

## **Virtual Mentor**

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# Virtual Mentor

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## From the editor

### Parents, children and their physicians: the complex journey of parenthood

In 1890 the city of Chicago competed with other American cities to be the staging ground for the 1893 World's Fair. Americans were worried that they had lost international prestige after the glamorous and exotic Parisian Exposition of 1889, which most visitors felt could not be surpassed. Chicagoans had additional motivation in securing the event for their city; they wanted to show the country and the world that they weren't citizens of a "greedy hog-slaughtering backwater"[1]. Congress ultimately approved Chicago as home to the fair, called The World's Columbian Exposition in celebration of metropolitan man and "four centuries of progress" since the discovery of the New World.

Organizers mounted a glittering affair. Lake Michigan provided the setting for the most accomplished architects, sculptors and landscapers in the country who participated in designing the monumental fairgrounds. When the fair's "splendid fantasy"—"a realization of Utopia" [2]—came to an end in 1895, a gray, sooty, chaotic, metropolis was left behind, one that was suffering a significant economic downturn. In the midst of the dreariness, one of the elegant, glittering buildings—for which the fair had been dubbed the "White City"—was given to the "Gray City," as post-1895 Chicago was described. A replica of the La Rabida monastery, the location from which Columbus had set sail to the New World, had been built in Jackson Harbor. During the fair, La Rabida housed relics of the historic voyage. After 1895, the Spanish Consulate made a gracious gift of the building to the city for use as a fresh air sanitarium for sick children.

Decades later, the hospital gained international recognition for research that led to the eradication of rheumatic fever and made a further commitment to treat chronic illnesses of childhood including arthritis, asthma, cerebral palsy, diabetes, Down syndrome, lupus, sickle cell disease and developmental disabilities. In the latter 20th century and into the present, La Rabida has been a leader in the state of Illinois for an extensive hospital-based program for neglected and abused children [3]. It continues to function as a hospital for sick children with the additional mission, declared by its Women's Board over one hundred years ago, to provide relief for the "tired and weary mothers" of the city.

Reaching across economic, racial and health barriers, La Rabida has embraced the gray city and through family-focused care has started, enriched and kept alive a

dialogue about the medical, social, political, legal, technological, moral and ethical issues facing the parents and families of sick children. It is one of only two remaining buildings from the original White City. La Rabida Children's Hospital, one of the teaching hospitals at the University of Chicago, was the site of my third-year clerkship in pediatrics and the inspiration for this issue of *Virtual Mentor*.

In this issue, we explore the extraordinary challenges pediatric physicians and the parents of their patients face together in this setting and in other clinical environments. In her case commentary, Dianne McBrien explores the complexities of raising children with mental disabilities and the ethical challenge doctors face in helping these children achieve their potential for independence. Next, we enter the complex and heart-breaking sanctuary of a dying child to explore how we might comfort his mother. Peter Smith's commentary on this case invokes an ancient ethical tradition, virtue ethics, to remind us that compassion for this child's parent is "the ultimate hope for a virtue ethicist." Sharon Hirsch and Rebecca Sheffield discuss the case of a nine-year-old girl with conduct disorder and the complex set of ethical issues and social biases confronting families and physicians who care for children with psychiatric illness. Through a case of adolescent obesity, Joseph Zanga and John Moskop draw our attention to the cultural and developmental complexities that often determine whether physicians are able to achieve lasting benefits. The clinical pearl written by Suma Jacob supports Dr. Hirsch's piece by describing current diagnostic criteria and treatment for conduct disorder.

Emily Anderson reviews a chapter of Lainie Friedman Ross's book, *Children in Medical Research: Access Versus Protection*, about twin aspects of informed consent in pediatric research—parental permission and child assent. She supplements her journal discussion with data from a number of articles that show a disturbing lack of understanding among parents who consent to research protocols for their children. Lee Black's piece on health law examines how the law sorts through parents' "willingness to make medically appropriate decisions" on behalf of their children. He looks at how the courts decide cases where the parental decisions for or against medical treatment are grounded in religious and nonreligious belief. In the policy forum, Nancy Berlinger examines the health and social consequences of parents' decisions not to have their children immunized against common childhood diseases.

In his thoughtful essay on medicine and society, "Talking with families about severely disabled children," Arthur Kohrman discusses the struggles faced by parents of disabled children. He offers physicians a glimpse of the psychological despair and unnerving demands placed on parents of children who will never realize the promise of childhood and a strategy for building long-term empathic relationships with these parents. David Collier and Joseph Zanga, in their medical education essay, revisit childhood obesity, a topic of growing national concern. It is now estimated that one out of every three children is overweight, increasing their risks for cardiovascular disease, diabetes mellitus, cancer and chronic disease. Drs. Collier and Zanga discuss ways residency programs can impart skills needed to encourage family health. In the

medical humanities section, I review the unique relevance of Francois Truffaut's film "The 400 Blows" for physicians who work with children.

Unfortunately, we do not have the space to examine other significant ethical issues facing parents: the alarming incidence of failure to thrive among toddlers in this country; the difficulties in treating children who live in chronic pain; the escalating problem of urban diseases like asthma and the particular challenges that these diseases pose. We have not examined severe cases of child abuse. Children hurled against walls or scalded across their buttocks, thighs and scrotum for failing to master potty-training. Neither have we the space to celebrate parents who have sacrificed careers, who live for long stretches of their lives in hospital rooms advocating tirelessly for their children. Parents who willingly carry their children, including their adopted children, to the furthest reaches of the globe seeking medical treatment because for them it is the right thing—the ethical thing—to do and because for some of these remarkable parents the journey they take with their sick children represents a mutual embrace.

Disparate styles of parenting are often on display in doctors' offices and in hospital settings. Parental behaviors become the source of derision, disbelief and sometimes awe. It's clear to most doctors and residents that adults come to their roles as parents with various levels of preparation, competence, desire and vision. The task of educating parents into parenthood is complicated. Our strategies for helping families make this important transition need to be grounded in basic, clinical or translational research. Current strategies are not well-grounded, but it's clearly an area of growing concern. For example, the Society of Behavioral Neuroendocrinology has recently organized the Parental Brain Conference to "bring together basic and clinical researchers using state-of-the-art scientific approaches to examine the role of the central nervous system in maternal and paternal care" [4]. The meeting will focus on neural adaptations of the maternal and paternal brain towards parenthood with emphasis on postpartum mood disorders, inadequate parental bonding, parental aggression and anxiety.

I am pleased that, through the serendipitous interweaving worlds of research and publishing (themselves forces of nature), this issue of *Virtual Mentor* coincides with the recent report published in *Nature* of a well-preserved 3.3-million-year-old juvenile skeleton, a three-year-old female *Australopithecus afarensis* discovered in Dikika, Ethiopia [5]. Scientists believe that this archaic hominid found buried in the sediments of a river basin, this "precious bundle" of skeletal remains, will provide crucial insight into the evolutionary history of man [6]. We hope the Dikika toddler, now carefully excavated, will shed new light on the long complicated history of who we have been. As the cases and themes our authors wrestle with demonstrate, scientists and the public alike remain anxious to discover, through ongoing investigations, what sort of parent our ancient ancestor will ultimately become.

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# Virtual Mentor

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## Clinical case

### Parental influence on level of functioning in a child with Down syndrome

Commentary by Dianne McBrien, MD

José Peres was admitted to Children's Hospital for replacement of a dislodged gastrostomy tube. He is 17 years old and has Down syndrome. During his hospitalization, pediatric resident Sharon Dalton observed that José could not bathe or feed himself or use the toilet without help. He refused to walk and got around only by wheelchair. In reviewing his medical record, Dr. Dalton noted that José's performance status had declined significantly since a previous hospitalization, and she wondered why.

Shortly after José's release from the hospital, his mother who is his only caregiver was called out of the country for a family emergency. She left José at a care facility associated with Children's Hospital for three weeks. During his stay at the facility, Dr. Dalton continued to follow José and manage his medical care. She wrote orders encouraging staff members to facilitate José's self-care. In the ensuing days, José was encouraged to walk, bathe, eat and use the toilet by himself, which he did successfully. By the middle of the third week, José was leaving his room on his own initiative and sitting in the community area looking at teen magazines and listening to his Walkman. He bobbed his head to the music and seemed to want to dance with the nurses.

As the time for José's mother's return approached, Dr. Dalton began to wonder what she should tell her about José's care.

## Commentary

Let's begin by determining whether this case presents an ethical or legal problem. An adolescent male with Down syndrome who required total care upon admission has acquired several self-help skills during his hospital stay. His rapid progress in the inpatient setting strongly suggests that he does not care for himself at home.

On its face, this situation presents no legal dilemma. The case provides us with no evidence that José is being abused or neglected. As a minor, José is the legal ward of his mother, who has the right to determine what is best for her son. Yet Dr. Dalton fears that the care she provides is inappropriate given José's demonstrated ability and thus not in José's best interest. How, if at all, should she address her concerns with José's mother?

Because Dr. Dalton is parsing what kinds of intervention are good or moral for her patient and his family, she is indeed faced with an ethical problem.

### **Children are different**

Unique ethical tasks accompany the practice of pediatrics. Patients are unable to consent to most forms of treatment by dint of their minor status. Physicians must therefore rely on the proxy decision making of parents and guardians, who may disagree with medical staff about what is best or most appropriate for a particular child. The child's dependent status means that his or her welfare is more directly affected by environmental or family factors than that of an adult [1].

Pediatricians also recognize that the practice of family-centered care, which is based on the acknowledgment of the family's primary role in supporting the child, leads to better patient outcomes as well as enhanced patient and family satisfaction [2]. Hallmarks of family-centered care include, among other core principles, recognizing and building on family strengths, supporting family choices regarding care and honoring family cultural diversity and its effect on the family's experience of care [2]. Family-centered physicians strive to partner with families, rather than administering to them. It should be noted that the respect for families inherent in this philosophy does not mean condoning or collaborating with abusive or neglectful family decisions.

Dr. Dalton considers several ethical principles—beneficence, respect for autonomy and justice—in thinking about José. Promotion of his independence, she believes, is a beneficent action, one that is in his best interests and one that will enhance his quality of life. She recognizes José as an individual and wishes to encourage his autonomy as he nears adulthood. She knows that she could simply discharge José to home without addressing her concerns with the mother but wonders if that would be just. If José were not mentally disabled, would she ignore evidence of inappropriate parenting?

Of José's mother, we are told little. Of course, she may be delighted to learn of her son's new independence, both for his sake and her own. But Dr. Dalton can think of several reasons why the mother might not welcome this news: she may fear that José cannot care for himself as well or as quickly as she can. For complex emotional reasons, she may be attached to José's role as a wholly dependent child and to her role as his sole caregiver. She may wish to retain guardianship of José after his 18th birthday and may worry that evidence of his increased competence will interfere with that goal. And, while the cultural identification of José's mother is not specified, the role of cultural influence should be considered in the importance she places on José's independence—while European-American cultures generally view independence and individuation positively, other cultures value family interdependence more [3].

