

PediatricsⁱⁿReview[®]

American Academy of Pediatrics Policy Statements on Bioethics: Summaries and Commentaries: Part 3

Mark R. Mercurio, Edwin N. Forman, Rosalind Ekman Ladd, Marilyn A. Maxwell,
Lainie Friedman Ross and Tomas J. Silber

Pediatr. Rev. 2008;29:e28-e34

DOI: 10.1542/pir.29-5-e28

The online version of this article, along with updated information and services, is located on the World Wide Web at:

<http://pedsinreview.aappublications.org/cgi/content/full/29/5/e28>

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American Academy of Pediatrics

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American Academy of Pediatrics Policy Statements on Bioethics: Summaries and Commentaries: Part 3

Mark R. Mercurio, MD,
MA,* Edwin N. Forman,
MD,* Rosalind Ekman
Ladd, PhD,* Marilyn A.
Maxwell, MD,* Lainie
Friedman Ross, MD, PhD,*
Tomas J. Silber, MD,
MAAS*

Author Disclosure
Drs Mercurio, Forman,
Ekman Ladd, Maxwell,
Friedman Ross, and
Silber disclosed no
financial relationships
relevant to this
article. This
commentary does not
contain a discussion
of an unapproved/
investigative use of a
commercial product/
device.

Introduction

The American Academy of Pediatrics (AAP) has a strong and longstanding interest in the field of bioethics and periodically publishes policy statements pertaining to specific ethical questions relevant to pediatrics. The subjects addressed cover a wide range of topics, from parental refusal of immunization to the care of critically ill children. These policies initially are authored by the AAP's Committee on Bioethics and undergo extensive internal review by other committees prior to publication.

This article is the third in a series of three intended to familiarize the reader with many of the AAP policies currently in place that address issues in bioethics. In this series, 16 policies published by the AAP are summarized, each followed by a brief commentary. The commentaries are intended to address, at least on a cursory level, some of the ethical principles underlying the policies. Some briefly point out possible alternative viewpoints.

The policies referenced in this article represent the efforts of various committees and committee members over the years. Each of the summaries presented here, as well as the commentaries that follow, represent the work of an individual serving on the Executive Committee of the Section on Bioethics, as indicated at the beginning of each summary. Understandably, some of the wording of these summaries is taken directly from the published policies. When quotations are used within a summary and not referenced, it can be assumed that the quote is taken directly from the policy being summarized. For ease of use, the references for each policy are provided with each individual summary and commentary.

Policies Reviewed

Part 1 of this series reviews: (1)

1. Informed Consent, Parental Permission, and Assent in Pediatric Practice
2. Religious Objections to Medical Care
3. Responding to Parental Refusals of Immunization of Children
4. Sterilization of Minors With Developmental Disabilities
5. Human Embryo Research

Part 2 of this series reviews: (2)

6. Guidelines on Forgoing Life-sustaining Medical Treatment
7. Forgoing Life-sustaining Medical Treatment in Abused Children
8. Do-Not-Resuscitate Orders for Pediatric Patients Who Require Anesthesia and Surgery
9. Do Not Resuscitate Orders in Schools
10. Ethical Issues with Genetic Testing in Pediatrics
11. Ethics and Care of Critically Ill Infants and Children

Part 3 of this series reviews:

12. Female Genital Mutilation
13. Appropriate Boundaries in the Pediatrician-Family-Patient Relationship
14. Infants With Anencephaly as Organ Sources: Ethical Considerations
15. Palliative Care for Children
16. Institutional Ethics Committees

References

1. Mercurio MR, Adam MB, Forman EN, Ladd RE, Friedman Ross L, Silber TJ. American Academy of Pediatrics Policy Statements on Bioethics: summaries and commentaries: part 1. *Pediatr Rev.* 2008;29:e1
2. Mercurio MR, Maxwell MA, Mears BJ, Friedman Ross L, Silber TJ. American Academy of Pediatrics Policy Statements on Bioethics: summaries and commentaries: part 2. *Pediatr Rev.* 2008;29:e15

*On behalf of the American Academy of Pediatrics Section on Bioethics.

