consultation, however, Dr. Black concluded that if the Moores' baby were born alive and weighed more than 500 g, the medical staff would be obligated by hospital policy to administer life-sustaining procedures even if the Moores did not consent to it. Dr. Black explained this to Mr. Moore who forcefully reiterated the couple's desire that their baby not be resuscitated. Consultation on the option of seeking court authority to treat was brought up but, with the estimated time of delivery unknown, no action was taken.

Approximately 11 hours later Heidi Moore was born. The attending neonatologist, Dr. Fields, determined that Heidi was viable and instituted resuscitative measures. Although Heidi survived, she suffered, as had been anticipated, from devastating neurological impairment.

Legal Analysis

The above facts are adapted from *HCA, Inc v Miller*.¹ The Millers filed a lawsuit against HCA, Inc, HCA-Hospital Corporation of America, Hospital Corporation of America, and Columbia/HCA Health Care Corporation (collectively "HCA"), asserting that they were liable for the actions of their subsidiary hospital. Based on

a negligence theory, the Millers asserted that HCA was liable for treating their daughter, Sydney Miller, without their consent, and second, for having a policy that mandated the resuscitation of newborn infants weighing more than 500 g. The Millers also asserted that HCA was directly liable for not preventing such treatment without consent. Based on the jury's findings, the trial court entered judgment in favor of the Millers in the amount of \$29.4 million in past and future medical expenses, \$13.5 million in punitive damages, and \$17.5 million in prejudgment interest. HCA appealed.

The central question before the Court of Appeals of Texas, Fourteenth District, was whether parents have a legal right to deny their child urgently needed life-sustaining medical treatment. If they did, what were the obligations of the doctors and hospital personnel? Should the doctors have sided with the Millers, the hospital, or should they have sought court intervention? "The question whether, and under what circumstances, a state may order medical treatment for a child over parental objections places 3 sets of interests in contention: (1) the "natural rights" of parents; (2) the responsibilities of the state; and (3) the personal needs, ie, the best interests, of the child."²

On the one hand, the court explained, parents have a legal duty to provide needed medical care to their children and, in Texas, the failure to provide such care is a criminal offense. "On the other hand, it is well-settled that parents enjoy a substantive constitutional right to make decisions concerning their children's care and welfare according to the dictates of their own consciences."³ The court noted that Texas law gives parents the right of informed consent regarding their children's medical care. "The logical corollary to the doctrine of informed consent is the right to informed refusal."⁴ Texas law at the time of Sydney's birth also allowed parents to withhold or withdraw life-sustaining medical treatment from a child with a certifiably terminal condition.

On this issue the court reasoned that the Texas legislature had expressly given parents a right to withhold or withdraw life-sustaining medical treatment, urgently needed or not, for a child with a certifiably terminal condition, but it did not extend that right to the parents of children with nonterminal impairments, deformities, or disabilities. Thus, the court concluded that the Millers had a right to withhold life-sustaining treatment for Sydney only to the extent that her condition was certifiably terminal and unless it was certified terminal that right could not be exercised. The court concluded that there was no evidence that Sydney's condition before or after birth was (or could have been) certified as terminal, and following her birth, Sydney's condition proved, with the efforts of her doctors, not to be terminal.

The third competing interest is that of the state. The court explained that the state, under the rubric of parents patriae (the parents' role), can act to guard the well-being of minors, even if doing so limits the freedom and authority of their parents. "Although parents enjoy the right to make decisions concerning their children's care, their decisions must yield to state intervention if they fail in their legal duty to

provide reasonably necessary medical care for their children."⁵ The court explained that in Texas, the rights of a parent are subject to court orders, including an order granting a governmental entity authority to consent to a child's medical treatment initially refused by the parents. Notably, in Texas, the court pointed out that it is not the physician who has the right or obligation to seek court intervention, but the appropriate governmental agency, which the physician must notify. Therefore, the court concluded, a health care provider's obligation is generally to comply with a patient's (or parent's) refusal of medical treatment until ordered by the court to do otherwise.