### **Whose best interests?**

Dr. Dalton obviously wishes to act in José's best interests. Determining what those

interests are, however, may prove difficult. The American Academy of Pediatrics (AAP) allows that “the concept of best interest is probably better suited to legal analysis than to medicine... (this) analysis involve(s)... some degree of subjectivity” [4]. In other words, there is no categorical method to determine whether José’s doctor’s definition of what is best for him is better than his mother’s.

How, then, should Dr. Dalton proceed?

### **Win-win**

If she can, Dr. Dalton should avoid addressing the problem of José and his mother as a zero-sum game, with mutually exclusive patient and family interests.

First, she may want to assess the mother’s understanding about José’s diagnosis. Parents of children with Down syndrome commonly report receiving inaccurate or limited information about their child’s condition [5]; doctors may have given José’s mother an excessively gloomy prognosis about his future abilities. A social worker may help determine if the family is eligible for any programs, such as the Mental Retardation Waiver, which pay for such supports as respite care, prevocational services and supportive services for residential care placements. Referral to a parent support group may provide José’s mother with peers who can offer help and feedback. Throughout her communication with Jose’s mother, Dr. Dalton should be certain that she is being understood. If English is not the mother’s primary language, all discussions and written information provided to her should be translated into her preferred language.

In addition, Dr. Dalton should gently inquire about the mother’s long-term plans for José, including any arrangements for his care when she can no longer provide it at home. She can add that if, at some point, José is placed in a group home or other nonfamily residential arrangement, his adjustment will be easier if his independence has been encouraged at home.

### **What about José?**

What input, if any, should José have into this discussion? The AAP Policy Statement on Informed Consent, Parental Permission, and Assent in Pediatric Practice states that pediatricians “...should not necessarily treat children as rational, autonomous decision makers, but they should give serious consideration to each patient’s developing capacities for participating in decision-making” [6]. The AAP Committee on Bioethics encourages physicians to seek assent of select patients in addition to the informed permission of their parents [6]. While José is 17 years old, his capacity for informed decision making lags several years behind that of his peers. Mental abilities can vary significantly among individuals with Down syndrome, however, and the possibility of dialogue with José should not be dismissed until his cognitive status is evaluated. The results of this evaluation may be helpful to both José’s mother and Dr. Dalton in directing their discussion.

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## Related article

[Adding burden to burden: cosmetic surgery for children with Down syndrome,](#)

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# Virtual Mentor

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## Clinical case

### The desperate parent and the lure of experimental treatment

Commentary by Peter J. Smith, MD, MA

As a third-year medical student, Alexandra was assigned to a six-week pediatrics clerkship at Hope Hospital, a long-term facility for chronically ill children. She saw this as an opportunity to learn about caring for young patients with incurable illnesses. Hope Hospital was a facility with only 26 inpatient beds, so Alexandra was often familiar with most of the children on the floor. After rounds one day, she decided to stop and visit with Paul, an eight-year-old boy who had been diagnosed with stage IV brain cancer. He was asleep when she entered his room, so rather than disrupt the quiet she took in his room more deeply than she had before, in particular a makeshift altar in one corner.

Parents of patients in the hospital often used counters or tabletops in the hospital rooms to place photographs, unlit candles, get-well cards with inspirational messages, pictures of saints and quotes from the Bible. The biblical quotes in Paul's room included references to Christ's miracles, the healing of the deaf, dumb, blind and infirm, and the raising of the dead. Alexandra was reminded that medicine had come nearly to the end of what it could offer Paul; she also remembered Paul's mother, an older parent, who had lost another son—her only other child—to brain cancer. She was now left with a slender hope; she had opted to enroll Paul in the latest, experimental drug trial from the NIH.

The physicians at the hospital were not convinced that Paul had the reserves of strength to withstand additional chemotherapy or radiation and had suggested to his mother that treatment for his cancer be discontinued. But any mention of moving to palliative care or hospice was rebuffed by Paul's mother. If a new drug was being tested, she insisted that Paul be included in the trial. When Alexandra turned to leave the hospital room, Paul's mother entered, smiling as always. Alexandra smiled in turn. The two had talked often over the weeks of Paul's hospitalization. Alexandra acknowledged that Paul was scheduled for further chemotherapy, to which Paul's mother replied, "Wouldn't you do the same? What's your honest opinion, Alexandra?"

## Commentary

"Doctor, if he were your child, what would you do?" In 1999, using this question (likely as old as medicine itself), Robert Truog wrote a classic article that has stimulated an important literature within bioethics on the role that personal beliefs

and opinions ought to play when clinicians counsel families. He argued that pediatricians ought *not* to answer this question, using an example from psychotherapy to make the point that physicians are *not* the experts in values, that they are experts in “medical facts”:

Complete objectivity is impossible between a physician and parent when discussing value-laden questions like whether to withdraw life support. Countertransference is the general term for describing the beliefs, prejudices, and feelings that the clinician brings to the discussion. Just as a good therapist would rarely, if ever, give a direct answer to the question, “Now tell me doctor, if you were me, would you divorce my wife?” so should pediatricians be reluctant to provide direct answers to similarly profound questions from parents. The job of the clinician in this case is to guide the patient or parent to a choice that is authentic and genuine for them [1].

A group of important commentaries responding to the original article by Ross, Ruddick, Halpern, Quist and a reprise by Truog [2-6] were published together and, as a group, serve as a useful primer for any learners wishing to acquaint themselves with the important points under debate. Learners will also benefit from noting that the discussion continues (and will likely continue indefinitely), as witnessed by the perspective on this question offered recently by Kon [7]. However, the discussion is usually framed with the understanding that the health care professional who is asked the question is both a real decision maker (or at least has strong influence in the outcome of the medical teams’ group opinion) and an experienced clinician. This commentary will attempt to address the question with particular reference to a caregiver who is neither the ultimate decision maker nor truly experienced in the practice of medicine: Alexandra is a medical student, and that makes all the difference.

### **Medical education and core competencies**

Learning the art and science of health care is a long and arduous process. During training, novices are frequently confronted with difficult questions from the patients and families they serve. Unfortunately, these experiences are often characterized as opportunities to “learn the right thing to do.” Currently, an educational model is in the ascendancy that mandates teaching of well-defined core competencies: patient care, medical knowledge, interpersonal and communication skills, professionalism, practice-based learning and improvement, and systems-based practice—and measuring the effectiveness of this teaching [8, 9]. The movement which stimulated the rise of this model has many positive aspects, especially the drive towards valuing medical education *as* education rather than as a source of labor for teaching hospitals where students and residents learn from older physicians who usually are not trained in teaching or understanding the needs of the learner.

This movement has, however, also fostered an atmosphere in which training increasingly focuses upon content, standardized tests or—potentially worse—

standardized patients, “objectively” measurable outcomes and generally anything that can be quantified. This has led, in turn, to an increasingly common attitude that there are right and wrong answers to all questions, problems and choices of action in a situation. Therefore, it is quite possible that Alexandra’s greatest anxiety was related to her ability (or inability) to remember what she was supposed to have learned in the mandatory session on “cultural competency” that certainly preceded her clinical rotations. She and her clinical supervisor will surely need to complete an evaluation at the end of this rotation, at which time Alexandra will receive appropriately constructed and delivered feedback. Part of that evaluation will attempt to measure her knowledge and skills in this area.

Alas, I suspect that anyone who has not attended medical school would hope that Alexandra’s greatest anxiety would arise from her desire to learn how best to be compassionate toward a very vulnerable fellow human in this situation. Alexandra herself may have hoped to learn that (and may have written an essay about just that worry on her medical school applications) prior to her immersion in the world of medical education.

Clearly, those who create courses in cultural sensitivity, no matter how well done and how highly rated, will not be able to adequately prepare their students for the infinitely varied and tremendously complex experiences they will confront. They often do give good advice on what *not* to do. However, because they need to utilize generalities—they are teaching a varied group of students to serve a multicultural society—they usually do not attempt to answer Alexandra’s problem, “what *ought* she to do?”

### **Virtue ethics**

One answer to this problem may be found in looking to a different and ancient paradigm of constructing ethical exchanges and deliberations: virtue-based ethics. Contemporary virtue ethicists often specifically define themselves as *not* attempting to create systems that promote virtuous *actions*. For one example, see Edmund Pellegrino’s “The Virtuous Physician” [10]. These ethicists do not spend the majority of their energies on debating the “right thing” to do in a circumstance. (Note that they do *not* believe that it is a *bad* idea to try to work out the right thing to do, and for examples of good forms of this principle-based model, see the articles referenced at the top by Truog and those who responded to him.) Rather, virtue ethicists focus upon creating environments and expectations that help foster the formation of virtuous *character*. As James Keenan, another virtue ethicist, writes:

Renewed interest in virtue ethics arises from a dissatisfaction with the way we do ethics today. Most discussions about ethics today consider major controversial actions... .Virtue ethicists are different. We are not primarily interested in particular actions. We do not ask, “Is this action right?” “What are the circumstances around an action?” Or, “What are the consequences of an action?” We are simply interested in persons. We believe that the real discussion of

ethics is not the question “What should I do” but “Who should I become?” In fact, virtue ethicists expand that question into three key, related ones: “Who am I?” “Who ought I to become?” “How am I to get there” [11]?

A virtue ethicist would view this clinical encounter not as a dilemma in which it is hard to know what to do but as a part of the formation of Alexandra’s character. Therefore, a virtue ethicist would hope that Alexandra had seen many good models of compassion (from the Latin “to suffer with”), especially at this facility which specializes in the care of children with complex and chronic conditions. The examples might not have all been doctors, but Alexandra might have been astute enough to learn from among *all* the humans in the institution. A virtue ethicist would hope that Alexandra’s training had included a message to watch *all* the care given to the children served at this special place. Finally, a virtue ethicist would hope that Alexandra would follow her heart and try to say something humane and humble and loving.

It is likely that Alexandra would feel awkward and uncomfortable and inadequate (just like a seasoned clinician, though she would not yet know that these feelings never fully go away), so a virtue ethicist would hope that she would have a chance to share her understanding of the experience with a seasoned, caring and wise mentor. Although there are many ways that a mentor would help Alexandra, one way would be to explore her feelings and thoughts about the experience as they relate to the three questions posed by Keenan: “Who am I?” “Who ought I to become?” “How am I to get there?” A mentor might reassure her that formalized processes are only useful as a stimulant to this type of self-reflection (which may lead to improved self-understanding). A good mentor would most certainly *not* believe that there is one right thing that an ethical person would or should say to Paul’s mother in this narrative and might try to help Alexandra to see this truth. Alexandra’s growth and the fostering of her attitude of compassion would be the ultimate goal of a virtue ethicist.

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# Virtual Mentor

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## Clinical case

### Coping with a child's conduct disorder

Commentary by Sharon Hirsch, MD, and Rebecca Sheffield

A nine-year-old girl named Sybil has been in five different grade schools because of antisocial behavior. Since the age of six, she has frequently initiated physical fights using broken bottles and bricks. In the past year, to the horror of her neighbors, Sybil stole several of their cats, doused them in gasoline and set them on fire. When asked why, she stated that she thought it was “funny” and that she likes “watching what they (the cats) do when they are on fire.” Most recently, she threatened to kill her second-grade teacher for preventing her from attending recess. Her family is no longer able to control her violent outbursts and has brought her to a psychiatric inpatient facility, Prentiss Hospital, in a major urban area. This is Sybil’s third such hospitalization.

