2.2.1 Pediatric Decision Making

As the persons best positioned to understand their child’s unique needs and interests, parents (or guardians) are asked to fill the dual responsibility of protecting their children and, at the same time, empowering them and promoting development of children’s capacity to become independent decision makers. In giving or withholding permission for medical treatment for their children, parents/guardians are expected to safeguard their children’s physical health and well-being and to nurture their children’s developing personhood and autonomy.

But parents’ authority as decision makers does not mean children should have no role in the decision-making process. Respect and shared decision making remain important in the context of decisions for minors. Thus, physicians should evaluate minor patients to determine if they can understand the risks and benefits of proposed treatment and tailor disclosure accordingly. The more mature a minor patient is, the better able to understand what a decision will mean, and the more clearly the child can communicate preferences, the stronger the ethical obligation to seek minor patients’ assent to treatment. Except when immediate intervention is essential to preserve life or avert serious, irreversible harm, physicians and parents/guardians should respect a child’s refusal to assent, and when circumstances permit should explore the child’s reason for dissent.

For health care decisions involving minor patients, physicians should:

(a) Provide compassionate, humane care to all pediatric patients.

(b) Negotiate with parents/guardians a shared understanding of the patient’s medical and psychosocial needs and interests in the context of family relationships and resources.

(c) Develop an individualized plan of care that will best serve the patient, basing treatment recommendations on the best available evidence and in general preferring alternatives that will not foreclose important future choices by the adolescent and adult the patient will become. Where there are questions about the efficacy or long-term impact of treatment alternatives, physicians should encourage ongoing collection of data to help clarify value to patients of different approaches to care.

(d) Work with parents/guardians to simplify complex treatment regimens whenever possible and educate parents/guardians in ways to avoid behaviors that will put the child or others at risk.

(e) Provide a supportive environment and encourage parents/guardians to discuss the child’s health status with the patient, offering to facilitate the parent-child conversation for reluctant parents. Physicians should offer education and support to minimize the psychosocial impact of socially or culturally sensitive care, including putting the patient and parents/guardians in contact with others who have dealt with similar decisions and have volunteered their support as peers.

(f) When decisions involve life-sustaining treatment for a terminally ill child, ensure that patients have an opportunity to be involved in decision making in keeping with their ability to understand decisions and their desire to participate. Physicians should ensure that the patient and parents/guardians understand the prognosis (with and without treatment). They should discuss the option of initiating therapy with the intention of evaluating its clinical effectiveness for the patient after a specified time to determine whether it has led to improvement and confirm that if the intervention has not achieved agreed-on goals it may be discontinued.
(g) When it is not clear whether a specific intervention promotes the patient’s interests, respect the
decision of the patient (if the patient has capacity and is able to express a preference) and
parents/guardians.

(h) When there is ongoing disagreement about patient’s best interest or treatment recommendations, seek
consultation with an ethics committee or other institutional resource.

AMA Principles of Medical Ethics: IV, VIII

Background report(s):

CEJA Report 3-I-18 Amendment to 2.2.1, Pediatric Decision Making
CEJA Report 3-A-16 Modernized Code of Medical Ethics
CEJA Report 1-I-10 Amendment to 10.16, Pediatric Decision Making
CEJA Report 8-I-07 Pediatric Decision Making
Subject: Amendment to E-2.2.1, “Pediatric Decision Making”
(Resolution 3-A-16, “Supporting Autonomy for Patients with Differences of Sex Development [DSD]”)
(Resolution 13-A-18, “Opposing Surgical Sex Assignment of Infants with Differences of Sex Development”)

Presented by: James E. Sabin, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Todd M. Hertzberg, MD, Chair)

At the 2016 Interim Meeting, the American Medical Association (AMA) House of Delegates referred Board of Trustees Report 7-I-16, “Supporting Autonomy for Patients with Differences of Sex Development (DSD),” responding to Resolution 3-A-16 of the same title introduced by the Medical Student Section, which asked:

That our AMA affirm that medically unnecessary surgeries in individuals born with differences of sex development are unethical and should be avoided until the patient can actively participate in decision-making.

Testimony regarding BOT 7-I-16 expressed concern about lack of expert insight into the medical complexities in treating differences of sex development in pediatric patients in its analysis and possible unintended consequences of its recommendations.


That our American Medical Association oppose the assignment of gender binary sex to infants with differences in sex development through surgical intervention outside of the necessity of physical functioning for an infant and believes children should have meaningful input into any gender assignment surgery.

Noting that the issue was under study by the Council on Ethical and Judicial Affairs (CEJA), the House of Delegates referred this resolution so that the council could address it during its ongoing deliberations in this area.

This CEJA report provides ethics guidance for physicians in relation to the concerns expressed in Resolutions 3-A-16 and 13-A-18. The council is grateful for participants’ contributions during reference committee hearings and for additional written communications received from multiple stakeholders, which have greatly enhanced its deliberations.

* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

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CLARIFYING THE QUESTION

Resolutions 3-A-16 and 13-A-18 speak to clinical decisions that have enormous significance for individual patients and families, decisions that also implicate socially and culturally sensitive issues of embodiment, gender, and sexuality. Each asks AMA to endorse specific broadly framed statements intentionally limiting the range of decisions physicians, patients, and families should reach. Yet as multiple stakeholders have pointed out, the label “differences [or disorders] of sex development” is problematic in that it encompasses a very broad range of conditions that carry quite variable implications for patients’ immediate and longer-term health, making for an extremely complex clinical picture overall [e.g., 1,2,3].

It is, moreover, a clinical picture in which the body of evidence available to inform decisions remains both limited and contested in important ways. In part, this reflects the difficulty in collecting data, given the relative rarity of these conditions and the sheer range of conditions currently labeled “differences of sex development” [e.g., 4]. Importantly, it reflects divergence among understandings of children’s physical and psychosocial development on which stakeholders’ perspectives rest [e.g., 4,5,6,7,8,9].

Literature reviews that stakeholders have provided to help inform CEJA’s deliberations indicate ongoing, significant differences in how the published evidence is interpreted [e.g., 1,10]. Concerns have been expressed about not just the quantity, but also the quality of the data available to inform clinical decisions, with questions raised about whether studies have asked the “right” question and about how well the framing of key research questions and the methodology, sample size, and data analysis support the conclusions drawn in a given study [e.g., 11]. Stakeholders concur on the need for systematic, well-designed research to provide robust evidence on the long-term outcomes that are meaningful to patients of different clinical approaches.

CEJA appreciates the challenge this state of affairs poses for families and physicians who strive to make clinically well-informed decisions for individual children. Thoughtful stakeholders differ in good faith, at times profoundly, about whether and at what developmental stage in the child’s life intervention should be considered medically essential, preferred, or acceptable for children born with differences of sex development. Despite these differences, stakeholders clearly share a deep professional commitment to serving the best interest of pediatric patients.