Female Genital Mutilation

American Academy of Pediatrics Committee on Bioethics. Female genital mutilation. *Pediatrics*. 1988;102:153–156. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;102/1/153>. Reaffirmed November 2002. Summary and comment by Edwin N. Forman, MD, and Rosalind Ekman Ladd, PhD.

Summary of Policy Statement

This statement educates pediatricians about this practice, notes that it violates the “do not harm” principle, and opposes all forms of female genital mutilation (FGM). FGM is seen in certain populations, particularly those from Somalia and the Sudan, and the spectrum of mutilation ranges from excision of the skin surrounding the clitoris (emphasizing the importance of careful physical examinations) to removal of the entire clitoris and labia minora and stitching of the labia majora together. Complications include serious physical effects that can be life-threatening (wound infection and sepsis), acute and chronic urinary and gynecologic problems (painful intercourse, infertility), and possible psychological problems. (An article published in *Lancet* in May 2006 found that FGM raised by more than 50% the likelihood that the mother or the newborn would die). (1)

The statement acknowledges the parents’ interest in their child’s welfare in that the procedure helps achieve group identity, family honor, and marriageability but also that it supports the subservient position of women in that culture. It notes the opposition by Islamic authorities (religious and medical leaders), the World Health Organization, the International Federation of Gynecology and Obstetrics, and the American Medical Association (AMA). The United States Congress criminalized FGM in individuals younger than 18 years of age (1996) and considers it child abuse.

Some physicians are concerned about respecting others’ cultures and the negative effect of criminalization on efforts to educate a population and develop a good physician/family relationship. These physicians might consider a lesser procedure such as pricking or incising the clitoral skin, thus allowing a symbolic initiation of the girl into the community. However, this practice also is opposed by the AAP, pointing out that it perpetuates implications for the status of women and that the act may be considered criminal.

The AAP recommends knowledge of and sensitivity to the cultural background of the family and the significance of this custom for them. The statement emphasizes the education of parents and the need to instruct them about female genital anatomy and function and the sig-

nificant acute and long-lasting harms of FGM. Parents should be educated about the statements of authorities in Africa against this procedure and informed that the procedure is illegal and constitutes child abuse in the United States. The AAP urges pediatricians to become aware of and use local counseling centers.

Comment

The strongest argument in support of the policy relates to the body of data detailing the harmful physical effects of all forms of genital mutilation. Avoiding harm rests on the general dictum embodied in the Hippocratic oath to do no harm, more recently referred to as the duty of nonmaleficence. This argument also is based on the generally accepted principle that pediatricians should do what is in the best interest of the child.

A somewhat weaker argument is the claim of psychologically harmful consequences from this practice. This effect may be especially true for an immigrant child whose family maintains customs that are out of the United States mainstream. However, are the psychological effects, in themselves, so harmful that families may not judge that they are overridden by the importance of maintaining their own culture?

There also is an argument about the rights of girls and women to better social status, freedom from arranged marriage, and sexual pleasure that is incompatible with this practice. A stronger argument could be made that FGM may have been advantageous to girls in the old culture where it was valued, but not advantageous as girls become assimilated into United States culture.

One question not addressed in the policy is whether one reason for condemning the practice is that it is performed on children who are unable to consent. Would we think differently if it were a practice freely chosen by women older than 18 years? We do allow people to choose procedures that are not medically necessary and that carry some risk of physical and psychological harms, such as sex change surgery.

This entire policy raises the question of ethical relativism, the position that what is morally wrong in one culture is not necessarily wrong in another. In addition, the principle of tolerance sometimes is invoked to justify a “hands-off” policy. This thinking clearly is rejected by the AAP policy, which takes the avoidance of physical harm to children as a universal principle.