When Sybil is first admitted to Prentiss, Timothy de Vore, a fourth-year medical student planning to pursue a psychiatry residency, is asked to interview her family. Sybil was brought to the hospital by her paternal grandmother and her father, who is wheelchair-bound. He has been in and out of jail for drug-related offenses since Sybil’s birth and is agitated throughout the interview. Sybil’s grandmother tells the story of Sybil’s life. At three months of age, she was removed from her mother’s custody because of neglect and has only seen her mother twice since then. She seemed to be doing OK until the age of six (records show she has a normal IQ and was doing well in school), but between the ages of six and seven she became increasingly aggressive and exhibited sexually inappropriate behavior. Sybil’s performance in school deteriorated rapidly, and she currently has domestic battery charges pending against her in court for hitting her cousin in the face with a brick. Her family appeared relieved but also concerned when they left Sybil at Prentiss Hospital that day, no longer able to cope with a problem they did not fully understand.

During her weeks-long stay at Prentiss, Sybil exhausts the staff with her violent outbursts and obsessive need for attention. Day after day, Tim sits down to talk with her and feels that he is getting nowhere. She won’t look him in the eye. Her answers to his questions are one-word responses, non sequiturs or deliberate provocation. “When I get out of here I am going to buy me some weed and some new jeans and go with my boyfriend.” Or “I like to be mean more than I like to be nice.” Weeks pass without stable emotional contacts; Sybil is no longer in touch with her family because phone calls home produced more volatility than calm or reassurance. Sybil

herself has lost interest in her family. Early in her hospitalization, Sybil's psychiatrist prescribed a mood stabilizer and an anti-psychotic medication, which are mildly effective in controlling her behavior. The drugs cause a blunted affect and are sedating.

Tim begins to worry that they are losing Sybil and that Sybil is becoming lost to herself. Her tenuous ability to hold on to relationships is being pushed to the brink, and he wonders if the staff shouldn't be more insistent on family connections; isn't some family connection, however difficult, better than none?

### **Commentary**

The hypothetical case of Sybil raises several interesting questions that clinicians commonly face in child and adolescent psychiatry. The first of these—that of custody—is central to the issues of consent and treatment. In Sybil's case, we are not told who her legal guardian is. The duty to protect minors from abuse or neglect is reflected in state and national mandatory reporting laws and is balanced by parental rights and the rights of others in society. The UN General Assembly Convention on the Rights of the Child further delineates the duties and responsibilities that the nations have to insure the safety of children [1].

We are told that Sybil's mother lost custody (both physical and legal, we assume) for reasons of neglect when Sybil was three months old. Her grandmother tells us that Sybil has only seen her mother twice since. Sybil's grandmother appears to be the legal guardian, but she may be a foster parent. It is also possible that Sybil's father remains a legal guardian. No mention is made of his parental rights having been terminated.

It is important when evaluating children to determine not only who the legal guardian is, but also who the primary caregiver is. Children who grow up in neglectful or abusive homes have more impairment in social and psychological functioning, do less well in school and are at increased risk for severe behavioral problems when compared with children from homes where they are not neglected or abused. Sybil's living situation is constantly changing since her father has been in and out of the home. Her current presentation of conduct disorder including hitting her cousin in the face with a brick reflects severe psychopathology. It is unknown if Sybil would have fared better in non-relative foster care, but a recent study by Bilha Davidson-Arad et al. shows that when children are removed from neglectful and abusive homes, their quality of life improves [2]. A study of children in the Illinois child welfare system by Romansky and colleagues highlights the importance of living arrangements and posthospital services in preventing re-admission [3]. Courts have repeatedly upheld the opinion that the state's duty to protect the interests of minors is greater than the rights of the parents to make decisions for their minor children. This is consistent with the Child Abuse Prevention and Treatment Act [4].

We must consider the competence of Sybil's guardian to make decisions. If her father is her guardian, and he presents as agitated and may still be using drugs, then

the treating physician is obligated to question his competence and ability to put Sybil's best interests first. If he is her guardian and is basing treatment decisions on his own needs and interests rather than on Sybil's, the state will probably appoint a guardian for the purpose of medical decision making.

Informed consent is directly tied to legal but not physical custody; only the legal guardian can give consent. So even though Sybil lives with her father, i.e., he has physical custody, he may not be responsible for consenting to Sybil's treatment. Informed consent is based on decision-making capacity, e.g., evidence of choice, rational reasoning and inferential understanding of proposed courses of action and their probable outcomes [5].

Sybil's current developmental level must be considered when including her in consent and treatment decisions. Children who have been abused and neglected often have more difficulty understanding and making important independent decisions [6]. At nine years old, normal children are less competent than adults in understanding information and using rational decision making [5]. Piaget's classic work on development defines how cognition develops. Formal operations, the final stage, signals the ability to do hypothetical-deductive reasoning. Children do not achieve this stage of development until after 11 years of age [7] and so are unable to give informed consent before that time.

Once treatment consent has been obtained from Sybil's legal guardian, the health care team must consider the family's and Sybil's treatment preferences, with the first decision being the best setting for treatment. Sybil is too severely ill to be treated in an outpatient setting, but she also has charges pending against her. It is unlikely that she will be sent to jail at the tender age of nine. She may be sent away from her family to live in a juvenile hall, a possibility that forces us to ask whether it is fair to punish someone for a psychiatric disorder. This complicated question weighs the duty of society to protect its most vulnerable members (other children) against Sybil's right to treatment. It is clear from a review of the research that children who are exposed to peers with similar problems (such as would be found in juvenile detention) and who do not have strict parental oversight fare much worse in the long run [8].

Sybil's severe behavioral problems fit the criteria for conduct disorder, but other diagnoses must be explored. Substance abuse should be considered given her comments about wanting "to buy me some weed," and, in light of the reports of her sexually inappropriate behavior, bipolar or post-traumatic stress disorder could be present. Regardless of her diagnosis, it is clear that her family must be involved in treatment but has not been. Neglect should be considered and reported according to mandatory reporting laws. The family should come for regular working visits with the treatment team to learn how to care for Sybil when she returns home, especially given her decompensation around simple phone calls.

Timothy de Vore, the medical student working with Sybil, raises an important point about the family's disconnectedness. The other question that must be raised is that of the staff's withdrawal and possible burnout. It is understandable that the staff reports being exhausted. Sybil is extremely ill. She is homicidal and has injured animals and people. She is no longer functioning in school or society. Critically ill patients, in an ICU or on a psychiatric ward, are emotionally and physically tiring for staff. This may be because the staff have unreasonable expectations for Sybil's outcome. Frequently health care professionals see a patient's death or lack of improvement as their own failure [9]. It is important to explore both the treatment team's expectations and the parent's expectations. Communication between the team and the family about the true prognosis for Sybil may help to decrease the feeling of burnout. If they acknowledge how difficult it is to work with patients like Sybil and talk together as a team, her caregivers will better understand their own feelings of frustration. If they don't do this, the team runs the danger of having their counter-transference feelings interfere with their treatment of Sybil.

Understanding that Sybil is indeed ill may be difficult. Media portrayals and historical perspectives often represent psychiatric illness as a failure of character. Popular television shows such as "Malcolm in the Middle" suggest that children with attention deficit hyperactivity disorder and conduct disorder need military school rather than psychiatric treatment. If only one were a stronger or more self-disciplined person, then mental illness would not be occurring, or so the mantra goes. Unfortunately, this occurs not only in the popular media but also in our medical journals, one of which published an article a couple of years ago called "Evaluating Wickedness in Children" [10]. It is hard to imagine a seriously ill cancer patient in the midst of chemotherapy being held responsible for his or her illness in the same way that psychiatric patients are.

In sum, then, this case poses questions about custody and consent for treatment, along with the overarching concerns about psychiatric diagnosis and its treatment.

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#### **Related article**

[Limiting parents' rights in medical decision making](#), October 2006

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## **Virtual Mentor**

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### **Clinical case**

#### **Obesity in kids: when appeals to vanity fail**

Commentary by Joseph R. Zanga, MD, and John C. Moskop, PhD

Robert has spent the summer in an intensive weight reduction program at Columbus Children's Hospital on the south side of Chicago. The highly selective program accepts only two or three adolescents each summer. Participants must demonstrate motivation and must have medical problems exacerbated by obesity. Robert has cardiomegaly, hypertension and prediabetes. At 14, Robert is 5 feet 7 inches tall and weighs 285 pounds.

Kelly Sumter, who is doing her third-year pediatric clerkship at Columbus, was asked to follow Robert's progress over several weeks. Kelly felt immediately sympathetic to Robert's situation. She had been overweight as a child, and nothing had been worse or more scarring than being the fat kid in the class. She thought she would never fully recover from the years of relentless ridicule. As she got to know Robert over the ensuing weeks, Kelly was surprised to discover that being overweight didn't bother Robert in the way it had bothered her. Clearly, obesity was viewed differently in his community than in the world where Kelly was raised. He had lots of friends, including a girlfriend. Other kids rarely bothered him about his weight. His parents were OK with his body size. In the end, it was his doctors' concern about his weight and their urgings that secured Robert's participation in this program.

After several weeks of living as a patient at the hospital, with tightly monitored caloric intake and daily exercise, Robert lost 30 pounds. He was pleased that he had accomplished this goal. Using a day pass, he had bought new tennis shoes and was getting ready to go home. All he had left was his family meeting. Kelly was invited to attend the meeting, which included Robert, his mother and father, brother and sister (all of whom were obese), a social worker, nutritionist and his doctor, Michael Smith.

It was clear from the meeting that, while his family was pleased that Robert had lost weight, it was not a priority for them, nor had they fully comprehended the seriousness of his related medical conditions. At the end of the meeting, Kelly was trying to understand what the hospital had accomplished for and with Robert. She asked Dr. Smith if he thought they had helped him and, if not, had it been worth all the time and resources? Could you really accomplish anything without the support of parents, family and the culture at large?

## **Commentary**

We must begin in pediatrics with a basic question: Who is the patient we are trying to serve? Though the family needs to be involved, Robert is the patient in this case, and he is the primary focus of our concern. He has probably been admitted to the inpatient service of this hospital on many occasions. Because he is a minor, this was done with the informed consent and authorization of his parents. Because Robert is an adolescent, his medical team discussed the admission with him and provided him with details about the medical work to be done so that he might at least assent to the admission and work.

But Robert is an adolescent and we now know more about the developing adolescent brain than we did when pronouncements about adolescent consent and assent were first promulgated [1]. We recognize that it is almost impossible to coerce adolescents to participate in a medical procedure or treatment if they are not inclined to do so. We also need to recognize that it is almost as difficult to reason with most adolescents as it is to reason with much younger children. While we once thought that brain development, begun in utero, was complete in the preadolescent or late adolescent years, we now know from a variety of studies that this is not the case [2]. Specifically we have learned that the so-called “executive functions” are not fully formed until the early to mid-twenties [3]. This should not be surprising since there have always been in the literature, both scientific and otherwise, examples of the inability of adolescents to make responsible decisions or even decisions in their own best interest.