However, to the extent that Resolutions 3-A-16 and 13-A-18 call on the council to address the lack of clinical consensus, they seek guidance that is not within CEJA’s purview to offer. It is not the council’s role to adjudicate clinical disagreement or to prescribe what manner of decision is “correct” or “best,” but rather to clarify the values at issue and identify what factors must be considered to arrive at an ethically sound decision in any given patient’s unique situation.

MAKING DECISIONS FOR PEDIATRIC PATIENTS

Health care decisions for pediatric patients necessarily have a different character than decisions for adult patients. Decisions for children are made in the context of a three-way relationship among patient, parents (or guardians), and physician rather than the patient-physician dyad typical of decision making for most adult patients. Further, except for emancipated minors, who are authorized to make their own health care decisions, or certain decisions that other minor patients are permitted to make independently (e.g., E-2.3.3, Confidential Care for Minors), decisions for pediatric patients are made, not by the patient, but by parents/guardians acting on the patient’s behalf. Finally, the substituted judgment standard for surrogate decision making on behalf of adult patients is for the most part unavailable to those who make decisions for minors, insofar as
children, especially very young children, are unlikely to have formed settled views and preferences upon which substituted judgment could be based.

The Patient’s “Best Interests”

Ethically, and legally, then, parents are expected to make health care decisions in their children’s best interests. As the persons best positioned to understand their child’s unique needs and interests, parents/guardians are asked to fulfill the dual responsibility of both protecting their children and, at the same time, empowering them and promoting development of the child’s capacity to become an independent decision maker. Parents/guardians are expected to safeguard their children’s physical health and well-being and to nurture their children’s developing personhood and autonomy.

Best interests, and thus goals for care, then, should be understood broadly, as encompassing more than simply medical considerations. Parents/guardians are indeed expected to weigh the clinical benefits and risks of treatment alternatives, including the option of no treatment or the timing of interventions, but to do so against the broader background of likely impact on the child’s psychosocial well-being, relationships within the family, and family resources and values. As CEJA noted in its original report on decisions for pediatric patients (2007), because families provide a child’s usual, often only, source of support and care, the family’s needs and interests can also be relevant to treatment decisions. The council further observed that, “If none of the reasonable alternatives the health care team recommends can be reconciled with the family’s circumstances, deciding on the best course of treatment may be ‘an exercise in psychosocial, as well as technical medical, expertise’” [12].

The Committee on Bioethics of the American Academy of Pediatrics similarly holds that best interest should be understood broadly, to encompass more than purely clinical considerations. The committee urges decision makers to “acknowledge the pediatric patient’s emotional, social, and medical concerns along with the interests of the child’s family in the process of medical decision making” [13]. However, the committee argues, the concept of “harm” may be a “more realistic standard” for decisions on behalf of pediatric patients, noting that,

The intent of the harm principle is not to identify a single course of action that is in the minor’s interest or is the physician’s preferred approach, but to identify a harm threshold below which parental decisions will not be tolerated … [13].

Using the harm principle to inform choices for individual patients, including pediatric patients, requires that decision makers take into account the kind, degree and duration of foreseeable harms, as well as the likelihood of their occurrence.

Engaging Children in Care Decisions

Absent reason to believe otherwise, parents/guardians are understood to be best able to take a child’s long-term interests to heart in reaching a decision about care and in general their decisions should be respected. But that does not mean children should have no role in the decision-making process. In its original report CEJA noted that “the ethical principle of respect for persons also applies to children” and urged physicians to seek pediatric patients’ assent to decisions made on their behalf [12,13]. Assent, the council observed, “weighs a child’s ability to understand options and potential outcomes and to communicate preferences” [12].

CEJA recognized that “the notion of assent can be applied most readily to adolescent patients,” but instructed physicians to evaluate younger patients’ “cognitive capacities and judgment to determine
if they can understand the risks and benefits of treatment” and to engage them accordingly in the
decision-making process. Not all information is cognitively and emotionally appropriate for every
pediatric patient, nor is it necessary to communicate all information about a diagnosis and proposed
care all at once. As for any patient, physicians should assess the amount of information the
individual is capable of receiving at a given time and tailor disclosure to meet patients’ needs,
preferences, and ability to understand (E-2.1.3, Withholding Information from Patients).

Respecting children as (developing) persons also entails seeking to understand their reasons for
disagreeing with treatment decisions. When an intervention is not immediately necessary to
safeguard the child’s welfare, CEJA has argued, physicians (and parents/guardians) should respect
a child’s refusal to assent to proposed treatment. Even when immediate treatment is essential to
preserve well-being, physicians should explore the child’s reason for dissent, when circumstances
permit. The more mature a minor patient is, the better able to understand what a decision will
mean, and the more clearly the child can communicate preferences, the stronger the ethical
obligation to engage young patients in decisions about their own care. As CEJA noted in refining
its guidance on decisions for pediatric patients in 2010, communicating even sensitive and
potentially frightening information—about HIV status or a terminal diagnosis, for example—can
improve a child’s well-being [14].

Preserving Future Choices

In fulfilling their responsibility to nurture their children’s developing capacity to make autonomous
decisions, parents/guardians are expected to make health care decisions that will least impinge on
children’s opportunity to make important life choices themselves in the future. In general, decisions
taken now on a child’s behalf should be made with an eye not to foreclose decisions the child can
reasonably be expected, in time, to want and be able to make independently, realizing that choosing
not to have a treatment or procedure performed also forecloses a future choice. This “right to an
open future” is not absolute, of course. Parents/guardians must balance their responsibility to
preserve the child’s opportunity for future exercise of self-determination with the need to protect
the child’s immediate well-being. Physicians should be prepared to support them in that process,
providing the best available data to inform their decision and directing them to appropriate
psychosocial and other resources.

Finally, the opportunity to meet with and learn from others who have faced similar decisions can
provide valuable firsthand insight and support that clinicians themselves may not be able to offer.
Physicians should familiarize themselves with local peer support groups as resources to help
inform decision making by parents and their minor children.

A CONTINUUM OF DECISIONS

The degree of difficulty faced by parents/guardians in making well-considered, ethically justifiable
decisions for young patients who are not able to make their own health care choices varies across a
continuum. At one end of that continuum are decisions that involve interventions about which there
is consensus in the professional community, whose benefits are significant, supported by robust
evidence, and significantly outweigh the risks they pose (the likelihood and magnitude of which are
themselves well understood). In those situations, physicians have a responsibility to persuade
reluctant parents/guardians to accept the intervention on their child’s behalf. Where the
intervention would preserve life or avert serious harm and disagreement persists despite efforts to
resolve the tension, physicians have legal and ethical obligations to seek court interventions against
parental refusal of treatment.
At the other end are decisions that involve interventions that carry significant risk of harm or that currently available evidence would suggest offer little prospect of clinical benefit or cannot reasonably be expected to achieve the intended goal. In these cases, physicians have a responsibility to dissuade parents/guardians from pursuing the intervention, especially when it is irreversible, and should decline to provide the requested care when a patient’s parents/guardian persist, in keeping with ethics guidance (e.g., E-5.5, Medically Ineffective Interventions).