The court explained that in a situation where the medical treatment proposed for a child is not life-saving or life-sustaining, a court order is needed to override a parent's refusal to consent to the treatment. By contrast, the court explained, where the need for life-sustaining medical treatment *is* an emergency, time constraints will often not permit resort to the courts. "A medical practitioner will generally not be liable for treating a minor patient without parental consent when an emergency makes it impractical or dangerous to delay treatment in order to obtain such consent."⁶ "The 'emergency exception' reflects the view that it is cruel to allow a child to suffer pain for an extended period of time because a health care professional refuses to treat for fear of being sued by the patient's parents."⁷ Thus, the court concluded that (1) where the need for life-sustaining medical treatment is or becomes an emergency while a nonterminally ill child is under a physician's care, and (2) where the child's parents refuse to consent to that treatment (ie, the situation Sydney Miller was in), a court order is *not* necessary to override parental refusal. That is, because of the existence of an emergency, treatment is legally permissible, and the court does not need to adjudicate the best interest of the child in approving the physician's decision to override a parental refusal for treatment.

In sum, the court held that because there was no evidence that Sydney's condition was certified as terminal, before or after birth (or could have been certified as terminal), the Millers had no right to deny her urgently needed life-sustaining medical treatment. If Sydney's condition had been certified as terminal, the Millers would have been legally allowed to withhold nonemergency, life-sustaining treatment under Texas law. The court also held that no court order was needed to override the Millers refusal of treatment because of the judge's characterization of Sydney's birth as an emergency necessitating swift action. In reversing the trial court's decision, the Court of Appeals rendered judgment that the Millers take nothing on their claims against HCA. The case, now on appeal, was argued before the Texas Supreme Court in April 2002, and has not been decided.

The dissenting opinion argued that the Texas law outlining when parents can withhold or withdraw life-sustaining medical treatment from a child with a certifiably terminal condition did not supercede their right to refuse. The dissenting judge explained that the act expressly allowed, and did not deny, the Millers the right to withhold or withdraw life-sustaining procedures in a lawful manner. That is, although Sydney's condition was not terminal and therefore not considered within

the act, the Millers still retained their right to refuse. More importantly, the dissenting opinion disagreed with the majority opinion's conclusion that, given the circumstances of Sydney's birth, a court order was not necessary to override the parents' refusal. Specifically, the dissent disagreed with the majority's contention that there was "no legal or factual issue for the court to decide regarding the provision of such treatment"¹ arguing that the most important issue, the best interest of the child, could have been determined to eliminate any conflict of interest. The dissenting opinion characterized the Millers' circumstances as analogous to a situation where nonemergency or nonlife-sustaining medical treatment is proposed and parents refuse. The dissenting judge disagreed that the time constraints did not permit resort to the courts, pointing out that 11 hours elapsed after the Millers informed their doctors that they would continue to standby their original decision to not seek resuscitative measures if the baby were born alive. The only emergency, the dissent admonished, if any, was due to the doctors and medical personnel's indecision and delay. The dissent argued that the majority opinion asserted that this was an emergency without a jury finding. The dissenting opinion suggested that the doctors and medical personnel decided to resuscitate Sydney, knowing the Millers were there and could be consulted for their consent; and that the situation was not a medical emergency, allowing the physicians to proceed with treatment without the Millers' consent.

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STATE OF THE ART AND SCIENCE

Antibiotic Treatment of Otitis Media

Audiey Kao, MD, PhD

Otitis media or inflammation of the middle ear is the most common reason for prescribing antibiotics to children. Yet, many cases of otitis media are caused by viruses and not bacteria, which raises concerns about whether current prescribing practices may be facilitating antibiotic resistance.