Risk-taking behavior, inability to see the short- and long-term consequences of actions, difficulties with abstractions and an inadequate concept of self-control, have all been noted as characteristics of adolescents. While recent scientific findings have provided information about the underlying neurobiological mechanisms for adolescent behavior, we are left with questions about our obligation to make Robert act in his own best interest.

## **Ethical problems in obesity counseling and care**

Kelly Sumter, the third-year pediatric clerk who has been working with Robert for the past several weeks in the hospital, appears confused and perhaps a little frustrated about his participation in this intensive weight reduction program. She is surprised that Robert, his family and his friends all share an accepting attitude toward obesity—an attitude very different from her own and that of her peers. But this marked difference in attitudes does not, in and of itself, constitute an ethical issue. What other features of the case, then, might raise it to the level of a substantive ethical problem?

Kelly asks her attending physician, Dr. Smith, if Robert’s hospitalization had been “worth all the time and resources.” It is not clear whether she suspects that Robert’s participation, or the intensive weight reduction program as a whole, is a poor use of health care resources and therefore a kind of ethical mistake. It might, in fact, turn out that Robert, or even the majority of program patients, realize no lasting benefit

from their participation, due to deficiencies in the program's goals, in the patient selection process, or in the treatments themselves. There is, however, not nearly enough evidence provided to establish this conclusion. Robert did, after all, complete the program and achieve his goal of losing 30 pounds. Kelly clearly fears that Robert will not continue to control his weight, but she might also hope that the positive experience of a significant weight loss and the new knowledge Robert has gained about diet and exercise will have a lasting effect. Assuming that the weight reduction program includes follow-up of program patients and reporting of results, even a subsequent finding that the program did not result in lasting benefits may point the way toward more effective weight loss initiatives for adolescents.

Another way to interpret Kelly's concern is not that too much is being done to address Robert's obesity, but rather too little. She clearly believes that Robert and his family should be much more concerned about his weight than they are. She might be inclined to argue that Robert's parents' failure to take his health problems more seriously and to take more aggressive steps to control his weight is ethically unacceptable behavior, in fact a kind of child neglect. If this conclusion were correct, it would represent not only an ethical but a legal transgression, and it would create a professional duty to report this suspicion of child neglect, followed by mandatory investigation by state child protective service officers and, if appropriate, required interventions to address the problem.

There are, however, several reasons to believe that such a conclusion would be premature, at best. First of all, Robert's parents did agree to his participation in the intensive, inpatient weight reduction program, and they did support the program, at least as evidenced by their attendance at the concluding family meeting and their reported pleasure at his loss of weight. Second, Robert's parents' relative lack of concern about his weight does not appear to be aberrant, but rather a commonly held attitude, at least in their cultural community. Thus, if Robert's parents' behavior constitutes child neglect, so would the behavior of many, if not most, of the other parents in that community. Such a standard of neglect seems too stringent, and, unless the community in question is very small, it would be prohibitively expensive to enforce.

The most important ethical issue in this case may ultimately be one of recognizing and responding to cultural diversity. Kelly recognizes that Robert and his family and friends have cultural attitudes and priorities about body weight that are very different from her own (and from those of most health professionals). Their attitudes conflict with her beliefs about how to pursue Robert's best interests. In light of this conflict, she might be tempted either to "write off" Robert as a hopeless case or to enlist the power of the state in order to impose healthier behaviors on him. We have argued that neither of these courses of action would be justified, given the situation described. Instead, we believe that Kelly, Dr. Smith and the other health professionals caring for Robert should continue to counsel Robert and his parents about the probable consequences of his obesity on his health, educate them about proper diet, exercise and health care, and encourage their continuing efforts to

control his weight. They should also recognize that Robert and his parents are ultimately responsible for the choices that will guide his life, and they are entitled, within reasonable limits, to make those choices based on their own beliefs and attitudes about human health, beauty, enjoyment and activity.

Both legally and ethically then, all we can do is make the appropriate recommendations for this young man's health and well-being to him and to his parents, noting our discussions and their responses in his medical record.

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### Related articles

[Teaching residents and students to help patients and their families with obesity](#), October 2006.

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# Virtual Mentor

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## Medical education

### Teaching residents and students to help patients and their families with obesity

by David N. Collier, MD, PhD, and Joseph R. Zanga, MD

#### Analysis of the problem

In the past three decades, the proportion of children and adolescents in the United States who are overweight has tripled. With nearly one of every three children now exceeding a healthy weight, overweight has become the most common chronic medical condition of childhood in the U.S. [1]. As a predisposing factor for the development of cancer, type 2 diabetes mellitus, cardiovascular disease and other chronic diseases, obesity across all populations has been estimated to account for more than \$100 billion per year in treatment costs and about 117,000 preventable deaths annually. At current rates of childhood obesity, it has been predicted that about one of every three children born in the U.S. in 2000 will develop type 2 diabetes during his or her lifetime [2]. The expected lifetime prevalence of diabetes among African American, Asian American and Hispanic children will be even higher, foreshadowing an impending public health crisis [2].

Not only is obesity an important early risk factor for much of adult morbidity and mortality, but medical problems including hypertension and dyslipidemia are common in obese children and adolescents [3]. The relative risk for disordered sleep breathing (DSB) (obstructive sleep apnea/hypoventilation syndrome) in obese children is five times that of those with normal weight [4]. DSB can result in attention deficit hyperactivity disorder (ADHD), hypersomnolence, irreversible cognitive defects, school failure and pulmonary hypertension [5]. Chronic systemic and pulmonary hypertension may lead to the development of cardiomyopathy with increased risk of congestive heart failure, cor pulmonale and arrhythmias [4].

Obesity, in particular excess central or visceral adiposity, is associated with insulin resistance at the level of skeletal muscle, which, in turn, is associated with a spectrum of disorders, including acanthosis nigricans (a velvety hyperpigmented rash most commonly found on the neck and axillae), fatty liver disease, polycystic ovary syndrome (the most common cause of amenorrhea and infertility) and type 2 diabetes mellitus (T2DM) [2]. Though once uncommon in children, T2DM now accounts for up to 50 percent of all cases of newly diagnosed childhood diabetes [6].

Nonalcoholic fatty liver disease (NAFLD) is the most common form of liver disease in children, with obesity as the single greatest risk factor. Though frequently silent,

NAFLD may present with abdominal pain, hepatomegaly or abnormal transaminase levels. Up to 15 percent of cases progress to cirrhosis and liver failure [7]. The kidneys can also be affected, with obesity-related focal segmental glomerulosclerosis in our population increasing tenfold, in parallel with the rise in pediatric obesity [8].

Misalignment of the lower-extremity joints and musculoskeletal pain are more common in obese children than in lean children. Significant joint problems that may require surgical intervention, including Blount's disease (idiopathic tibia varus) and slipped capital femoral epiphysis, are also associated with obesity [9].

Many studies have found that obese children are at significantly higher risk than their lean counterparts for experiencing poor psychological well-being, including low self-esteem, depression and low health-related quality of life (QOL) scores [10]. In some instances, obese children have QOL scores similar to those of children diagnosed with cancer and receiving chemotherapy. QOL scores and the degree of obesity are inversely correlated. Similarly the QOL scores in obese children with symptomatic comorbidities, such as orthopedic complications or obstructive sleep apnea, also tend to be significantly lower [11].

### **Approach to teaching**

As an American journeying to a Scandinavian country I noticed only an occasional person who could be regarded as moderately overweight. Back home, at the facility for mostly impoverished patients where I spend my clinical hours, I tend instead to notice the rare underweight patient who might present for an evaluation. The problem of overweight and obesity in the United States has become so pervasive that it appears almost normal, as Dr. Collier has explained in the analysis above. How then do we teach our students to deal with this problem and the attendant issues previously noted?

The medical system in the United States has often been said to be not a health care system but an illness care system. This may be especially true with the problem of obesity since its best hope for cure lies in prevention. While the point at which this prevention should start is often discussed, as a pediatrician, I choose to start at the time most relevant to my practice, the birth of the child.

We begin by providing our students with detailed information that enables them to counsel and work with new mothers who are endeavoring to breast feed their infants, since "breast is best." We also teach them about community and other resources that can assist them and their patients in this effort.

Some new mothers don't breast feed, or they use both breast milk and formula, and for them we must give more structured guidelines about the number of calories (100-120 per kilo) that the newborn and young infant need each day for optimum growth. We also provide an end point for parents, with a range of ounces per day. We then monitor length and weight and show parents these points plotted on a growth curve,

along with the body mass index (BMI). We inform parents that doubling of birth weight is not expected until about six months and tripling, not until about one year.

At the age of one year, growth becomes less rapid, but many parents have difficulty understanding that during the second year children will appear to eat less than they had previously. A simple teaching point helps to make parents more comfortable with this decrease. Using as an example a child born at seven pounds, we note that the child would ordinarily be approximately 21 pounds at one year of age. If the child continued eating the same relative quantity of food during the second year and beyond, the child would be 63 pounds at two years of age and 189 pounds at age three. This provides an image that the most and least sophisticated of parents can grasp.

We teach that parents must be aware of others who feed their children. This is particularly true in out-of-home child care situations where high-calorie, high-fat convenience foods are often the mainstay of meals provided. Beyond this we teach that water is the preferred beverage and that “fast food” should be regarded as an occasional treat and not a regular part of a daily or even weekly diet. Parents are asked to consider fiber-dense fruits and vegetables as the preferred snack. Other snack foods should be available in the home only infrequently, and children should be monitored in their spending for snacks outside the home.

Students are taught that this is a family issue—regardless of the body habitus of the family members. We provide examples of inexpensive, culturally sensitive, healthful diets for the family and make formal nutrition counseling available if and as needed.

Finally, we encourage exercise, preferably as a family, with attention to the unfortunate fact that some neighborhoods are not safe for unmonitored children. Related to the emphasis on exercise is the suggestion that media of all types be restricted to one to two hours per day. Meals should be eaten as a family with attention to each other and not to a television program. Since sleep is also essential for appropriate growth and development, we teach that television and other media should not be available in a child’s room or for that matter in any unmonitored place.

If all of the things noted here had been done for Robert and his family, (see [“Childhood obesity.”](#)) beginning at the time of his birth, he would not likely be a clinical case for discussion in this issue of *Virtual Mentor*, and if he were, both he and his parents would be concerned about the problem and eagerly searching for a solution.