Between are decisions that involve interventions about which physicians may in good faith reach diverging professional judgments, and for which evidence as to short- and long-term benefit and risk is limited, equivocal, or contested. In such situations, how physicians interpret available evidence and its implications for an individual patient is shaped in significant part by their understanding of how to balance the competing values of beneficence and respect in upholding medicine’s foundational commitment to serve the patient’s (best) interests. In this “grey zone” physicians are challenged to negotiate with decision makers a shared agreement about how to understand this patient’s medical and psychosocial interests and what plan of care will best serve those interests in the individual’s unique circumstances and in most cases should give great deference to parental preferences.

SHOULD DECISIONS ABOUT DSD BE DIFFERENT FROM OTHER DECISIONS?

Helping parents/guardians make decisions for young patients with differences of sex development is inescapably challenging given the range of conditions at issue and the physiological/clinical complexity of many of those conditions. The fact that DSDs are entangled with socially and culturally sensitive issues of bodies, genders, and sex compounds that challenge—the more so in an environment in which a binary understanding of sex and gender is increasingly contested.

Yet whether these decisions are more challenging than decisions for pediatric patients with other diagnoses—say, decisions about cochlear implants for congenitally deaf newborns—is far from clear. The specific interventions about which decisions must be made and the timing of those decisions will be sensitive to the child’s clinical situation, of course, but the fundamental task facing parents/guardians and physicians will still be to agree on a path forward that balances safeguarding the child’s well-being, short and longer term, and nurturing the child’s development as an individual with capacity to make decisions autonomously.

Regardless of the specific decision at issue, it is important that parents/guardians and physicians appreciate the fact that a pediatric patient will of necessity live out the consequences of a choice made by others—one with which the individual may ultimately come to disagree. Moreover, when decisions implicate issues that are socially and culturally divisive, such as sex assignment and “normalizing” surgery for DSD patients, patients and their families can be thrust into the role of agent of social change or preserver of the status quo, knowingly, willingly, or otherwise [4]. Ensuring that parents/guardians have the information and—absent immediate, life-threatening emergency—the time to make well-considered decisions is essential.

For physicians, supporting thoughtful, ethically sound decision making for all pediatric patients, especially very young patients, requires that they consider several fundamental questions and tailor recommendations to the individual’s specific circumstances:

• What is this child’s likely developmental course without (immediate) intervention? How strong is the evidence to support this prognosis?
• What are these parents/guardians’ (and this patient’s) overall goals for care?
• To what extent is the clinical anomaly a significant threat to health, immediately and in the long term?
• Is providing the proposed intervention at this stage in the child’s development supported by clear, high quality evidence?
• Could other interventions reasonably be staged developmentally to allow the patient and family time to gain experience living with the condition and to reflect on and perhaps adjust goals for care?
• To what extent would the proposed intervention (or lack of intervention) foreclose important life choices for the adolescent and adult the child will become? Are there reasonable alternatives that would address immediate clinical needs while preserving opportunity to make important future choices?
• What resources will the child and family need to support the child’s healthy physical and psychosocial development? How can the physician assist in making those resources available to the patient and family?

COMING TO COMMON GROUND

Parents/guardians are expected to make health care decisions in children’s “best interest.” In doing so, they are expected both to protect children and, at the same time, to empower children and promote children’s developing capacity to become independent decision makers. To nurture this developing capacity, health care decisions are preferable that will least impinge on children’s opportunity to make important life choices themselves in the future.

Making decisions for children that involve socially or culturally sensitive issues—for example, whether or how to discuss a terminal diagnosis with a child, or whether, when, or how to intervene medically for conditions that involve differences of sex development—is always challenging. The greater the uncertainty or lack of robust evidence supporting alternative courses of action, the more difficult the task becomes.

In such circumstances, despite a common commitment to serving the best interest of pediatric patients, thoughtful stakeholders may, in good faith, differ about whether a particular intervention, at a particular time is medically essential, preferred, or acceptable. When no single approach can be said a priori to be “best.” Ethically sound practice requires that decisions be carefully tailored for each patient in a process of shared decision making among parents/guardians, physician and the patient (in keeping with the child’s capacity to participate). Decision makers should seek a shared understanding of goals for care in creating a treatment plan that respects the unique needs, values, and preferences of the individual patient and family.

RECOMMENDATION

In light of the foregoing analysis, the Council on Ethical and Judicial Affairs recommends that Opinion E-2.2.1, “Pediatric Decision Making,” be amended by substitution as follows in lieu of Resolutions 3-A-16, “Supporting Autonomy for Patients with Differences of Sex Development (DSD),” and 13-A-18, “Opposing Surgical Sex Assignment of Infants with Differences of Sex Development,” and the remainder of this report be filed:

As the persons best positioned to understand their child’s unique needs and interests, parents (or guardians) are asked to fill the dual responsibility of protecting their children and, at the same time, empowering them and promoting development of children’s capacity to become independent decision makers. In giving or withholding permission for medical treatment for
their children, parents/guardians are expected to safeguard their children’s physical health and well-being and to nurture their children’s developing personhood and autonomy.

But parents’ authority as decision makers does not mean children should have no role in the decision-making process. Respect and shared decision making remain important in the context of decisions for minors. Thus, physicians should evaluate minor patients to determine if they can understand the risks and benefits of proposed treatment and tailor disclosure accordingly. The more mature a minor patient is, the better able to understand what a decision will mean, and the more clearly the child can communicate preferences, the stronger the ethical obligation to seek minor patients’ assent to treatment. Except when immediate intervention is essential to preserve life or avert serious, irreversible harm, physicians and parents/guardians should respect a child’s refusal to assent, and when circumstances permit should explore the child’s reason for dissent.

For health care decisions involving minor patients, physicians should:

(a) Provide compassionate, humane care to all pediatric patients.

(b) Negotiate with parents/guardians a shared understanding of the patient’s medical and psychosocial needs and interests in the context of family relationships and resources.

(c) Develop an individualized plan of care that will best serve the patient, basing treatment recommendations on the best available evidence and in general preferring alternatives that will not foreclose important future choices by the adolescent and adult patient will become. Where there are questions about the efficacy or long-term impact of treatment alternatives, physicians should encourage ongoing collection of data to help clarify value to patients of different approaches to care.

(d) Work with parents/guardians to simplify complex treatment regimens whenever possible and educate parents/guardians in ways to avoid behaviors that will put the child or others at risk.

(e) Provide a supportive environment and encourage parents/guardians to discuss the child’s health status with the patient, offering to facilitate the parent-child conversation for reluctant parents. Physicians should offer education and support to minimize the psychosocial impact of socially or culturally sensitive care, including putting the patient and parents/guardians in contact with others who have dealt with similar decisions and have volunteered their support as peers.