In the spirit of showing sensitivity to others’ cultural practice even while opposing it, this practice could be referred to with more neutral language, such as “female genital cutting” or “female circumcision” rather than “mutilation.”

References

1. WHO Study Group on Female Genital Mutilation and Obstetric Outcome. Female genital mutilation and obstetric outcome: WHO collaborative prospective study in six African countries. *Lancet*. 2006;367:1835–1841

Appropriate Boundaries in the Pediatrician–Family–Patient Relationship

American Academy of Pediatrics Committee on Bioethics. Appropriate boundaries in the pediatrician-family-patient relationship. *Pediatrics*. 1999;104:334–336. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;104/2/334>. Reaffirmed November 2002. Summary and comment by Marilyn A. Maxwell, MD.

Summary of Policy Statement

In this statement, the Committee on Bioethics addresses appropriate professional boundaries between the pediatrician and patients and family members. Accountability in medicine and high moral standards are expected of physicians. Competence and integrity can be demonstrated by a number of measures, including board certification, hospital credentialing, and peer review of practice. Professional organizations such as the AMA have published codes of ethics that address personal and other nontechnical aspects of physician conduct.

Well-conducted, reliable studies regarding romantic and sexual relationships between physicians and their patients or patients' family members are lacking. The literature has been more prolific among psychiatrists and obstetrician-gynecologists. One concern is whether a patient or family member has the ability to make clear and free choices regarding affections for the physician in the context of an unequal physician-patient-family relationship. Another question is that whether a proper and effective therapeutic relationship can be maintained once intimacy develops.

Pediatrics has its own special concerns. "Pediatricians who feel sexually attracted to children may put patients at risk of sexual abuse or exploitation." In addition, difficulties may ensue with the pediatrician being misunderstood when discussing sexual development and issues with patients as well as discomfort on the part of the patient during the examination of the genitals or breasts. "Pediatricians should develop and follow clear and consistent office policies about the presence of a chaperon during parts of the physical examination, taking into account local customs, the family's religious and cultural traditions, and the need for patient privacy."

Although the pediatrician's interactions with parents

or guardians do not constitute a doctor-patient relationship, appropriate professional boundaries with families also must be maintained. Otherwise, family members may feel exploited, and children may become concerned that their treatment is compromised by the relationship.

In this statement, the AAP also provides guidance on gifts. Acceptance of modest gifts does not "involve a serious conflict—in fact, refusal of a gift may constitute a social or cultural affront." More expensive gifts do breach the appropriate boundaries in the professional relationship. It is acknowledged that some families may wish to compensate physicians by services or with barter. Nonmonetary payments, as with gifts, may become precursors to boundary violations and should be approached with caution.

Comment

There is no justification, ethical or otherwise, for violation of professional boundaries in the pediatrician-family-patient relationship. Society has a right to expect children to be protected. Physicians approaching child or adolescent patients for sexual relationships are not only unethical, but criminal. There may be more of a blur when considering adult family members of patients, but romantic and sexual relationships between family members and the child's pediatrician are deemed inappropriate by the AAP.

The physician is responsible for maintaining appropriate boundaries between patients and families, which includes paying attention to words and body language. However, this policy statement brings up a good and practical point: "The need to avoid untoward personal intimacy should not lead to a cold, indifferent manner in their interactions with patients or family members."

The AAP's position on gifts from patients or families is that modest gifts may be appropriate for the physician to accept. Caution needs to be exercised when the physician feels uncomfortable accepting a gift or where the monetary value of the gift could appear to influence the physician's professional judgment. The AAP maintains that the "success of the doctor-patient or the doctor-parent relationship depends on the ability of the patient or family member to trust the doctor completely." The AAP's final recommendation in this policy is that medical students, residents, and physicians should receive continuing education on the importance of appropriate boundaries in professional relationships. This advice is practical; such an education serves as a significant preventive measure.