Tympanocentesis of patients with acute otitis media reveal that it is characterized by the presence of:

- Streptococcus pneumoniae (20 to 35 percent of cases),
- Haemophilus influenzae (20 to 30 percent of cases),
- Moraxella catarrhalis (20 percent of cases),
- No bacteria (20 to 30 percent of cases),
- Virus with or without bacteria (17 to 44 percent of cases).

Amoxicillin is as effective as any another antibiotic and is generally recommended as the first line of treatment, even though at least 1/4 of *S. pneumoniae* strains have increased resistance to amoxicillin; 1/4 to 1/3 of *H. influenzae* strains are resistant in vitro to amoxicillin; and virtually all strains of *M. catarrhalis* are resistant to amoxicillin.^{1,2}

The apparent contradiction between prescribing recommendations and the percent of cases where that treatment will be effective may, in part, reflect the lack of solid scientific evidence on the use and benefit of antibiotic therapy for otitis media.³ It also may be partly explained by the practical challenge of identifying the percentage of children who will benefit from antibiotic treatment.

One strategy to minimize overprescribing antibiotics in otitis media is to delay antibiotic treatment for 48 to 72 hours. This treatment approach is used in the Netherlands and Scandinavian countries, and has led to much less antibiotic use than in the US and Canada.^{4,5} The one impediment of delaying antibiotic treatment is that doing so increases the risk of acute mastoiditis from 2 cases per 100,000 children per year in the US to 4 cases of mastoiditis per 100,000 children in the Netherlands.⁶ Despite this slightly increased risk for mastoiditis, the American Academy of Pediatrics and the US Centers for Disease Control and Prevention have recently announced guidelines that recommend delaying antibiotic treatment for otitis media to help reduce antibiotic resistance.

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POLICY FORUM

Prescribing for Behavior

Arthur J. Farley, MD

What are the major pitfalls in prescribing behavior-changing drugs for children, especially young ones (ages 3-10), on the basis of symptoms alone?

First, there is the risk of perpetuating the myth that medication alone will take care of all problems for the child and parent. An aging pediatrician colleague of mine quipped, "Aspirin was the drug of my generation. It looks like Ritalin is the drug of yours!" His comment ignited my concerns about the unintended consequences of the utilization of many psychotropic medications for very young children and their families. Slowly we are accumulating information regarding safe and appropriate dosages of drugs which are commonly used in the United States and Europe; however, the US outstrips other countries in utilization. We need to ask ourselves why that is.

When the first intervention is medication, there is another risk—namely that the medication will lead to obfuscation of the child's actual diagnosis. Another related potential difficulty presents itself when the young child's response to medication for hyperactivity is used as a "diagnostic tool" in clinical practice. This is particularly common with stimulant medications used for ADHD. More often than not, these potent mood elevators obscure a child's underlying depression, causing the subsequent inability to address the multiplicity of clinical factors (biological, psychological and social) which must be addressed in cases of childhood depression as well as other anxiety disorders of early childhood. Young children's behavioral actions have various meanings, not to mention causes, which require further investigation.

Finally, there is the risk of leaving unanswered the question, "For whom is the medication given?" Are the drugs given for the overworked and underpaid preschool/day-care teacher in an understaffed setting? Are the drugs given for the frustrated, distressed parents who need support and guidance? Are the drugs given for the physicians who are pressured by teachers and parents to do something immediately and have little time to assess the multiple determinants of behaviors in young children?

Disruptive behavior gets attention. Let me illustrate with William's case. William is an adopted child whose parents are in their late fifties. His adoption was "open;" his adoptive parents were present at his birth. His 17-year-old biological mother's

general health history was uneventful except for a period of substance abuse (marijuana) during her 15th year. She had dropped out of high school and knew nothing about the personal, family, or individual health history of William's biological father except his age of 25 years. The prenatal delivery and postnatal period were uneventful. William is her first and only child. He weighed 8 ½ pounds at birth.