(f) When decisions involve life-sustaining treatment for a terminally ill child, ensure that patients have an opportunity to be involved in decision making in keeping with their ability to understand decisions and their desire to participate. Physicians should ensure that the patient and parents/guardians understand the prognosis (with and without treatment). They should discuss the option of initiating therapy with the intention of evaluating its clinical effectiveness for the patient after a specified time to determine whether it has led to improvement and confirm that if the intervention has not achieved agreed-on goals it may be discontinued.

(g) When it is not clear whether a specific intervention promotes the patient’s interests, respect the decision of the patient (if the patient has capacity and is able to express a preference) and parents/guardians.
(h) When there is ongoing disagreement about patient’s best interest or treatment recommendations, seek consultation with an ethics committee or other institutional resource.

(Modify Current HOD/CEJA Policy)

Fiscal Note: Less than $500
REFERENCES

1. Joint communication from the American Urological Association, Societies for Pediatric Urology, American Association for Clinical Urologists, American Congress of Obstetricians and Gynecologists, Pediatric Endocrine Society, and North American Society for Pediatric and Adolescent Gynecology. March 7, 2018. See Appendix A.

2. Communication from Arlene B. Baratz, MD, on behalf of Androgen Insensitivity Syndrome—Differences of Sex Development (AIS-DSD) Support Group. September 14, 2018. See Appendix B.

3. Communication from Dina M. Matos, Executive Director, and Karen Lin Su, MD, Medical Director, CARESFoundation. September 4, 2018. See Appendix C.


5. Communication from Kyle Knight, Researcher, Human Rights Watch. February 2, 2018. See Appendix D.

6. Communication from Homer Venters, MD, MS, Director of Programs, Physicians for Human Rights. February 1, 2018. See Appendix E.

7. Communication from Tara Demant, Director, Gender, Sexuality, and Identity Program, Amnesty International USA. February 21, 2018. See Appendix F.

8. Communication from Eliza Byard, PhD, Executive Director, GLSEN. January 31, 2018. See Appendix G.


10. Communication from Jerome Jeevarajn and Kieran McAvoy, Delegates, on behalf of the American Medical Association Medical Student Section. February 15, 2018. See Appendix H.


Unlike health care decisions for most adult patients, decisions for pediatric patients usually involve a three-way relationship among the minor patient, the patient’s parents (or guardian), and the physician. Although children who are emancipated may consent to care on their own behalf, in general, children below the age of majority are not considered to have the capacity to make health care decisions on their own. Rather, parents or guardians are expected, and authorized, to provide or decline permission for treatment for minor patients. Nonetheless, respect and shared decision making remain important in the context of decisions for minors, and physicians have a responsibility to engage minor patients in making decisions about their own care to the greatest extent possible, including decisions about life-sustaining treatment. [New content sets out key ethical values and concerns explicitly, drawing in part on CEJA background report 8-I-07]

Decisions for pediatric patients should be based on the child’s best interest, which is determined by weighing many factors, including effectiveness of appropriate medical therapies and the needs and interests of the patient and the family as the source of support and care for the patient. When there is legitimate inability to reach consensus about what is in the best interest of the child, the wishes of the parents/guardian should generally receive preference.

For health care decisions involving minor patients, physicians should:

(a) Involve all patients in decision making at a developmentally appropriate level.

(b) Base recommendations for treatment on the likely benefit to the patient, taking into the effectiveness of treatment, risks of additional suffering with and without treatment, available alternatives, and overall prognosis. [new guidance addresses gap in current opinion]

(c) For patients capable of assent, truthfully explain the medical condition, its clinical implications, and the treatment plan in a manner that takes into account the child’s cognitive and emotional maturity and social circumstances for patients capable of assent.

(d) Provide a supportive environment and encourage parents to discuss their child’s health status with the patient. Offer to facilitate the parent-child conversation for reluctant parents. [new content incorporated to be consistent with 2.2.2]

(e) Recognize that for certain medical conditions, such as those involving HIV/AIDS or inherited conditions, disclosing the child’s health status may also reveal health information about biological relatives or disrupt existing presumptions about the child’s relationships within the family.

(f) Work with parents/guardians to simplify complex treatment regimens whenever possible and educate parents in ways to avoid behaviors that put the child or others at risk.

(g) Ensure that when decisions involve life-sustaining interventions, patients have opportunity to be involved in keeping with their ability to understand decisions and their desire to participate. Physicians should ensure that the patient and parents/guardian understand the patient’s diagnosis, both with and without treatment. Physicians should discuss with the patient and parents/guardian the option of initiating an intervention with the intention of evaluating its clinical effectiveness after a specified amount of time to determine if it has led to improvement. Confirm that if the intervention has not achieved agreed-on goals it may be withdrawn. [New content addresses gap in current guidance, consistent with 5.3.]

(h) Respect the decisions of the patient and parents/guardian when it is not clear whether a specific intervention promotes the patient’s best interests.

(i) Seek consultation with an ethics committee or other institutional resource when:
(i) there is a reversible life-threatening condition and the patient (if capable) or parents/guardian refuse treatment the physician believes is clearly in the patient’s best interest; or

(ii) there is disagreement about what the patient’s best interests are. Physicians should turn to the courts to resolve disagreements only as a last resort.

(i) Provide compassionate and humane care to all pediatric patients, including patients who forgo or discontinue life-sustaining interventions. [New content addresses gap in current guidance.]

AMA Principles of Medical Ethics: IV, VIII
INTRODUCTION

This report is submitted in response to adopted Resolution 2-I-09 (Policy D-60.970, AMA Policy Database), “Disclosure of Health Status to Children and Adolescents”, which was introduced by the Medical Student Section. Resolution 2-I-09 asked that the American Medical Association (AMA) encourage relevant members of the Federation of Medicine and nonphysician organizations to provide ongoing communication, support, and training to health care providers to assist parents with disclosing their children’s health status to them in a timely and prudent manner. The resolution asked the AMA to specifically address the case of a child with human immunodeficiency virus (HIV). Because informed consent and pediatric decision making are ethical issues discussed in the AMA’s Code of Medical Ethics, the Council on Ethical and Judicial Affairs (CEJA) was asked to review the proposed policy.

Based on its review of the data available, relevant policy of members of the Federation of Medicine, and the ethical analysis that informs current AMA policies, CEJA concludes that there are currently no compelling reasons to issue new policy specifically related to disclosure of health status to children and adolescents. Rather, CEJA recommends that editorial changes as noted below be made to clarify CEJA Opinion E-10.016, “Pediatric Decision Making.” This report examines issues of disclosure with the goal of amending current policy to clarify ethical guidance.