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# Virtual Mentor

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## Journal discussion

### Parental consent for pediatric research

by Emily E. Anderson, MPH

**Ross LF. Informed consent in pediatric research. In: *Children in Medical Research: Access Versus Protection*. New York, NY: Oxford University Press; 2006:87-103.**

Despite an historic emphasis on protecting children from research risks, over the last few decades medicine has come to recognize the need to include children in systematic efforts to evaluate treatments in order to ensure their safe and effective medical care. In her new book, “Children in Medical Research: Access Versus Protection,” Lainie Friedman Ross, MD, assesses the state of human subjects protections in pediatric research [1]. Ethical analyses of U.S. federal regulations and research practices are supplemented by case studies and a rich variety of empirical data. Questioning whether federal policies and initiatives overemphasize access at the expense of adequate protection, Ross challenges the ethics of greater acceptable research risk for children with acute or chronic illness, critiques current policies on parental consent and child assent, discusses the debate regarding subject payment in pediatric research and examines the meaning of “prospect of direct benefit.”

In Chapter 5, “Informed Consent in Pediatric Research,” Ross addresses the unique aspects of informed consent in research with children, focusing on parental rights. In pediatric research, the informed consent process includes two elements: parental (or guardian) permission and child assent, where “assent” means an affirmative agreement to participate and *not* mere failure to object. Regulations guiding research with children are outlined in Subpart D (Additional Protections for Children Involved as Subjects in Research) of the Common Rule (Protection of Human Subjects, 45 CFR 46) [2]. In most research, permission from one parent and provisions for soliciting child assent are required. Additional provisions are necessary for research involving: (a) greater than minimal risk but presenting the prospect of direct benefit to individual subjects, or (b) a minor increase over minimal risk and no prospect of direct benefit.

Child dissent may be overridden (either for an individual child or for all children in a particular study) in certain cases, for example, if the child is not capable of providing assent (due to age, maturity, psychological state, etc.) or when the prospect of direct benefit from a particular treatment is available only through research. In the latter case, child dissent may be overridden even if the child is deemed capable of

providing assent. Parents' rights to be involved in the decision may be waived if an institutional review board (IRB) determines that contacting parents or mandating permission would potentially harm or fail to protect subjects (as in the case of neglected or abused children).

The ethical justification for requiring parental permission for children's research participation is grounded in respect for parental decision-making authority. Because parents know their children intimately and care deeply for their welfare, parental decisions can be reasonably assumed to promote children's best interests. Ross argues that parents also have the right to raise their children according to their own standards and values without state intervention. She believes that over-regulation is not in children's best interest and that parents ought to be the primary decision makers regarding their children's health care.

Children should play an active role in health care decision making, and their voices should have greater weight in research decisions than in those that concern clinical care. Federal guidelines do not suggest specific age limits, but it is generally agreed that efforts to involve children in health-related decision making should begin around age seven; assent or dissent should be given more serious consideration as the child enters adolescence (around age 12). While in most states 18 is the legal age of consent for health care decisions, exceptions are made to the need for parental permission for those under 18 for certain types of treatment such as reproductive health or substance abuse treatment or for mature minors (e.g., minors who are themselves parents).

Ross argues, however, that the requirement for parental permission should not be waived in pediatric research if there is no prospect of direct benefit for the child. While regulations allow waiving the requirement for parental permission to protect children who need medical care and whose parents are unavailable, unable or unwilling to consent, Ross does not believe that this justification should be extended to the research setting, especially where there is no prospect of direct benefit to the child.

According to Ross, applying the principle of respect for persons to children by soliciting assent for research participation is not—as it is for competent adults—about self-determination, voluntariness and comprehension; it is about respecting the *developing* autonomy of the child. For example, parents may compel research participation against a child's wishes in order to respect the child's future autonomy by forcing him or her to undergo potentially life-saving medical treatment. In the case of a sick child, study participation may offer the possibility of direct benefit by treating a rare disease or disorder for which there is no effective treatment available outside of the research context. Parents may coerce a healthy child, who, out of fear, may be hesitant to serve as a case-control subject for an ill sibling, into participating in order to promote altruism, family unity and, again, the well-being of the autonomous adult that child will become.

Alternately, parents may prohibit their child from participating in a study even if the child assents. For example, a child may want to participate in a nontherapeutic asthma study that pays \$50 but involves two extra doctor visits. It is reasonable that a parent may not want to give permission for this because the time conflicts with other commitments such as piano lessons or family dinners that will be of greater benefit to the future adult than the \$50 they forgo now.

Ross acknowledges that parents who give permission for their child's research participation may be misguided regarding the therapeutic value of the protocol but argues that parental discretion must be respected unless it is abusive or harmful. When research does not offer the prospect of direct benefit to the child, Ross supports limiting parents' rights to override the child's dissent.

Ross's work prompts discussion of the reasons why parents agree or refuse to enroll their children in medical research, how they understand the potential for benefit or harm and how they balance risks against potential benefits. Several interesting studies published in the last few years shed light on these questions and complement Ross's ethical analyses [3-7]. In a study of children participating in clinical anesthesia and surgery research, Tait et al. found that many parents had inadequate understanding of the research as it was presented to them during the informed consent process [3]. Parents who consented had greater understanding than those who did not. Factors shown to be significantly associated with greater parental understanding included age over 30, higher education level, lower anxiety, greater perceived clarity of information, greater degree of listening to the explanation of the research, greater degree of reading the consent document and perceptions of the study's importance, risks and benefits [3].

In a study of parents with children in leukemia trials, approximately half failed to understand random assignment at the time of enrollment and six months later [4]. Factors associated with better understanding in this study included being a member of a majority ethnic group, higher socioeconomic status, presence of a nurse during informed consent, parental reading of the consent document and physician discussion of specific components of the randomized controlled trial [4].

Among other determinants of parents' decisions (beyond their understanding of the proposed research) their perceptions about its risks and benefits and their opinions about the importance of the research seem to carry the most weight [5]. A study comparing parents who consented to their child's research participation to those who declined to give permission found that the consenters exhibited less uncertainty in their decision making, were more trusting of the medical system and believed that the environment in which the consent was sought was less pressured [5]. Rothmier et al. discovered that, although many parents exhibit altruistic motives such as a desire to contribute to medical knowledge, the most compelling motive for parents who enroll their child in clinical research is learning more about their child's illness [6].

Cost was another factor in decisions about whether to participate. While payment for participation was not found to play a significant role in parental decisions, obtaining free medications gained importance as socioeconomic status declined [6]. Hulst et al. learned that, although illness severity did not decrease the probability of obtaining parental permission for observational research, parents of children with a history of disease and parents who perceived that the research would be burdensome to the child were significantly less likely to consent [7].

Ross argues that federal policies governing pediatric research should focus on minimizing risks and that respect for parental autonomy and family privacy should limit state interference in parental decision making. Nevertheless, review of the data suggests that, although parents may have their child's best interests in mind when enrolling them in research, much could be done by institutions and investigators to improve the quality of parental decision making. Parents may not understand the potential risks of the research, they may refuse participation in potentially beneficial research because they do not adequately understand what is being asked of them, or they might decide about research participation before listening to and understanding the specifics.

Some factors shown to influence parental decision making that are amenable to intervention include anxiety; inadequate reading of the consent form or inadequate attention to the researcher's explanation of the research (these may be issues of time or timing); trust in the medical profession; and perceptions of risks, benefits and burden. Other factors that affect understanding, such as parental age and education level, are not amenable to intervention. Researchers may need to spend more time discussing potential study enrollment with parents or developing innovative strategies to improve understanding among certain parent populations.

### **Questions for discussion**

- Do you think parental permission for participation in pediatric research should be allowed to override child dissent? When, if ever, should the need for parental consent be waived?
- What circumstances might lead a researcher to consider refusing to enroll a child in (or withdrawing a child from) a pediatric study even if the child meets the inclusion criteria?
- What changes to the parental permission or child assent processes are suggested by the empirical data discussed above?

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# Virtual Mentor

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## Clinical pearl

### Diagnosis and treatment of conduct disorder

by Suma Jacob, MD, PhD

As many as 5 percent of preadolescent boys, 8 percent of adolescent boys and a quarter to a half that percentage of girls of those same ages fulfill criteria for a diagnosis of conduct disorder [1]. In contrast to isolated behavior problems, this diagnosis requires a repeated, persistent pattern of violating the rights of others and age-appropriate societal rules for six months or more. Multiple factors are probably responsible for this developmental pathway [2]. The primary features of conduct disorder are:

- Aggression
- Vandalism
- Theft
- Frequent lying
- Violation of rules, running away

About 40 percent of children with the diagnosis of conduct disorder will grow into adults with antisocial personality disorder.

### Diagnosis

Correct diagnosis rests upon distinguishing typical adolescent risk-taking and experimentation from enduring antisocial behaviors that repeatedly involve serious harm to individuals or property. Some questions that help in differential diagnosis of conduct disorder are [3]:

- Have you had any run-ins with the police? If yes, what were the circumstances?
- Have you been in physical fights? If yes, what were the circumstances? How many?
- Have you been suspended or expelled from school? If yes, how many times? What were the circumstances?
- Do you smoke, drink alcohol or use other drugs? If yes, how often? How long? Which drugs?
- Are you sexually active?

Comorbid disorders such as the following should be identified in making the diagnosis because their existence can influence presentation and treatment options:

- Attention deficit hyperactivity disorder (ADHD), which has features of disinhibition, inattention and distractability.
- Substance abuse or dependence; these show functional impairments and withdrawal or tolerance symptoms that need to be carefully elicited and managed. Early (at or before 13 years of age), repeated use is associated with overlapping conduct symptoms.
- Mood disorders, which have sleep, appetite, energy level or thought pattern changes. Watch for increased risk of suicide with impulsivity.
- Intermittent explosive disorder, which is characterized by sudden aggressive outbursts in isolation from all other persistent symptoms. It is unprovoked and without intent to harm anyone.
- Oppositional defiant disorder, closely related in the continuum of disruptive behavior disorders, but may be distinguished by less physical aggression and less likely history of problems with the law.

### **Treatment**

Treatment options for conduct disorder are family therapy, behavioral modification and pharmacotherapy, often in combination. The clinician must assess the severity of the individual child's disorder and should refer the child and family to a subspecialist if any of the following conditions apply: there are concerns about safety, diagnostic behaviors escalate rapidly, psychoeducational interventions are ineffective, there is conflicting information from multiple sources or many comorbid symptoms exist [4]. Substance abuse problems should be treated first with appropriate interventions and rehabilitation.

If the family is open to working with a therapist, the therapist should:

- Explain that long-term prognosis is poor without intervention.
- Emphasize that structure and parental monitoring of activities (e.g., where the child is and with whom) are critical to effective management. Preference should be given to supervised peer activities such as organized sports or clubs in the school or community.
- Discuss and practice ways to communicate clearly, illustrating statements that do and do not work.
- Stress the importance of positive attention. Show family members how to set up appropriate rewards for desirable behavior and how to establish a daily routine of age-appropriate, child-directed play or fun activity with the parent (e.g., drawing together, playing catch with younger children).
- Encourage consistent responses to behaviors and enforcement of curfews. Help the family learn to establish realistic consequences for noncompliance and avoid threats they are unwilling to follow through on.

