REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS

CEJA Report 1-I-10

Subject: Amendment to E-10.016, “Pediatric Decision-Making”

Presented by: John W. McMahon, Sr., MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Daniel B Kimball, Jr, MD, Chair)

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

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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. 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.

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. 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.

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. 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 (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. 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.

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.

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. Disclosure has the potential to cause psychological harm if the child lacks the cognitive capacity to understand the diagnosis of HIV and
its implications.\(^4\) 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.\(^7\) 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.\(^4,13\) In this sense, promoting autonomy through disclosure 
does not conflict with the principle of beneficence, but coincides with it.\(^7\)

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. \((E-10.016, E-5.055).\) The physician should seek the patient’s assent, or agreement, by explaining the 
medical condition, its clinical implications, and the treatment plan. \((E-10.016).\) 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. \((E-10.016).\) 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 \((E-8.12, E-5.055, E-3.22),\) physicians may become 
increasingly uncomfortable with secrecy as children age into older childhood and adolescence.\(^1\) It is also possible to imagine instances when parents (especially if separated or divorced) or guardian 
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.\(^17\) The 
Committee on Pediatric AIDS of the American Academy of Pediatrics holds that:

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\text{[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.}^{5}\]

That said, in practice disclosing a child’s HIV status without parental support can be 
problematic.\(^7,17-20\) 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.\(^7\)

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 

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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