BACKGROUND

Some of the questions faced by the parent(s) or guardian of a seriously or terminally ill child are how much to tell the child about his or her health status, when and how to do so, and who should lead the discussion. AMA ethics policy recommends that minor patients be involved in decisions about their health care in developmentally appropriate ways (E-10.016, E-5.055). Meaningful involvement requires that minor patients be informed about their health status in ways that are sensitive to their level of cognitive and emotional maturity (E-10.016). However, these situations can be ethically complex, particularly when the child has acquired a condition such as human immunodeficiency virus (HIV). An ethical conundrum may arise in the case of disclosure of an HIV diagnosis, which is one case where parent(s) or guardian and child may have disparate interests. With increasing numbers of HIV-infected children reaching cognitive, physical, and
emotional maturity, the question of when and how to tell a child that he or she has HIV has become more challenging.

History of Disclosure to Children with Terminal Illness

Historically, children with terminal illness were given limited information about their diagnosis and prognosis, due to a desire to protect them from emotional burdens associated with illness and a belief that children would not understand their situation. Communication with minors about their illness improved as a result of better survival rates, the children’s rights advocacy movement, and the results of studies that showed that open communication about terminal diagnoses improved children’s psychological development. Changes in disclosure practices to HIV-infected minor patients began to take place in the mid-1990s with the advancement of highly active anti-retroviral therapy and improvements in the morbidity and mortality of HIV-infected children. HIV-infected minors are presently reaching a level of cognitive development that allows them to understand their diagnosis and participate in treatment decisions, and a level of physical and emotional development that can lead to sexual activity and risk for sexual transmission of HIV.

Factors Associated With Disclosure and Nondisclosure

Parents and guardians provide a variety of reasons for disclosure or nondisclosure of their child’s HIV status. There is no consistent link between timing of disclosure and the child’s health status or specific clinical factors. Stated reasons for nondisclosure, include concern that the child cannot handle the emotional burdens associated with the diagnosis and that a breach of confidentiality will have negative psychosocial consequences for child and/or parent. Parent(s) or guardians who choose to tell their child his or her health status often do so in support of the child’s autonomy or with hope that their child will better understand and adhere to a sometimes unpleasant medication regimen and refrain from engaging in risk behavior, including unprotected sexual activity or activities that could result in open wounds and the exchange of bodily fluids (for example, fighting or high contact sports). Other considerations influencing disclosure include fear of accidental disclosure and opposition to or weariness of secret-keeping. Notably, parents who disclose to their child his or her HIV status are more likely to be HIV-negative themselves. The decision to tell a child that he or she has HIV clearly involves consideration of not only the minor patient’s best interest, but also familial and social circumstances.

Effects of Disclosure

Though a parent(s) or guardian may wish to keep their child’s diagnosis secret, children often understand more than that has been assumed, having become aware of their illness through direct information or by reasoning about their health care experiences. Health professionals may be privy to children’s explicit references to their disease, even if the child’s parent(s) or guardian think that their child is ignorant of his or her condition. As Myra Bluebond-Langner’s landmark study of terminally ill children indicated, patients as young as three years of age are often aware of their diagnosis and prognosis without ever having been told by an adult. The developmental literature similarly indicates that children older than four years of age understand the concepts of illness and death in keeping with their stage of emotional and cognitive development.

Talking to children about their terminal diagnosis may be beneficial to their mental health and to their families’ psychological adjustment. While some children experience anxiety, depression, and withdrawal after having been told of their health status, positive outcomes of disclosure
include improved physical, emotional, and psychological well-being; better adherence to treatment; greater family communication and support; and for HIV, fewer risk behaviors and better adherence to demanding antiretroviral treatment.\textsuperscript{1,3-5,13-16} Because disclosing to a child that he or she has a terminal illness often does not have the negative effects parents or caregivers fear, and can have great benefits, “an incomplete ability to understand does not justify a lack of discussion” with a minor about his or her illness.\textsuperscript{2,3}

\textit{Legal Environment}

While parents or guardians generally have the authority to make decisions related to their child’s welfare and health care, there is no clear legal mandate concerning disclosure of diagnosis to children.\textsuperscript{4} Under state informed consent laws, minors cannot make decisions about their health without the permission or their parent(s) or guardian, with some exceptions. In some circumstances, a pediatric patient can be deemed a mature decision-maker, legally authorized to make medical decisions. Also, emancipated or mature minors may be legally permitted to make their own health care decisions. Adolescents who are neither emancipated nor mature are allowed by some states to consent to treatment in specific circumstances—testing and treatment for sexually transmitted infections, reproductive care, drug or alcohol abuse, and mental health care—without parental notification.\textsuperscript{13}

Many state privacy laws may prevent a physician from informing a child over the objection of parent(s) or guardian that the child is perinatally infected with HIV, since such a disclosure would violate confidentiality of the mother’s diagnosis.\textsuperscript{4} In at least one state (Georgia), physicians may tell a child that his or her mother has HIV, given the reasonable belief that the child is at risk of being infected with the virus\textsuperscript{4} (OCGA § 24-9-47). Nonetheless, state statutes that impose a “duty to warn” third parties of possible exposure to HIV generally fail to address the patient’s child.

State laws also govern parental rights. While the law generally assumes that a parent(s) or guardian is acting in the child’s best interest, according to the principle of parens patriae, protection of a child’s welfare sometimes outweighs the right of parent(s) or guardian to refuse medical treatment for the child. However, this principle has limited application since it most often applies to medical treatment, not disclosure of health status.\textsuperscript{4} As there is no legal mandate that governs when and how to tell a child his or her health status, physicians should turn to their ethical and professional values for guidance.

\textbf{ETHICAL CONSIDERATIONS}

Decisions regarding disclosure require careful consideration of the potential harm resulting from disclosure or the failure to disclose the child’s health status in light of concerns to respect and promote patient autonomy. In making decisions regarding disclosure physicians must balance their dual and sometimes conflicting loyalties to the minor patient and his or her parents or caregivers.

\textit{Autonomy, Beneficence, & Nonmaleficence}

Beneficence and nonmaleficence may suggest that children should be protected from harsh and painful information that is otherwise not necessary to know.\textsuperscript{4} Disclosure has the potential to cause psychological harm if the child lacks the cognitive capacity to understand the diagnosis of HIV and its implications.\textsuperscript{4} That said, allowing an HIV-infected child to age into older childhood and adolescence without knowledge of his or her condition risks physical and emotional harm to the patient and physical harm to others.
Respect for patient autonomy applies to children as well as adults. Since a child’s autonomy develops along with cognitive and emotional capacities, increased age or maturity may equate to an increased right to know his or her health status. Involving children in communication about their health and decisions regarding their medical care shows respect for their capacities and will enhance their decision making capacity. In this sense, promoting autonomy through disclosure does not conflict with the principle of beneficence, but coincides with it.

AMA ethics policy calls on physicians to promote the autonomy of minor patients by involving them in the medical decision making process to a degree commensurate with their abilities. The physician should seek the patient’s assent, or agreement, by explaining the medical condition, its clinical implications, and the treatment plan. If the patient does not or cannot assent, the physician should still explain the plan of care and tell him or her what to expect, without deception. In the case of an adolescent patient who has decision making capacity, the physician should encourage the patient’s active participation in decision making. (E-10.016).