Pharmacotherapy can be an adjuvant treatment for children who are highly aggressive, impulsive or have mood-disorder symptoms. No medications have been formally approved for conduct disorders in general, so medications are directed at

specific symptoms. Symptom control may help the child participate in family or systemic interventions or treatments. Symptom-control medications include:

- Stimulants for patients with comorbid attention deficit hyperactivity disorder (ADHD) and impulsivity. Parents may need to be involved in administering or monitoring the medication because of its street value and potential for abuse by peers. Medical monitoring of cardiac history, height and weight, sleep, and symptom reports from parents and teachers are recommended.
- Antidepressants such as fluoxetine (a selective serotonin reuptake inhibitor, or SSRI) may benefit patients with depressive, rigid or inflexible aggressive behaviors. Restlessness, behavioral activation and suicidal ideation should be monitored, particularly early in the treatment, and parents need to be notified of side effects. If ADHD is a comorbidity, some physicians prefer bupropion to an SSRI.
- Anticonvulsants including lithium have been used to treat aggression and mood lability symptoms associated with bipolar disorder. Because monitoring side effects and blood levels is important, a family's ability to comply with treatment and follow-up should be considered.
- Beta-blockers such as clonidine have been used to control impulsivity and aggression. Vital signs, dizziness, sedation and potential tolerance or dose changes should be monitored.
- Atypical antipsychotics such as risperidone are used to treat aggression. These medications are also used to treat mood lability and bipolar symptoms. Weight gain and risk for metabolic disorder should be followed closely.

Treatment approaches need to intervene at many levels. Early interventions may influence the course and may prevent the need for "treatment" in the juvenile justice system. An ideal, comprehensive treatment plan integrates the individual, family, school and community. There are evidence-based treatment programs such as functional family therapy, multisystemic therapy and Oregon Treatment Foster Care that are working at the various levels required [5].

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[Coping with a child's conduct disorder](#), October 2006

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# Virtual Mentor

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## Health law

### Limiting parents' rights in medical decision making

by Lee Black, LL.M.

The law's inquiry into parental competence to provide medical care for a child does not stop at assessing their physical and mental ability to do so; it also examines their willingness to make medically appropriate decisions. The decision of a physically and mentally competent parent to pursue a particular path of treatment may, for example, not accord with the best interests of the child, particularly if a child is not of an age where he or she can contribute to the process. Parents have a legal obligation to refrain from actions that may harm their child. Medical decision making, though, has a certain ambiguity—when does a particular choice indicate that the parent is unable to decide on appropriate care? Religious objections to treatment have a long history of acceptance and, while not absolute, can at times be codified into law [1]. Objections motivated by other beliefs may not receive the same protections and may cause parental objection to specific treatment to be overturned by a court or other authority with more ease than objections based on religious beliefs.

### Religious objections

The Supreme Court of the United States has long upheld the right of parents to make decisions for their children based on religious grounds. Generally, when the physical or mental health of the child is not at stake, states and courts defer to the decisions of the parents. For medical decisions, mental or physical health will always be at stake, so a different balancing process must be employed to ensure that the state carries out its duty to protect its citizens but does not infringe on the rights granted to individuals by the First Amendment to the Constitution.

When attempting to declare a given medical treatment decision inappropriate, the state has a high burden of proof because of the great value placed on autonomous parental decision making. The court must weigh the rights of a parent against the interests of the child. One important factor in this process is the expected outcome of the illness or disease: if the proposed medical treatment has a good chance of success and the predicted outcome without treatment is death, courts are more likely to intervene and overrule parental decisions; if the proposed medical treatment does not have a high likelihood of success or the predicted outcome is not death, courts frequently uphold the decision of parents. Generally, it is only when the child's life is at risk that the weighing of interests favors the child and the government authority that is asserting the child's rights.

In one litigated case of religious objections to care by Christian Scientists, the interests of the parents, the child and the state were weighed with consideration of a state law that permitted medical decision making to be influenced by religious doctrine. The Supreme Court of Delaware in *Newmark v. Williams* landed on the side of the parents. The child in *Newmark* was diagnosed with Burkitt's lymphoma and was given a 40 percent chance of survival if he obtained chemotherapy treatments. His parents decided that, rather than allowing an uncertain and painful medical treatment, they would seek treatment through their church [2]. The state objected and filed for temporary custody of the child.

The court determined that the parents were within their rights to forgo the treatment. According to the court,

...the spiritual treatment exemptions reflect, in part, “the policy of this State with respect to the quality of life” a desperately ill child might have in the caring and loving atmosphere of his or her family, versus the sterile hospital environment demanded by physicians seeking to prescribe excruciating, and life-threatening, treatments of doubtful efficacy [3].

The determining factor was that the treatment proposed by the child's physician had only a 40 percent chance of success. From the court's discussion of other legal precedents, if a treatment was more likely to succeed than fail (i.e., had greater than 50 percent chance of success), the state could be justified in gaining custody of a child to obtain medical treatment over the religious objections of his or her parents, although the court made no definitive statement on this matter.

In a more recent case, the Court of Civil Appeals of Oklahoma came to a different conclusion based on a set of facts much more favorable to the state. *In the Matter of D.R.*, the child suffered from seizure activity and developmental difficulties. While in physical therapy to address these problems, she experienced a severe seizure, after which her parents discontinued therapy and sought no other treatment. The state intervened, alleging medical neglect by the parents because the child's condition was potentially life-threatening.

The court decided in favor of the state based on the severity of the medical problem, the likelihood of success of the proposed treatment and the limited potential harm of the treatment. It was “well-settled that the state may order medical treatment for a nonlife threatening condition, notwithstanding the objection of the parents on religious grounds, if the treatment will, in all likelihood, temporarily or permanently solve a substantial medical problem” [4]. The court recognized that the state could not order treatment over religious objection of the parents if the treatment was “risky, extremely invasive, toxic with many side effects, and/or offers a low chance of success” [5]. This decision, consistent with *Newmark*, illustrates the difficulties in determining who should make medical decisions for a child.

### **Nonreligious objections**

Religious objection has a firm foundation in the Constitution and legal precedent. It

is much more difficult for courts to justify parental refusal of treatment for reasons not based in recognized religion (a somewhat arbitrary distinction, but consistently used). For example, if a parent prevented needed care because of a fear of nonexistent risks, the state would be able to intervene with little opposition by courts. Parents have more flexibility in choosing among different treatments that all have some scientific validity; they need not choose the best available treatment. The caveat here is what constitutes valid treatment—courts do not always agree on this.

For decades, laetrile, a chemical compound found in various foods, has been considered by some to be an effective form of cancer treatment. Mainstream medicine has never embraced laetrile use, and there have been no clinical trials of its efficacy [6]. Yet, within a month two courts in the Northeast decided cases based on the use of laetrile and metabolic therapy and came to very different conclusions about its use.

The case of Joseph Hofbauer in New York concerned the definition of “neglected child” [7]. Joseph had Hodgkin’s disease, and his physician recommended that he be seen by a specialist for further treatment that could include radiation or chemotherapy. Joseph’s parents rejected the recommendation and took him to Jamaica where he received a course of metabolic therapy that included the use of laetrile. After his return to the U.S., the state sought to remove Joseph from the custody of his parents on the grounds that failure to enroll him in conventional treatments constituted neglect. A court order authorized continued treatment with metabolic therapy on the condition that Joseph be monitored by a second physician.

At trial, there was voluminous testimony concerning treatments for cancer. Physicians for the state testified that metabolic therapy was inadequate and ineffective for the treatment of Hodgkin’s disease. Physicians for the parents testified that metabolic therapy was beneficial and effective, although they did not preclude the use of conventional treatments that the parents sought to avoid. A scientist testified to an animal study conducted on mice showing the effectiveness of laetrile and other substances. Both sides admitted to the dangerous potential side effects of conventional treatments.

The court began by noting that the statute pertaining to adequate medical care for children required a parent to “entrust the child’s care to that of a physician when such course would be undertaken by an ordinarily prudent and loving parent ‘solicitous for the welfare of his child and anxious to promote (the child’s) recovery’” [8]. Parents can rely on the advice of licensed physicians, because those physicians are “recognized by the State as capable of exercising acceptable clinical judgment” [9]. The question most important to this court was whether the parents provided an acceptable course of care in light of surrounding circumstances. The court determined that the parents were justified in their concern over conventional treatments, that there was medical proof of the effectiveness of laetrile and that metabolic therapy had fewer risks than radiation or chemotherapy. Therefore, Joseph was not neglected within the meaning of the statute.

A month after the New York decision, Massachusetts had occasion to answer the same question: was laetrile appropriate medical treatment? In *Custody of a Minor*, a three-year-old boy suffered from acute lymphocytic leukemia [10]. An earlier court decision had ordered that the child undergo chemotherapy, which was successfully completed. Thereafter, his parents discontinued his medications and the leukemia recurred. The parents sought to supplement their child's chemotherapy with metabolic therapy, including laetrile.

Both the parents and the state introduced expert testimony pertaining to the safety and efficacy of laetrile. None of the parents' experts claimed expertise in the area of blood diseases or leukemia. The state presented various experts in blood diseases, including the child's physician. At an earlier hearing, a judge had concluded that "not only are the assertions concerning metabolic therapy's alleged palliative effect unconfirmed by any well-documented evidence, but there are several alternative explanations for this observed phenomenon" [11].

The court found that the use of laetrile was potentially harmful to the child because of the possibility that it would interfere with chemotherapy and because it posed a risk of cyanide poisoning. The court also decided that "family autonomy is not absolute, and may be limited where, as here, it appears that parental decisions will jeopardize the health or safety of a child" [12]. The court determined that the use of laetrile in this specific case was "not consistent with good medical practice," but it did not address the use of laetrile in all circumstances, drawing a careful distinction with *Hofbauer* by noting the additional testimony of laetrile's possible effectiveness and the different type of cancer at issue in that case.

### **Interpreting the courts' rulings**

The end result of a court battle over the provision of medical treatment depends on the type of objection—religious or secular, the proposed treatment and the prognosis for survival with and without treatment. Religious objection to standard medical therapy is often legally valid when the treatment is more likely to fail than succeed. Respect for religion has forced courts to recognize that medical decisions are not always scientific—many people rely on faith to heal them. On the other hand, the right to refuse treatment based on religious objection is not absolute. In cases where adherence to religious tenets that prohibit standard, life-saving care, e.g., blood transfusion, would almost certainly lead to a child's death, the courts have decided that parents cannot make martyrs of children who are too young to have consented to embrace the faith.

Objection for other reasons leads to more varied court decisions, but these objections can be overruled more easily than faith-based objections. Parents cannot refuse all medical treatment as they can if the objection is based on recognized religious doctrine. If alternatives may be successful and are less invasive than a risky standard medical treatment, courts may defer to parents. If the alternative treatment has no scientific merit, courts will most likely prevent parents from standing in the way of their child's health.

It is important to remember that legal competence to make medical decisions for children is not just about physical or mental capacity; it is also about making appropriate, best-interest decisions. Medical neglect statutes examine whether appropriate care was provided, not how it was provided. A parent who refuses care based on an objection to treatment, whatever the basis, is just as likely to have the state intervene to make medical decisions as a parent who is not physically able to provide care or not mentally capable of making decisions.