Infants With Anencephaly as Organ Sources: Ethical Considerations

Committee on Bioethics. Infants with anencephaly as organ sources: ethical considerations. *Pediatrics*. 1992;89:1116–1119. Available at: <http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;89/6/1116>. Reaffirmed October 2006. Summary and comment by Lainie Friedman Ross, MD, PhD.

Summary of Policy Statement

This older statement was written in 1992. The article reviews the request by some parents and some transplant personnel to use organs from these infants for transplantation. At the time, the law permitted the procurement of solid organs only from infants who are declared dead, a law that remains in effect (“the dead donor rule”). However, the transplant community and some parents of children who have anencephaly asked whether the law should be modified to permit the procurement of organs from infants who are not “brain dead,” but “brain absent,” who should “be treated as if they were brain dead.”

The AAP concludes that no convincing basis exists for deviating from the legal rules governing organ transplantation and that the organs should be procured only after determination of death with parental consent. In fact, they go further and argue that “even if strong support were to emerge for legislation either defining anencephalic infants as legally dead or allowing retrieval of their organs prior to legal death, serious questions would remain about the wisdom of enacting such legislation.”

The statement expresses two societal concerns against the use of living anencephalic infants as organ sources. One is the danger of the “slippery slope,” in which organ retrieval might be considered from other permanently unconscious patients, such as those in a persistent vegetative state or who have hydranencephaly, conditions that have less diagnostic certainty. The second issue is the importance of the symbolic value of human life and that respect for human life requires that we not allow the killing of one human being to benefit another.

Comment

This statement is understood best contextually. In 1988, the Council on Ethics and Judicial Affairs (CEJA) of the AMA examined the ethical issues surrounding the use of organs from anencephalic neonates and concluded that it is ethically acceptable to remove organs from anencephalic neonates only after they have died, whether the death occurs by cessation of cardiac function or brain

function. (1) In that same year, Loma Linda Medical Center suspended its program to procure organs from infants who have anencephaly, and a protocol was designed to provide “modified medical care” for up to 7 days until the infants met brain death criteria. (2) The program was abandoned because only 2 of 12 infants met the criteria for brain death within 1 week, as required by the protocol. (2)

Although this statement by the AAP takes a view similar to that of the AMA, the CEJA of the AMA revised its position in June 1994, at which time it stated that it is ethically acceptable to transplant the organs of anencephalic neonates even before the neonates die, as long as there is parental consent and certain other safeguards are followed. (3) The CEJA of the AMA published its position in May 1995, (4) and severe public criticism led to a revision of its policy in December 1995. (5) The revised policy, which remains in effect, permits organ procurement only after the infants are declared dead, although it did state it was permissible to use medical therapy and mechanical ventilation to sustain organ viability until death is declared. (4)

Since this statement was written, newer data suggest that we need to be careful about assuming that anencephaly is a “clear-cut” diagnosis. (5) (6) This concept makes more poignant the AAP’s position not to treat such children differently. In addition, the concept of donation after cardiac death has become more mainstream, and this practice may be a path for more children, and not just those with anencephaly, to serve as organ donors. (7)

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Palliative Care for Children

American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics*. 2000;106:351–357. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics%3b106/2/351>. Reaffirmed October 2006. Summary and comment by Rosalind Ekman Ladd, PhD, and Edwin N. Forman, MD.

Summary of Policy Statement

“Adding life to the child’s years not simply years to the child’s life” captures the essence of this statement. Published in 2000, it notes the insufficient state of palliative care for children in the United States.

The statement argues for an integrated model to provide palliative care for children who have life-threatening or terminal conditions. It identifies the needs of such children and their families and emphasizes the general lack of available support. Principles of palliative care are defined and include respect for the dignity of the patient and family (including their preferences for management), access to palliative care therapies and specialists, support for caregivers, removal of regulatory and financial barriers to palliative care, and continued improvement in palliative care through research and education.

Palliative and curative treatments can and should be combined when appropriate. This goal is achieved best with an integrated model using an interdisciplinary team, including primary care and specialist pediatricians, nurses, social workers, spiritual advisors, child-life specialists, teachers, and bereavement counselors.