Dual Loyalties

Decision making in the pediatric setting is complicated by the direct involvement of more than two parties in the patient’s management: patient, parent(s) or guardian, and physician. At times, parent(s) or guardian and physicians may disagree about whether disclosure is the course of action that best serves the minor patient’s interests. Yet given the fundamental professional obligation to deal honestly and openly with patients, physicians may become increasingly uncomfortable with secrecy as children age into older childhood and adolescence. It is also possible to imagine instances when parents, especially if separated or divorced, are not in accord with when, how, and how much to tell the child about his or her health status. As with other decisions involving minor patients, when consensus cannot be reached on whether disclosure is in the “best interest” of the child, the wishes of the parents should generally prevail.

However, the decision of parent(s) or guardian should not go without question in every case, such as when a parent has been adjudicated not to be acting in their child’s best interest. The Committee on Pediatric AIDS of the American Academy of Pediatrics holds that:

> [A]lthough physicians can listen to and discuss with parents potential reluctance to disclose, pediatricians should not accept parental or guardian requests to withhold the diagnosis under all circumstances. Pediatricians need to inform parents that if older children question them about their HIV infection status they will answer direct questions truthfully.

That said, in practice disclosing a child’s HIV status without parental support can be problematic. Physicians may risk harm to parent(s) or guardian by telling the child that he or she has HIV—for example, telling a child that he or she was perinatally infected with HIV effectively violates the HIV-positive parent’s right to medical confidentiality.

When disagreements occur about when or how to disclose, physicians should follow institutional policies for timely conflict resolution, including consultation with an ethics committee, pastoral service, or other counseling resource. If a health care facility does not have policies for resolving conflicts in a timely manner, physicians should encourage that policy be developed. Resolution of disagreements in the courts should be pursued only as a last resort.
RECOMMENDATIONS

The Council on Ethical and Judicial Affairs recommends that the following be adopted, and that the remainder of this report be filed. That Opinion E-10.016, “Pediatric Decision-Making,” be amended as follows:

Medical decision making for pediatric patients should be based on the child’s best interest, which is determined by weighing many factors, including effectiveness of appropriate medical therapies, the patient’s psychological and emotional welfare, and the family situation. When there is legitimate inability to reach consensus about what is in the best interest of the child, the wishes of the parents should generally receive preference.

Physicians treating pediatric patients generally must obtain informed consent from a parent or a legal guardian. Certain classes of children, such as emancipated or mature minors, may provide consent to their own medical care. Physicians should give pediatric patients the opportunity to participate in decision making at a developmentally appropriate level. The physician should seek the patient’s assent, or agreement, by explaining the medical condition, its clinical implications, and the treatment plan in ways that take into account the child’s cognitive and emotional maturity and social circumstances. The physician should provide a supportive environment and encourage reluctant parents to discuss their child’s health status with the patient, in private themselves or with the physician. For HIV-infected children in particular, the physician should be sensitive to the fact that disclosure of health status can have implications for the child’s relationships with biological relatives, household members, and peers; adherence to a complex medical regimen; and participation in behaviors that put the child or others at risk. Physicians should also be sensitive that disclosure of HIV and other conditions (e.g., some inherited conditions) can also have implications for family members other than the child. If the patient does not or cannot assent, physicians should still explain the plan of care and tell him or her what to expect, without deception. In the case of an adolescent patient who has decision making capacity, the physician should encourage the patient’s active participation in decision making. The use of force such as with using physical restraints to carry out a medical intervention in adolescent patients who do not assent should be a last resort.

Parents and physicians may disagree about the course of action that best serves the pediatric patient’s interests, including how much to tell the child about his or her health status, when and how to do so, and who should lead the discussion. When disagreements occur, institutional policies for timely conflict resolution should be followed, including consultation with an ethics committee, pastoral service, or other counseling resource. If a health care facility does not have policies for resolving conflicts in a timely manner, physicians should encourage their development. Physicians should treat reversible life-threatening conditions regardless of any persistent disagreement. Resolution of disagreements in the courts should be pursued only as a last resort. (IV, VIII)

(Modify HOD/CEJA Policy)

Fiscal Note: Staff cost estimated at less than $500 to implement.
REFERENCES

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 8-I-07

Subject: Pediatric Decision-Making

Presented by: Mark A. Levine, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Jane C.K. Fitch, MD, Chair)

INTRODUCTION

Recent events challenging parents’ authority to make health care decisions for their children have received considerable national media attention. Generally, pediatric patients are unable to make informed health care decisions for themselves, so their parents or guardians have this responsibility under common law and the statutes of most states. The decision-making process for pediatric patients can be complicated. For example, parents and the treating physician may disagree on the care of a young child. An older minor patient may disagree with the decision, and parents may disagree among themselves.

This report examines the ethics of medical decision-making for pediatric patients, especially when disagreements arise among physicians, parents, and sometimes the patients themselves. In this report, “pediatric patients” refers to patients in early childhood through adolescence, to the age of majority. The scope of this report does not include the fetus or the neonate because the AMA’s Code of Medical Ethics already contains relevant guidance (see Opinion E-2.215, “Treatment Decisions for Seriously Ill Newborns”).

BACKGROUND

Parents make decisions regarding a child’s rearing, including decisions related to the child’s welfare and health care. This authority is well established in law, and grants parents or legal guardians the responsibility to consent to the medical treatment of minors.

The statement of the Committee on Bioethics of the American Academy of Pediatrics (AAP) on “Informed consent, parental permission, and assent in pediatric practice,” similarly affirms that physicians have an ethical, as well as legal, obligation to obtain parental permission to perform a recommended medical intervention on a pediatric patient. Likewise, the Code of Ethics of the American Academy of Child and Adolescent Psychiatry (AACAP) states that a parent or legal guardian is responsible for a minor’s health care decision-making and that a psychiatrist may not need to obtain agreement of a child or adolescent patient to pursue “evaluation, treatment, or prevention efforts.” The guidelines from both the AAP and the AACAP further suggest that young patients be informed of a medical treatment plan and that assent be obtained directly from the patient when developmentally appropriate.