### Notes and References

1. For example, the Illinois Compiled Statutes define “neglected child” to exclude a child whose “parent or other person responsible for his or her welfare depends upon spiritual means through prayer alone for the treatment or cure of disease or remedial care...” 325 ILCS 5/3. (2006).
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# Virtual Mentor

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## Policy forum

### **Parental resistance to childhood immunizations: clinical, ethical and policy considerations**

by Nancy Berlinger, PhD, MDiv

School immunization laws in all 50 states provide for medical exemptions for children whose specific underlying health conditions, such as HIV infection, cancer or immunosuppressive therapies, place them at undue risk from one or more routine childhood immunizations [1]. In all but two states, “nonmedical” exemptions are permitted: 48 states permit exemptions based on religious belief, while more than one-third of those states also permit exemptions based on nonreligious personal convictions [2]. States vary in how they define “religious” or “philosophical” beliefs and in the standards of proof required of parents; in some states parents have been required to defend their beliefs at a “religious sincerity” hearing or to provide written documentation that their religious beliefs are incompatible with state immunization law. In other states they simply sign a form or check a box to claim a nonmedical exemption. This is an active area of legislation, with trends tending toward adding nonmedical exemption categories or making it easier for parents to obtain such exemptions [3]. States where it is easy to get an exemption tend to have the largest numbers of exemptions [4].

Nationwide, only a tiny percentage of parents—one percent is the estimate commonly cited by pediatricians—invoke nonmedical exemption. However, because families with similar beliefs may choose to live together, worship together, send their children to the same schools or be part of the same home-schooling networks, local rates of vaccination refusal may far exceed one percent. Parental refusal has been implicated in the development of “hot spots”: locations where the herd immunity provided by compulsory vaccination has been weakened sufficiently for disease outbreaks to occur.

In Boulder, Colo., endemic pertussis (whooping cough) has been linked to vaccination rates of about 50 percent among children at a local private school [5]. In 1991, a measles epidemic in Philadelphia that resulted in more than 500 cases and seven fatalities was traced to unvaccinated children whose families were members of two faith-healing churches [6]. Herd immunity can also be weakened in communities where large numbers of children are *undervaccinated*, having missed or not completed vaccinations due to lack of access to health care or frequent family relocations [7]. While undervaccination is a different public health problem than vaccination refusal, laws that ease nonmedical exemptions are of special concern to

physicians and public health officials in states with communities where undervaccination already threatens herd immunity [8].

The reasons parents seek or consider nonmedical exemptions may include strongly held religious convictions about faith healing, such as those characteristic of Christian Science [9]. The U.S. Supreme Court's landmark decision on the limits of parents' religious freedom in such cases states that the "right to practice religion freely does not include the liberty to expose the community or the child to communicable disease or the latter to ill health or death" [10]. This ruling is also relevant to cases in which parents claim a religious right to forego medical treatment for a child who is not suffering from a communicable disease. The classic example here is the Jehovah's Witnesses' prohibition on treatments involving blood products.

When such cases arise, courts may intervene to protect the health and welfare of the affected children and, in cases where there is a risk of disease outbreak, to protect the health of the community in general. During the 1991 measles epidemic in Philadelphia, public health officials were granted a court order to immunize six children whose families were members of one of the faith-healing congregations identified as the source of the outbreak.

### **Medical neglect**

"Medical neglect" refers to a parent's failure to obtain adequate medical care for a child despite having the ability to do so [11]. The American Academy of Pediatrics regards medical neglect as a form of child abuse and neglect and opposes state laws that allow religious exemptions to child protection statutes [12]. What is unclear among physicians, legal scholars and bioethicists is how the concept of medical neglect applies to immunization refusal cases. Families with deeply held convictions concerning faith healing may not have strong or trusting relationships with health care providers in general because of the nature of their religious beliefs. In a public health emergency, there is the risk that characterizing as abusive or neglectful those parents who have refused to vaccinate their children on religious grounds will work against efforts to prevent or control disease outbreaks within or involving religious communities. The interests of these children and of other vulnerable children—including those with medical contraindications—may be better served by ongoing efforts to strengthen herd immunity through vaccination campaigns, greater access to preventive health care in general, and strong epidemiological surveillance and public education programs.

### **Resistance on nonreligious grounds**

Parental resistance based on philosophical or personal beliefs about immunization presents a somewhat different clinical, ethical and policy challenge. Many, perhaps most, of these parents have strong personal beliefs about the dangers of vaccines, in particular, the belief that childhood vaccines are linked to rising rates of autism. Some may not believe in the need for vaccines. This belief may co-exist with a preference for alternative medicine, may be the product of a lack of firsthand knowledge of lethal childhood illness (given that these parents themselves received

routine childhood immunizations) or may result from a lack of knowledge of how herd immunity works. Resistance to immunization may also be associated with opposition to perceived government intrusion into the lives of families and the rights of parents.

Parents with these personal and philosophical objections to immunization may take advantage of “religious” exemptions simply because the latter are far more likely to be available under the laws of most states. While some of these parents join mail-order or Internet “churches” to bolster their case for a religious exemption, it is not clear how much common ground they have with parents whose resistance to vaccination is an aspect of their religious faith [13].

### **Physicians’ role**

A recent survey of pediatricians’ attitudes toward families who refuse vaccines focuses on families whose philosophical refusals are based on safety concerns [14]. (The family whose refusals are grounded in a belief in faith healing, or whose children are *undervaccinated* rather than *unvaccinated*, might not have a pediatrician at all.) Where some professional caregiving relationship is in place, it affords an opportunity for education and conversation about the risks and benefits of immunization for the individual child and for the community. Physicians should take this opportunity, while bearing in mind the difficulty that even well-educated parents may have in sorting out fact from fear, given the extraordinary number of Web sites dedicated to this particular issue, and on the assumption that parents who refuse vaccines but otherwise attend to medical care for their children do so in the sincere belief that they are acting in the best interests of their children. Clinicians should help these parents understand and acknowledge that they are relying on herd immunity to keep their unvaccinated children safe from life-threatening disease. They can alert these parents to the fact that, while some individuals in a community—a child being treated for leukemia, for example—must be “free riders,” physicians have a duty to the public health as well as to individual patients to ascertain that parents understand the medical and social consequences of refusing immunization. And finally, family physicians can educate themselves about the extent of undervaccination in their communities, advocate for strong, well-funded immunization programs and remind policy makers that permitting nonmedical exemptions has public health consequences.

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#### **Related articles**

[Limiting parents' rights in medical decision making](#), October 2006

[School vaccination laws](#), November 2003

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# Virtual Mentor

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## Medicine and society

### Talking with families about severely disabled children

by Arthur F. Kohrman, MD

For medical professionals, whose elemental process is diagnosis leading to intervention with the intent to cure or at least ameliorate the patient's disorder, patients with chronic disease or disability are confounding. For them, improvement may be unlikely or incremental at best, and maintenance of the status quo is often the best to be hoped for. When the patient with the chronic condition is a child, the frustrations seem even greater; we see in childhood the promise of growth and attainment of new skills leading to competent adulthood, a state that many chronically disabled children will never achieve. To add to our confusion and frustration, many of these children's lives are dependent upon complicated technologies that require sophisticated medical skills to initiate and immense vigilance and dedication by the child's caretakers to sustain.

In this brief synopsis, we will examine the problems for physicians and their colleagues in dealing with children who do not fit the standard medical model, discuss the events and feelings that the families of those children experience and suggest some approaches and inquiries that should bring the expectations of physicians and families and caregivers into closer alignment.

In the necessarily long-term relationships with their doctors, nurses and therapists, families of severely disabled children understandably want to know what they can realistically expect and, at the same time, want to believe that their efforts will result in gains for the child. We as physicians wish to guard against projecting unrealistic hopes for the child and, at the same time, want to encourage their often heroic families and caregivers in the endless and complicated tasks they have undertaken (or, rather, have had thrust upon them). We must also acknowledge our own optimistic bias, which is helpful to families when there is reason for optimism, but possibly misleading and even harmful when there is not.

We must be frank about the things that medicine does well and those that it does not do so well: we are excellent at prescribing and explaining technologies and therapies; we are rarely prepared, however, to help in the organization of the myriad services that families of disabled children must count on when the child is at home, especially those in nonmedical realms, such as school, transportation and respite services.

While we respond to illnesses and medical crises with the full gamut of sophisticated interventions and short-term therapies, our systems generally do a poor job of coordinating the services and recommendations of the many different medical personnel that families encounter; often, they are sent from specialist to specialist, with little communication between the specialty clinics and even less to the families themselves or to the primary physician or medical home (if, indeed, there is one). We should also recognize that families often feel ambivalence about medical professionals who may fail to understand their needs and who are so damnably unable (they might say unwilling) to offer clear prognoses or some measure of certainty; and yet whom they respect and upon whom they are so dependent.

There is only one way to know what concerns families of disabled or chronically ill children and to learn about their expectations—ask them, listen to the answers and, especially, look for the very painful and worrisome things that remain unspoken. To find the last, it may be necessary to gently probe subjects that are often hidden from the families themselves, such as: unresolved anger (at the spouse, the medical establishment or even the child herself); guilt; depression and hopelessness; financial stresses; problems arising from loss of intimacy within the household; sadness (and sometimes anger) at the loss of the imagined family and of the parents' plans and dreams; the effects on siblings of the attention necessarily paid to the disabled child; and fears of future burdens of caring for the child as both parents and child become older. All of these feelings and the realities of the child's care are components of families' expectations—of the child, of themselves, of medicine—and for some, of God. The present perceptions and attitudes of the family condition and shape the child's future and, thus, our ability to be effective on the child's behalf.

How do we as physicians and physicians-in-training help these families and children achieve a realistic understanding of the limitations of the child's situation and still maintain a supportive and trusted relationship?

### **What we need to know—beyond technology and medical management**

First, we must acknowledge the social forces and expectations that surround and influence—both directly and tacitly—the families of disabled children. Society expects (as do we) that, no matter how difficult the task, families will assume responsibility for their children's care, and it looks with disapproval upon those who cannot or fail to do all that's needed. Failure to meet societal expectations can reinforce the family's guilt and resignation.

Next, we must learn from our patients and their families (indeed the child's entire caregiving community is the “unit of care”) what they know about and how they perceive the challenges and possibilities for their disabled child. Each family has constructed a very individual story of its situation and equally individual ways of dealing with it, and our first task is to learn those stories. Parents and caregivers of disabled children have a variety of motivations and feelings that fluctuate during interactions with medical personnel at different times. Sometimes there is a strong “can do” mindset, which often is “must do,” yet the enormity of the task and its

apparent endlessness may create a sense of despair—“no way out.” While many families are buoyed by a deep spiritual commitment—and some feel that God has designed this challenge to test them—there is often much guilt about causality in the child’s predicament and about the inevitable feelings of antipathy arising from the burdens and losses that the child has placed on the family. Resignation and hopelessness may manifest as failure to execute important functions in the care of the child and may even be interpreted as neglect.