Specific recommendations are given for working with dying children and their parents and siblings. The statement emphasizes the need for: 1) developmentally appropriate and sensitive education of the patient concerning his or her condition, 2) the elicitation of his or her feelings and preferences, and 3) the support of his or her ability to communicate with his or her family.

Concerns about “hastening death” are discussed. Escalation of analgesics to control pain often is necessary and justified, the goal of which is death with dignity and without pain. This practice does not constitute active euthanasia or physician-assisted suicide for children, both of which are rejected by the AAP.

One barrier to pediatric palliative care is reimbursement based on the federal Medicare model designed for adult patients. Such a model limits palliative care significantly, often requiring life expectancies of 6 months or less and the forgoing of life-prolonging or curative treatments. (Fortunately, since 2000, some limitations have

been removed or modified in several states.) Another barrier is the lack of personnel trained in pediatric palliative care in pediatric medical centers and community hospice programs.

Minimal standards for pediatric palliative care are listed and include seamless transitions between settings, a consistent caregiver, availability of experts in palliative care 24 hours a day, the presence of an interdisciplinary team with a coordinator at all pediatric tertiary care centers, and sufficient financial support for pediatric palliative care. The policy strongly recommends education in this form of care for pediatric trainees as well as for practitioners and makes an appeal for including questions on palliative care in pediatric board and sub-board certifying examinations.

Comment

Four value assumptions underlay this policy. Each is an important component in informing the practicing pediatrician.

Assumption 1: Pain and suffering is bad and should be alleviated. This concept is in opposition to the belief that pain is ennobling or a necessary condition of human life or that “God does not give us more than we can handle.” The goal of palliative care is “management, relief, and alleviation” of pain.

Assumption 2: Pain and suffering include psychological, emotional, and spiritual as well as physical pain. The goal of palliative care is to treat the whole child, which is why the team should include chaplains, bereavement counselors, and social workers as well as community members such as school staff. All of these people are needed to achieve the goal of the best quality of life for child and family.

Assumption 3: The child is to be treated with respect. This value is achieved by the requirements to keep the child informed about benefits and burdens of treatment options and to solicit and listen to the child’s own preferences. Although this does not offer minors total decision-making power, children are to be a part of the decision-making process to the degree that they are able. One provision that is open to challenge is acceptance of the adolescent’s informed decision to refuse life-sustaining treatment. This capability empowers the adolescent beyond the legal limit, which places medical decisions for all minors younger than the age of 18 years in the hands of parents, with the exception of certain conditions, such as venereal disease.

Assumption 4: The family of the child patient also is the responsibility of the pediatrician. The policy clearly recognizes the importance of the family to the well-being

of the child and acknowledges the physical, emotional, and financial burden that caring for a dying child places on the family.

The ideal that is articulated here is a holistic approach: Anything that affects the well-being of child or family is of potential concern. Assuming that continuity of care requires that the treating physician continue to be involved, such responsibility could place an unrealistic burden on one person to coordinate the team effort, especially in geographic areas where resources are limited.

EDITOR'S NOTE. Readers who are interested in learning more about this topic are referred to the following article: Korones D. Palliative care. *Pediatr Rev.* 2007;28:e46

Institutional Ethics Committees

American Academy of Pediatrics Committee on Bioethics. Institutional ethics committees. *Pediatrics.* 2001;107:205–209. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;107/1/205>. Reaffirmed January 2004. Summary and Comment by Tomas J. Silber, MD, MAAS.

Summary of Policy Statement

This statement discusses three typical roles for an institutional ethics committee (IEC): 1) case consultation; 2) drafting and review of institutional policy; and 3) education of health-care professionals, other health-care employees, and patients. The statement also describes the membership and structure of an IEC. Finally, the statement advises physicians and other health-care professionals about their participation as IEC members or as members of an ethics consultation team.