* Reports of the Council on Ethical and Judicial Affairs are assigned to the reference committee on Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.
The authority to consent to medical treatments implies that parents may also refuse treatment for almost any reason, including on the basis of religious beliefs; however, this authority may be limited when the life of the minor is at risk or when there is a threat to community health. If parents refuse life-saving treatment and members of the health care team believe the decision is placing the child at significant risk of serious harm, the matter can be brought before the courts or other welfare agencies, which may overturn parents’ decisions.6

Parties other than parents may make health care decisions. If a parent is not available to approve a medical intervention in an emergency situation, it is legally and ethically permissible to provide emergent care with presumed parental consent as the duty to preserve the health and life of the pediatric patient is paramount.6

In some circumstances, a pediatric patient can be deemed a mature decision-maker, legally authorized to make medical decisions. A court may make a decision to this effect based on the age of the patient, the patient’s understanding of the relevant medical procedure and potential outcomes, as well as the degree of risk of the intended treatment. Also, emancipated minors—minors who are living on their own and self-supporting, are married, or are parents themselves, or, in at least one state, pregnant—may be legally permitted to make their own health care decisions.6 The AACAP’s Code of Ethics acknowledges that there are circumstances when minors have been given the legal authority to make decisions on their own and emphasizes that it is the ethical responsibility of a physician to attempt to resolve conflicts that may arise within families.5

There are specific areas of health care—notably reproductive care—where laws specify the circumstances in which decisions can be made by parties other than a parent, including minors themselves. Many state laws similarly permit minors seeking treatment for substance use or mental health care to provide their own consent.6

Although the AMA’s Code of Medical Ethics does not currently include comprehensive guidance regarding pediatric care, several Opinions are worthy of consideration. Opinion 8.081, “Surrogate Decision-Making,” which outlines the factors to be considered when a surrogate or proxy is making health care decisions for a patient, is particularly relevant. It is pertinent to decision-making for pediatric patients who are either too young to have a health care value system or, due to cognitive disabilities, lack the decision-making capacity typical for children their age.7 It states that a surrogate decision:

. . . should be based on the best interest of the patient or the outcome that would best promote the patient’s well being. Factors that should be considered when weighing the harms and benefits of various treatment options include the pain and suffering associated with treatment, the degree of and potential for benefit, and any impairments that may result from treatment.5

Opinion E-2.015 provides further guidance on parental involvement in reproductive care for minors. It states:

Physicians should strongly encourage minors to discuss their pregnancy with their parents. Physicians should explain how parental involvement can be helpful and that parents are generally very understanding and supportive. If a minor expresses concerns about parental involvement, the physician should ensure that the minor’s
reluctance is not based on any misperceptions about the likely consequences of parental involvement.\textsuperscript{8}

ETHICAL CONSIDERATIONS

Determining the decision-maker

Whereas decision-making for adult patients is guided both in law and in medical ethics by the principle of autonomy, there is little ethical concordance when it comes to pediatric patients. While the law generally grants a patient the right to make health care decisions only upon reaching the age of majority, it is well recognized by health care professionals that minor children are often capable of understanding their circumstances and of expressing their preferences in ways similar to adult patients. In such circumstances, physicians can find themselves torn between the decision of parents, the legally authorized decision-makers, and the differing preferences of the child who is actually being treated. It is also possible to imagine instances when two parents, especially if separated or divorced, or guardians are not in accord. If every effort has been made to fully inform equally authorized decision-makers of all options and related risks and benefits and all available means of conflict resolution have been exhausted, persisting conflicts may have to be resolved in courts of law.

When consensus about what is in the “best interest” of the child cannot be reached despite reasonable efforts to do so, the wishes of the parents should prevail. Though parents ordinarily make all health care decisions for their children, the decision of a parent should not go without question in every case.\textsuperscript{9} It may be necessary to challenge their decision-making authority. The law recognizes that parental decision-making authority can be removed when it is abusive, negligent, or otherwise places their children at risk. Parents should not make health care decisions for their children if they clearly are not committed to serving the child’s interests, are emotionally unstable, or lack capacity to make informed decisions.\textsuperscript{9-12}

When the health care team finds it necessary to challenge a parental decision, attempts should be made within the institution to resolve the conflict; for example, through the involvement of an ethics committee, ethics consultant, pastoral service, or other counselor. Legal or regulatory intervention should be used as a last resort, because it can diminish the collaborative nature of medical care, it is a trying process for all parties, and it can place considerable strain on a family.

The ethical principle of respect for persons also applies to children, so treating physicians should make efforts to seek the pediatric patient’s assent, which is similar to consent, but is not binding. It weighs a child’s ability to understand options and potential outcomes and to communicate preferences. Though the notion of assent can be applied most readily to adolescent patients, it is important that the cognitive capacities and judgment of younger patients be evaluated in order to determine if they can understand and evaluate risks and benefits of treatment.\textsuperscript{9} Pediatric patients with a history of a chronic condition often acquire knowledge about their condition and treatment that gives them a greater ability to give assent than other children of the same age.

The AAP lists factors that should be considered when asking for a child’s assent: explaining, at a developmentally appropriate level, the medical condition and its clinical implications, and assessing how well the patient can understand the situation and how willing the patient is to proceed with the proposed care.\textsuperscript{5} The assent process may be compromised if parents do not want their child informed of their diagnosis, prognosis, or other aspects of medical care. Yet, the
opportunity for children to be informed and to provide assent is analogous to the right of adults to
make informed decisions and consent to medical care. The cooperation of parents in the assent
process should be sought through assurance that knowledge and participation in decision-making
has great value for the child.

This being said, not all information is cognitively and emotionally appropriate for all pediatric
patients; thus, the information provided should be individualized as developmentally appropriate.
Opinion E-8.082, “Withholding Information from Patients,” states: “All information need not be
communicated to the patient immediately or all at once; physicians should assess the amount of
information a patient is capable of receiving at a given time, delaying the remainder to a later, more
suitable time, and should tailor disclosure to meet patients' needs…” This standard applies to
pediatric as well as to adult patients. In the case of an adolescent patient who has decision-making
capacity, the physician should encourage the patient’s active participation in decision-making. If it
seems likely that a pediatric patient will not assent to the course the parents and physician have
chosen, the pediatric patient should still be provided with sufficient information to understand the
proposed treatment. A pediatric patient’s refusal to assent should be respected in instances when a
medical intervention is not immediately necessary to safeguard the welfare of the patient. In
situations where the treatment is essential to preserve wellbeing, reasons for dissent should be
explored to achieve a more complete understanding of the patient’s circumstances. It may be
necessary to use force (e.g. physical restraints) in situations when the parents and physician agree
that a particular medical intervention is necessary to preserve the welfare of child patient lacking
decision-making capacity. However, the use of force should be a last resort in situations when
adolescent patients with decision-making capacity refuse life-saving interventions.

Decision-making criteria

In determining treatment options for a child, it is important for physicians to rely on the principles
of beneficence and non-maleficence and discuss with parents and, to the extent appropriate, their
child, the severity of the condition, the risks and benefits of the treatment, and therapeutic
alternatives. The best interest standard guides decision-making for young patients and is the basis
for laws that empower parents to make decisions for their children. The substituted judgment
standard is often employed for incapacitated adult patients. This standard is not applicable to
pediatric patients who do not and never did possess the maturity and capacity to make informed
health care decisions, such as very young patients and older children whose cognitive disabilities
prevent them from making informed decisions. Under the best interest standard, a surrogate aims
to determine the course of action that offers the greatest net benefit to the patient by weighing the
risks and benefits of possible courses of action. For the large group of pediatric patients who
have some ability to understand their condition, the best interest standard should be augmented by
discussing the situation with the patient, whose priorities should influence the decision-making
process.