A wiry, freckle faced little boy of 4 ½ years, William had been "expelled" from his third pre-school. He had trouble sleeping by himself and wet his bed at night. His most recent expulsion replicated the others. His teachers felt he was unable to take naps, sit still or follow directions. School directors felt medication would help him attend to his preschool tasks. Volatility and mood swings were also noted during his first preschool experience. He had bitten several children. The family's physician had known William since birth and followed up on the observations of the parents and teachers. William was given several trials on stimulant medications and mood stabilizers to treat his attention problems and his "mood swings," respectively. He was given a tricyclic antidepressant to treat his "sleep disturbance" and bed wetting. William was on a "cocktail" comprising Ritalin (Methylphenidate-hydrochloride), Tegretal (Carbamazepine), Tofranil (Imipramine) and Klonopin (Clonazepam) when a referral was made to the Harris School, a therapeutic school for children ages 3 to 10 years old.

William's parents were concerned and confused. William's situation was not new to the Harris School. Gradual reduction of his drugs revealed an anxious boy who had not mastered the ability to sleep by himself, to dress by himself, and to eat by himself. He had no difficulty telling others what to do; however, he had enormous difficulty when others told him what to do. He used his actions to speak for him rather than using his words. In short, William was "stuck in toddlerhood," evidencing extreme separation anxiety from his adoptive mother. How can we avoid the pitfalls William and his caregivers fell into? It is very important to develop a diagnostic/therapeutic relationship with the perplexed parents. Rushing into symptomatic medical treatment without assessment of the many issues surrounding and involving disturbed children and families often leads to a rushed, reductionistic approach to their treatment. It is better to take a more patient approach and do a careful biopsychosocial evaluation even in the face of the many appeals for immediate symptomatic relief.

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POLICY FORUM

The Ethics of Research with Children

Timothy F. Murphy, PhD

In 1885, chemist Louis Pasteur tested his new rabies vaccine through the injection of 9-year-old Joseph Meister, who is otherwise unknown to history. Rabies was not widespread in France at the time, but it was highly fatal and widely feared. In fact, many parents pleaded with Pasteur to give injections to their children. In the course of reporting his results, Pasteur freely published the names, addresses, personal circumstances, and outcomes of his subjects. His methods drew criticism even in his own time.¹

The history of research is littered with examples of ill treatment and insensitive ethics when it comes to the use of children. This is not to say that the science was not useful; it often was. In the late 1930s, William C. Black, MD, selected 23 children more or less at random from his patients and injected them with infected tissues in order to show that disparate symptoms were caused by a single virus, the newly discovered herpes virus.² In 1939, Wendell Johnson, PhD, of the University of Iowa, tried to *trigger* stuttering patterns in normal-speaking children, with the result that some developed life-long speech impairments.³ He also tried to *reinforce* stuttering in children who already had stuttering patterns, with similar results. His conclusion that stuttering has its roots in learning has been widely influential. From the mid-1950s through the early 1970s, Saul Krugman, MD, was able to distinguish two strains of hepatitis virus (A and B) through his studies involving children. He did so by feeding virus samples to poor and retarded children at Willowbrook State School in New York. Children faced a long waiting list for admission to the school. Parents who agreed to enroll their children in the study won immediate acceptance.⁴ Dr. Krugman won several awards for this groundbreaking work. Other examples of the misuse of children are not hard to come by.⁵

Perhaps by way of reaction to research abuses, some ethicists took a highly protective view of children. In the 1970s, theologian Paul Ramsey put forward the view that children should not be used as research subjects when their own health is not at stake and when the research involves any physical aspect.⁶ He thought that research should occur only in people capable of consent, after they thoroughly review the nature and risks of the experiment. As most children are incapable of this kind of evaluation, they should be excluded from research unless the research carries some measure of benefit for them, in which case their parents should be entitled to consent on their behalf. Ramsey recognized that a great deal of research might go undone if this approach were taken, but he believed it better to err on the

side of avoiding harm than to expose children to risk. Most ethicists and legislative bodies do not accept so stringent a standard.