### **How can we help beleaguered and bewildered families?**

1. Find out what works for them in the care of their child; they have much to teach us—they are experts in this particular case.
2. Reinforce the value and benefits of seeking help widely.
3. Don’t be afraid to open for discussion things often avoided by doctors—fear, sadness, financial burdens, loss of intimacy.
4. Be clear about what the family and child expect of medicine and of the particular encounter.
5. Do not let your sense of impotence over the inability to cure the children or even to solve the pressing problems of the moment cause distance between you and the patient and family. Your willingness to discuss and problem-solve is at times more important for them than any specific medical intervention. Parents of children who have been disabled for a long time often acknowledge (better than we do) that cure is not possible; nonetheless, the very presence and concern of a thoughtful, compassionate medical professional is important, and your view of them is critical to their self-esteem.
6. Reassure families that they are doing a good job in the face of great challenge (when they are), and work within their values, capabilities and beliefs when trying to bring improvement. Always remain within the boundaries of what is realistic and possible.
7. Limit prescriptions and orders to things that really matter to the child and family, not to all those that are dictated by “standard medical practice.”
8. Honor the values and constructs that families hold and have assembled; if they want to do some things you recognize as ineffective, but of no harm to the child, let them go ahead—often they are the beliefs or practices that sustain the whole enterprise.

We must continually remind families that there are many vulnerable children whom medicine cannot cure or restore, that we understand their sadness and frustrations and that we, too, are sad; in modeling humility, we can create a bond with the families of disabled and chronically ill children that will permit us to help them through the inevitable crises—even, possibly, the death of the child. Reassure them that you and your colleagues are with them for the long journey—that they do not

need to be alone nor afraid to discuss very difficult things with their doctors and nurses and therapists.

Listening, questioning and reflection are always important skills for a physician; with the families of disabled children, they are *essential* tools for a candid therapeutic relationship; they will lead to better understanding of mutual expectations and realistic planning for the child who cannot be cured, for the family that cares for that child and for the physician.

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# Virtual Mentor

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## Medical humanities

### “The 400 Blows”—children lost in the health care system

by Gretchen Hermes, PhD, MTS

*We speak of Heaven who have not yet accomplished  
Even this, the holiness of things  
Precisely as they are, and never will!*  
—Franz Wright, *Prescience*. [1]

*Where is the father?  
Where is the father?  
Where is the father?  
Where is the father?*  
—Francois Truffaut’s *The 400 Blows* [2]

“Les Quatre Cents Coups”—“The 400 Blows”—was made by Francois Truffaut in 1959. It was his first film, and the first of four films which he would write, direct, produce and sometimes star in, devoted to the inner life of the child. The inspiration for the script was the story of Emperor Frederic II, who instructed that his children be raised without affection, permitted contact with only their nurses, not treated with brutality but never spoken to or touched [3]. These children all died very young. Truffaut said in an interview:

It is of this experiment by Emperor Frederic that we were thinking in writing the scenario of *The Four Hundred Blows*. We tried to imagine what would be the behavior of a child who survived such a treatment, on the brink of his thirteenth year. On the verge of revolt [3].

The deprivation of both language and physical comfort was for Truffaut the nadir of human experience. How could these “subtractions” be more poignant than in childhood, where the power and magic of words are first discovered? When the need to be held is greatest? Truffaut, a leading light of the French New Wave film movement, would not have said that he set out to make a film about ethics or healing. But this is a film for everyone who works with children and their parents, including, maybe even especially, physicians, given the deprivations, both necessary and chosen, of the environments in which we work. It’s difficult to watch “The 400 Blows” without feeling that this child could be any child in one of our hospital rooms or clinics anywhere in the world. Its value to our profession is that through Truffaut’s

eyes, we are asked to see, hear and hope for a child along with his parents, without his parents, despite his parents but also, in part, as his parents.

### **To see**

“The 400 Blows” opens with a pin-up of a nude female circulating among a group of prepubescent boys sitting at their classroom desks. The overbearing and often cruel instructor finds it in the hands of Antoine Doinel, the central figure of the film (and several others by Truffaut). So begins the growing antagonism between Antoine and the adults around him. Unable to concentrate on his studies, Antoine continually plays hooky, while at home there are often indiscreet fights about whether to send Antoine off to boarding school. In an attempt to salvage his academic career, Antoine devours the works of Honoré de Balzac. He creates an altar to the novelist and lights a votive candle beneath it for inspiration. But the shrine goes up in flames and Antoine is expelled for plagiarizing from Balzac’s “Search for the Absolute.” Finding his son uncontrollable, Antoine’s father turns him in to the authorities and relinquishes his custody to the state. When Antoine is taken to a correctional facility, his mother joins him on family day to make this announcement: “...don’t go crying to your father. He told me to tell you he doesn’t care about you anymore. So you will be sent to a labor center.”

As physicians and health professionals, we see the letting go and abandonment of ill children by their parents every day. The abandonment may be more subtle, it may have happened years before we see the child; it may not be conscious or deliberate, but for every parent who clings tightly to hope, there is another who has reached the end of his or her stamina or competence or capacity to care. Our facilities are often the labor centers to which these children have been sent.

Four years after making “The 400 Blows,” Truffaut called it his first Hitchcockian film because “one identifies with the child (Antoine Doinel) from the first shot to the last” [4]. In the final seconds of the film as Antoine escapes from the reformatory and runs to edge of the sea, he turns back and faces us; Truffaut freezes the frame, so the final image is of Antoine looking back at us almost as sculpture. In a film filled with the inevitable march of images and erasure, the permanence and finality of this image is especially significant, his haunted gaze back at the audience, the only ones to see him and therefore his true guardians.

We have all seen this look in a child who is brought into our care. The look that asks for affirmation, for understanding; it is a deeply personal look that, like Antoine’s, can shock us because, as viewers of this film, we realize that he hardly knows us at all. A trapped, exposed, yet expectant and appraising, even judging, look. In our daily practice, it can be relatively easy to pass through the moment that Truffaut freezes and seeks to burn into us, but Truffaut makes that impossible in the film because, unlike the case of the child in our clinic from whom we will soon move on, we have witnessed the complex regrettable circumstances of Antoine's life that finally converge in this moment. So that when he turns to us for the first and last time in the film, we understand that he is asking, even demanding, to know what we

are going to do about what has happened to him. But so are many of the children who look up at us when we walk into the examination room.

### **To hear/to say**

Language is one of Truffaut's deepest preoccupations. All of the four films he made about children examined language in one way or another. His interest in language culminated in "L'Enfant Sauvage" (1969), "The Wild Child," which explored the origin, development and use of language through the story of a feral child initiated into civilization by a physician trying to teach him to speak. For Truffaut, language offered special solace and retreat from the banality and cruelty of life and, in "The Wild Child," salvation from the abyss of lost connection with one's own species. In "The 400 Blows," as with the children of the Emperor who were never taught language so that they never understood nor were heard by others, Antoine Doinel inhabits a world in which his inner life, his feelings and sufferings are opaque to all, except to us [the audience] [5].

Throughout the film, Antoine engages in numerous petty thefts all connected with language in some way. He steals a pen, a book and a typewriter. When he runs away from home he sleeps in a printing factory. In his last-ditch effort to redeem himself at school he plagiarizes Balzac. The stolen typewriter makes him a ward of the state and plagiarizing Balzac gets him kicked out of school. When asked in his sole session with an analyst why he's always lying, Antoine replies, "I lie because the truth I tell they don't believe." Here Truffaut is exploring a theme which interested him for most of his career, how children are not allowed to express or receive authentic communication [6].

As physicians, we often find ourselves particularly challenged to offer children this opportunity. We see children who have never been read to, or who have never received a kind word or compliment from the mother or father who has brought them to our clinic. We often speak directly to the parent over the head of the child, as if he or she were not present. The message of "The 400 Blows," as with all of Truffaut's films, is for us (as it is for other viewers) that this is not good enough. Given the extent to which our patients' health is so profoundly shaped by their behavior (and the behavior of their parents) outside our presence, and given that our standard medical tools often can do little more than poorly mitigate the effects—such as obesity, mental disease, diabetes—of that behavior, it seems difficult to argue that we don't have an obligation to at least attempt to communicate more authentically—to model that empathy—with the children in our care during the limited moments and opportunities we have to influence change.

### **The environment**

At home, Antoine sleeps in a converted closet between two rooms so that every passage of his parents intrudes on him; he is constantly in the way. The kinds of treatment he receives under four roofs—home, school, jail and reform school—are not terribly different from one another [7]. The interiors are all filled with callousness and gloom. The blows in this film are indeed physical; we are aware of

how deeply the environments Antoine finds himself in close in on, reach into and strike him from all directions. He seems constantly running through the streets of Paris, from school, home, correctional facilities, parents, teachers and finally to the sea, in a futile effort to escape and in a desperate attempt to save himself.

At one point, after having run away from home, Antoine finds himself in the principal's office with his mother and his English teacher who, while reaching for explanations for Antoine's chronic misconduct, blurts out: "maybe it's in his genes." The remark lacks subtlety to say the least and may be taken as an accusation since Antoine's mother, his genetic lineage, is actually present to take the blame. The film came along just six years after Watson and Crick's landmark discovery of the structure of DNA. Genetic explanations for behavior were in vogue then as they have continued to be ever since.

What this explanation neglects is what "The 400 Blows" so powerfully illustrates in its title and in the pure physicality of each environmental attack—that nurture has as profound a physical effect on who we are as our genes, that nurture becomes as much a part of our bodies and minds as our genetic endowment, hard-wiring us as surely as our genes. Acts of violence and neglect cause new biochemical neuronal connections to be made in our brains, cause other connections to be lost and leave us with real physical scars and disabilities in our minds as well as our bodies.

There is, of course, great resonance in our own experience with this aspect of Truffaut's masterwork. The medical environment itself is so clearly not designed to make a child feel comfortable, let alone to inculcate hope and well-being. The English teacher's superficial understanding of Antoine and his family finds its echo in the collision of incomprehension between, on the one hand, medical students and residents largely from privileged backgrounds and, on the other, patient populations typically served by teaching hospitals, an incomprehension that can do particular injustice to a child.

### **To hope despite all**

In the end, the process by which some transcend their environments is actually as ineluctable as the miraculous achievements of those born with physical or mental disabilities. When we celebrate the achievements of someone who has overcome the limitations of an impoverished background and hold up this individual as a reproving role model to his or her fellows, we are as ridiculous as if we were to hold up a pancreatic cancer survivor as proof that all others with cancer should be able to follow the same path to recovery. At best, and it is not an insubstantial best, the survivor offers hope.

"The 400 Blows" illustrates how hard and necessary it is to focus on hope by showing us how easily and inevitably Antoine's considerable talents, middle-class resources, friends, acute self-awareness and attempts to escape can be overwhelmed by all-too-common parental and social neglect. From a medical perspective, the film calls for a greater awareness of this reality on our part and for recognition of our

power to either add to or form a bulwark against the forces that drive children into despair and sickness—as Antoine was driven to the sea. For Truffaut, as crystalized in Antoine’s final look back at us, it is not just a power, but an obligation to see and to hear children and to find hope and purpose in their beckoning, innocent stare.

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## Virtual Mentor

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## Virtual Mentor

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