When assessing the risks and benefits of a course of action, it is appropriate for parents to consider
the psychosocial welfare of the child, as well as the medical impact of the possible treatments. The
needs and interests of the patient in relation to those of the family may also be relevant
considerations, because the family usually represents the child’s only means of support and care. If
none of the reasonable alternatives the health care team recommends can be reconciled with the
family’s circumstances, deciding on the best course of treatment may be “an exercise in
psychosocial, as well as technical medical, expertise.” Under those circumstances, the treatment
team should seek help from an ethics committee, ethics consultant, pastoral service, or other
counselor to help in reaching a decision.

Special health care decisions

Childhood immunization

Over the past half century, a universal childhood immunization program has evolved whereby all
50 states have laws that require children to receive specified vaccines before entering school. At the same time, all state laws exempt children whose medical history provides a contraindication,
and at the time of publication 48 states have exceptions for religious beliefs. Furthermore, an
increasing number of states (19 in 2004) allow children to enter school without vaccinations if their
parents present a philosophical reason why they do not want their children immunized. However,
this can present a problem for physicians, who have an ethical obligation to protect the health of
their patients as well as the health of the community.

When parents refuse to have a child vaccinated, not only the child is at risk, but also the health or
life of others who were not vaccinated and those for whom the vaccination did not result in
adequate immunization.

Therefore, physicians should educate parents on the preventive benefits of vaccines for their child
and the community at large. A parent’s refusal to have a child vaccinated, however, generally
should be respected.

Reproductive health

Issues related to reproductive choices remain highly contentious socially and politically,
particularly when adolescents are involved, due in part to religious and moral beliefs. The medical
profession as a whole, however, has reached a significant degree of ethical consensus on many
aspects of reproductive health care. The American Academy of Family Physicians, the American
Academy of Pediatrics, the American College of Obstetricians and Gynecologists, and the Society
for Adolescent Medicine jointly released a position paper on access to confidential health care for
sexually active minors, which the AMA has endorsed (See Policy H-60.938, “Adolescent Sexual
Activity”). Studies have shown that almost half of adolescent females would discontinue seeking
prescription birth control, and ten percent would stop treatment of a sexually transmitted disease if
informing their parents were required. The confidentiality of reproductive care may be
compromised, however, by legal requirements to report sexual abuse, which some states define
broadly to include consensual sexual activity among same-age minors.

In assessing disclosure requirements, physicians must weigh the minor patient’s capacity to make
decisions, the physical and psychosocial risks the patient faces, and the benefits of maintaining a
confidential, trusting relationship. In some instances, it may be justifiable for physicians to
disclose patient information to a third party, but when more harm than good would likely result
from reporting sexual activities, physicians should opt to protect their adolescent patients’
confidential information unless disclosure is required by law.
The selection of one treatment over another or the choice either to continue or cease treatment can lead to fundamental disagreements between the health care team and the parents of terminally ill children. Additional difficulties may arise when parents claim to be making decisions on the basis of religious beliefs.

Physicians must provide parents clear and timely information about the clinical situation and the possible outcomes if a recommended treatment is continued or is not carried out. In addition, physicians should provide parents with information about alternative treatments and their probable outcomes. Reciprocally, physicians should gain as much understanding as possible about the parents’ concerns. At times, this may require seeking information from a religious source or the intervention of a religious advisor, an ethics committee or consultant, or other counselor. Such consultations often reveal parental misunderstanding of the risks and benefits of the medical interventions, point to a fundamental parental distrust of medical care, or uncover a misunderstanding on the part of the health care team.

In assessing the reasonableness of parents’ decisions that are contrary to medical recommendations, physicians should consider the strength of evidence of the treatments’ effectiveness, the risks of additional suffering, and the availability of alternative options. If a physician determines that an intervention other than the course chosen by the parents would medically serve the patient best, and the parents’ reasons for rejecting the recommendations are inadequate, they should seek reconciliation using available resources. If attempts to resolve the conflict fail, the physician may appropriately seek regulatory intervention or court authorization to provide the recommended treatment. Overriding parental decision-making authority is a very serious step and will almost certainly result in added stress for the medical team, the patient, and the family, and could result in separation of a seriously ill child from his or her parents. Therefore, physicians should seek regulatory or legal intervention only after every other avenue for resolution has been exhaustively pursued.

CONCLUSION

In pediatric practice, medical decisions are usually made by the parent or guardian of the patient. In most circumstances, physicians are legally required to obtain consent from a parent before treating a child. Medical emergencies and the autonomy of emancipated minors represent two exceptions to this rule. The best interest of the patient should be the paramount consideration when weighing the medical and psychosocial risks of any course of treatment. Though pediatric patients cannot legally consent to medical care, physicians should provide them with developmentally appropriate explanations of their conditions, intended courses of action, and likely consequences of proposed treatments. Physicians should, when appropriate, elicit assent from the patient; however, dissent should be respected. If a physician believes the best interest of the patient is not being considered, or suspects child abuse, the physician should challenge the decision through institutional conflict resolution resources. Involvement of the regulatory or legal system should be a last resort but legal requirements must be respected.
RECOMMENDATION

The Council on Ethical and Judicial Affairs recommends that the following be adopted and that the remainder of this report be filed.

Medical decision-making for pediatric patients should be based on the child’s best interest, which is determined by weighing many factors, including effectiveness of appropriate medical therapies, the patient’s psychological and emotional welfare, and the family situation. When there is legitimate inability to reach consensus about what is in the best interest of the child, the wishes of the parents should generally receive preference.

Physicians treating pediatric patients generally must obtain informed consent from a parent or a legal guardian. Certain classes of children, such as emancipated or mature minors, may provide consent to their own medical care.

Physicians should give pediatric patients the opportunity to participate in decision-making at a developmentally appropriate level. The physician should seek the patient’s assent, or agreement, by explaining the medical condition, its clinical implications, and the treatment plan. If the patient does not or cannot assent, physicians should still explain the plan of care and tell him or her what to expect, without deception. In the case of an adolescent patient who has decision-making capacity, the physician should encourage the patient’s active participation in decision-making. The use of force such as with using physical restraints to carry out a medical intervention in adolescent patients who do not assent should be a last resort.

Parents and physicians may disagree about the course of action that best serves the pediatric patient’s interests. When disagreements occur, institutional policies for timely conflict resolution should be followed, including consultation with an ethics committee, pastoral service, or other counseling resource. If a health care facility does not have policies for resolving conflicts in a timely manner, physicians should encourage their development. Physicians should treat reversible life-threatening conditions regardless of any persistent disagreement. Resolution of disagreements in the courts should be pursued only as a last resort.

(Fiscal Note: Staff cost estimated at less than $500 to implement.)
References