Six recommendations are provided:

1. Membership on an IEC should be diverse and reflect different perspectives within the hospital and general community.

2. An IEC should have responsibility within an institution for clinical ethics consultation; review of policies; and education of professional, administrative, and support staff about ethical issues, regardless of whether these functions are delegated to other subcommittees or programs.

3. An IEC that is engaged in clinical ethics consultations should have policies and procedures that conform to ethical principles of fairness and confidentiality.

4. An IEC should establish continuing education and training programs that assure that its members are qualified to perform their specific duties within the IEC.

5. Independent ethics committees, such as an infant care review committee, should be dissolved or restructured to report to the larger IEC.

6. IECs within a general hospital setting should ensure an adequate degree of multidisciplinary expertise for addressing ethical issues specific to pediatrics.

Comment

This policy is a “must read” if you are a member of or are considering membership in an ethics committee. The statement recognizes the importance of the IEC by calling attention to: 1) case law suggesting that IEC deliberations may serve as evidence in court, 2) state proposals to establish an IEC as an alternative to judicial review, and 3) the requirement by the Joint Commission that every health-care organization have an established mechanism to address conflicts, which most often is met by establishing an IEC.

The AAP insists, throughout the document, that IECs need to have established policies on “who can request a consultation, how the IEC is contacted, who responds to the request, how the consultation is conducted, who is to be included in the consultation, proper notification of affected persons, protection of patient confidentiality, how the consultation is documented, whether in some circumstances an ethics consultation is required, and the advisory nature of the consultant’s recommendations. Information about the availability and process of ethics consultation should be widely distributed to patients, parents, family members, physicians, nurses, and other individuals who may have reason to call on the consultation services of the IEC.”

In dealing with the membership of an IEC, the document stresses that integrity and interest per se do not guarantee sufficient knowledge in areas such as clinical ethics, law, policy, group process, and communication. Therefore, each IEC is exhorted to have a continuing education program designed to assist IEC members. The advice given on the role of an IEC in policy review, organizational ethics, and the proposals about membership structure provides useful guidelines for those immersed in this task.

For the practicing pediatrician and especially for the experienced pediatrician who has retired or is about to retire, participation in an IEC may be very rewarding; such pediatricians can provide a unique experience. A word of caution, however, is to avoid the fallacy of generalization of expertise, instead committing to the study of clinical ethics.

Finally, because the IEC has a variety of functions, it is important that pediatricians participate according to

their level of knowledge and comfort. Pediatricians most commonly engage in clinical ethics consultation; if that is the case, it is reasonable to request institutional coverage for legal liability while offering this service. This advice holds true even if the IEC is strictly advisory or educational because of the apparent authority in the institution.

Conclusion

The AAP periodically publishes policy statements and guidelines addressing the difficult ethical issues that physicians caring for children continue to face. This review is intended to provide the reader with an overview of some of those guidelines and to stimulate additional thought and dialogue within the profession. It is presented by the AAP Section on Bioethics, as part of its mission to foster education in this area among pediatricians. As the commentaries suggest, there may not be unanimity about the positions taken, and that is important to recognize. The full text of each policy, as well as other relevant references and information, can be found on the web site for the

Section on Bioethics at <http://www.aap.org/sections/bioethics>.

The Section on Bioethics serves primarily an educational role within the AAP and beyond. They organize educational forums in bioethics at the annual AAP National Conference and Exhibition, publish a newsletter that includes original articles in the area of bioethics, and carry out other educational efforts intended primarily for pediatricians. In addition, they provide input to the Board of Directors and other committees regarding proposed policy statements and guidelines. Membership in the Section is open to all AAP Fellows who have an interest in bioethics. Affiliate membership also is available to physicians and other health professionals not eligible for AAP membership.

ACKNOWLEDGMENTS. The authors would like to thank Mary B. Adam, MD, MA, and Brenda Jean Mears, MD, who are their colleagues on the AAP Section on Bioethics Executive Committee, for guidance and helpful comments in the preparation of this manuscript.

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