In the United States, federal regulations specify several thresholds in regard to permissible experimentation with children. The regulations allow research that presents risks that are "no greater than minimal" so long as parents consent and the child assents as appropriate to his or her age. Some research that exceeds the threshold of minimal risk is allowable but only if it offers the child some prospect of direct benefit. For example, if a child might suffer serious side effects from an experimental drug, that treatment must on balance also hold out hope in treating the child's disease.

What if there are pressing reasons to expose children to some degree of experimental risk that is *not* offset by a possible direct benefit? What if that research would help advance knowledge about a disease or condition in a significant way? Federal regulations allow for studies of this kind if they involve only a minor increase over minimal risk. Researchers and oversight bodies must see to it, though, that the expected results of the study are in line with the experiences children will undergo, and consent and assent requirements still apply. If researchers want to conduct studies that involve *more than a minor increase* over minimal risk, a federal oversight panel must review the study, the public must be offered the opportunity to comment, and the Secretary of Health and Human Services must give his or her approval. Standards of parental consent and child assent apply here as well.⁷

Most medical drugs and devices are tested with adults, not children. It is important, though, to study the ill health and disorders of children in their own right. For this reason, Congress has approved incentives to spur research on the health of children. Researchers who study children receive additional years of patent protection for their drugs and medical devices. It is to the good that better treatments become available for children, yet it is to be hoped that as more and more children are involved with research their experiences will look less and less like those of their historical counterparts. For this reason, it is wise to attend to the spirit of Paul Ramsey's counsel when conducting research with children. A strong justification is surely needed in order to expose children to research risks in the name of improving the lives of others.

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POLICY FORUM

Learning to Decide: Involving Children in their Health Care Decisions

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In pediatric medicine, increasing attention is being paid to the desirability of children's participation in decisions regarding their medical care.^{1, 2} After noting that physicians have a professional duty to involve the pediatric patient in decisions, this piece proposes a basic framework to approach the child's role in shared decision making.

Sometimes described as "triadic," the pediatric relationship is complex in that it almost always involves the patient, the patient's parent(s) or guardian(s), and the physician. Traditionally, only the latter 2 parties have been involved in health care decisions for the patient, on the assumption that the pediatric patient is legally incompetent and that parents or guardians, with the assistance of physician's medical expertise, generally are the most appropriate decision makers for minors.

However, these conceptions, which are rooted in the legal tradition, are inadequate in shaping the partnership between the 3 parties. Indeed, a system based primarily on legal circumstances fails to consider several essential principles that are at the core of medical ethics and professionalism.

In its Convention on the Rights of the Child, the United Nations recognizes the right of every child to self-determination, dignity, respect, noninterference, and the right to make informed decisions.³ Though these rights may represent a departure from the way decisions have been handled in the pediatric setting, they are more directly aligned with notions of respect for the patient's dignity and rights.⁴ They also serve to acknowledge that physician's primary obligation is to the child, whose preferences and insights therefore are helpful to guide decisions.^{1, 5}

Above and beyond the law, the requirements that are delineated in the United Nations' Convention are necessary to developing the pediatric patient's trust in the medical profession. They are also important to ensure that medical decisions are directed to the needs of the child, not those of another party. After all, it is the child's life that is most directly affected by the outcome of a medical decision. Besides, involvement in health care may give the child a sense of control and ownership over a decision, positively impacting the medical experience.⁶ It is for these reasons that children, as soon as they are able to communicate and to participate in decisions that affect their medical care, should be encouraged to do so.⁷

Involving children neither means excluding parents, whose support children usually need, nor giving children the final say. Rather, it entails involving children at a level commensurate with their development, experience, and desire to participate, while affirming parents' responsibility.¹ In this vein, the American Academy of Pediatrics, which maintains the position that children and adolescents should not be excluded from medical decision making without persuasive reasons, advocates participation of children in these decisions to the extent that their ability allows.⁸

Mirroring the progression of their development, children's involvement in health care decisions should occur along a spectrum, the first stage of which is being informed. At the very least, health care professionals should help children to achieve awareness of the nature of their condition and should convey full and accurate information regarding tests, treatment, and expectations.

This step is significant inasmuch as the strength of participation depends on information the child receives. Unfortunately, limited information exists regarding how to design materials for children. Currently, most materials are directed to parents or do not take into account that children at different stages have different needs.⁹

Children who are able to communicate at least should be consulted. This step provides them with an opportunity to express their views. At the next level, children's views may be taken into account, requiring other parties in the partnership to explore the reasons behind the child patient's preferences. Finally, children can be respected as primary decision-makers, who still function in a partnership with parents or guardians and physicians. These children may grant or withhold consent.

In addition to the stage of a child's decision-making capacity, the other variant that impacts level of involvement is the complexity and significance of the decision. For example, the same child, at an early stage of development, might act as the main decision-maker in determining the site of a needle stick, while she will only be informed or consulted regarding a more weighty decision, such as whether to undertake another course of chemotherapy.

This framework for the involvement of children in decision making is rather basic, as are most existing ones. There is a lack of extensive research-based evidence regarding outcomes of shared decision making and how to assess children's aptitude to participate in making health care decisions. As a result, providing a more sophisticated and specific mode for managing shared decision making is difficult. Research is needed to develop explicit, formalized rules to govern

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Effective Health Coverage for America's Children: Reformation and the Pediatrician's Role

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In 1997, Congress enacted the State Children's Health Insurance Plan (SCHIP), committing \$40 billion dollars over 10 years to protect more than 10 million children who were uninsured and not eligible for Medicaid.¹ Today, most American children without private health coverage are enrolled either in SCHIP or Medicaid. Approximately 23.9 million children—nearly 1 in 4—are covered under Medicaid and another 5.4 million children are enrolled in SCHIP.^{2, 3} Clearly, Medicaid and SCHIP have improved child health by providing the coverage needed to effectively promote regular care; data support claims that children covered by one of these programs are more likely than uninsured children both to access the care to which they are entitled and to seek out preventive care, possibly preventing more costly medical procedures down the line.^{4, 5} Children enrolled in Medicaid are 4 times more likely to access a regular source of care than unenrolled, Medicaid-eligible children.⁴ If free or reduced-cost pediatric services are available, uninsured families are still less likely to use them than families whose children are enrolled in Medicaid or SCHIP. Even uninsured children who attend urban public schools with free in-school primary care clinics use those services less frequently and are also more likely to visit an emergency room than peers enrolled in SCHIP.⁵ What is unclear, however, is whether and how these programs can be more effective in reaching those who are eligible but not enrolled. Although SCHIP enrollment has nearly doubled since the program began, there are still 7 million children eligible for federal health coverage but not enrolled—4.7 million for Medicaid and 2.3 million for SCHIP.⁶ Further, data provided by the Centers for Medicare and Medicaid Services (CMS), the most accurate count of enrollees, only indicates whether a child was enrolled at some point during the year, potentially missing large populations of transient children who aren't consistently covered over the entire year.³

What research does exist discusses only general barriers to enrollment. A report by the Urban Institute shows that large proportions of Medicare and SCHIP applications are denied for largely procedural reasons.⁷ However, the report doesn't describe the demographics of the 7 million eligible for federal health coverage but unenrolled, nor does it offer any commentary about the possible needs of those who are not covered. Reforming these programs to capture more eligible children may be difficult without clearer research on who is being left out. Two studies (with very limited data sets) do exist suggesting that Medicaid and SCHIP are leaving out a

disproportionate high number of Hispanic children (a group with historically significant disease burden) without a regular source of care or recent insurance.^{8, 9} That data also hint that those likely to enroll in federal health insurance are those who have been previously insured and likely to be receiving medical care already. Additionally, while there is evidence that increasing children's health coverage leads to better health outcomes, little data exist on how many enrollees actually take advantage of their coverage (ie, utilize primary care personnel). The General Accounting Office (GAO) notes that states have very poor monitoring systems to determine who is accessing care and how often.¹⁰ Children enrolled at some point, while healthier than unenrolled children, could still be using the system more effectively. Thus, the problem is identifying who is without coverage and reforming the federal children's health insurance system to increase enrollment. Physicians, in particular pediatricians, can play an important role.

Nearly 80 percent of Americans believe the government should guarantee health care for all children.¹¹ Likely, the percentage of pediatricians, de facto advocates for children's health, who believe in guaranteed coverage for children is even higher. Groups like the American Academy of Pediatrics (AAP) continue to call upon their members to push for more and better care in state and federal legislatures, public policy forums, and the media.¹² Pediatricians have been a driving force behind the creation of SCHIP and efforts to maintain its funding. However, states are reluctant to expand SCHIP coverage to more children because SCHIP suffers from an uneven funding structure. As the law was originally written, funds unspent within 3 years were to be returned and reallocated to states that had spent all their funds and needed more. Funds still unspent after a fourth year would be returned to the US Treasury. To meet congressional budget limits, federal funding was designed to decline from \$4.3 billion in 2001 to \$3.1 billion in 2002, and then gradually increase to \$4.1 billion in 2005.¹³

Budget crises in almost every state have further jeopardized funding for health coverage, pressuring lawmakers to significantly alter the administration of Medicaid and SCHIP dollars which states have broad discretionary authority to administer.¹⁴ There are now strong incentives to trim "fill-in" programs, like California's Children's Health and Disability Prevention Program, a wholly state-funded program that provides health, vision, and dental screenings each year to more than 1 million children, including undocumented immigrants.¹⁵ Additionally, while work is being done to help states keep unspent SCHIP funds, they will be reluctant to expand coverage without the certainty of more federal funding.¹⁶

Because of this increased budget scrutiny, many health policy experts believe the time is ripe for children's health coverage reform, and pediatricians can play a key role in this process. First, as clinicians, pediatricians are in the best position to observe whether children who most need the care are enrolled in federally funded programs. One of the top problems reported by pediatricians is lack of consistent care—children enroll, then drop out.¹⁷ Pediatricians can make sure children whose families can't pay for care know how to enroll in programs for which they may

qualify. The AAP has gone so far as to request that pediatricians be placed on SCHIP monitoring and advisory panels involved in developing and reviewing changes, annual reports, and evaluations.¹⁸

Second, those pediatricians who engage in public health research have the prerogative to investigate how and why effective coverage is or is not delivered and distribute those findings to the entire pediatrician community.¹⁸ Current research methodologies, although they give us a glimpse of the problem, are still imperfect. We have no information about the health status of the millions of children who have no coverage. Researchers could focus more attention on the demographics of unenrolled children and their incidence of health problems. With this information, policy makers could reformulate these programs to increase enrollment.

Third, as advocates for children's health, pediatricians should think about what types of reform would best serve America's children, whether that means improving existing programs or a complete system overhaul. Being well-informed enough about current policy initiatives to advocate for their patients is a part of a physician professionalism. Besides those eligible for federal programs, 2.5 million children lack coverage but don't qualify.¹⁹ Although the number of so-called "gap children" has shrunk significantly since SCHIP was established, there are still many who aren't poor enough to qualify for federal assistance but are too poor to afford private insurance. The current child health coverage system thus shares many of the access and financing problems that characterize US health care delivery in general. Plans have been proposed by policy institutes and Congress to cover all children, regardless of financial status. For example, the "Leave No Child Behind" Act proposed in Congress includes a plan to require parents to provide health insurance to their children either through an employer or "buy-in" to federally funded insurance. The political difficulties in enacting such a program are obvious; similar initiatives have been bandied around Washington for years to no avail. The 2004 elections have already begun drawing attention to improved health coverage, and calls for more extensive coverage are likely to increase. Pediatricians have a role in advising both policy makers and the general public as to what steps are necessary to insure the health and well-being of America's children.

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