



Ethical and Legal Issues in Adolescent Health Care

Tomas J. Silber, MD, MASS

Abigail English, JD

Editors

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ADOLESCENT MEDICINE: STATE OF THE ART REVIEWS

Ethical and Legal Issues
in Adolescent Health Care

GUEST EDITORS

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Adolescent Medicine: State of the Art Reviews

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ETHICAL AND LEGAL ISSUES IN ADOLESCENT HEALTH CARE

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Diane Plantz and John D. Lantos

Emergency contraception (EC) is a generic term used to describe a group of hormonal methods taken within the first few days after unprotected sexual intercourse to prevent an unintended pregnancy. EC is safe and effective in preventing pregnancy. Plan B or the generic levonorgestrel is available over-the-counter for women 17 years and older. A prescription is still required for women younger than 17 years of age. Even with its safety, effectiveness, and ease of accessibility for older adolescents and women, EC remains morally controversial. This article reviews the development of EC, presents data on the prevalence of conscientious objection, discusses how the change in status from prescription drug to over-the-counter medication has changed the debate, and makes recommendations for dealing with the controversies.

Achieving a Decision-Making Triad in Adolescent Sexual Health Care 183
Alisa A. Padon and Jill M. Baren

It is well known that adolescents delay and avoid sexual health care and fail to disclose necessary information to providers when their confidentiality is not ensured. However, it is not always clear if adolescents are psychosocially, affectively, or cognitively ready for independent decision-making. Whether confidentiality can and should be maintained necessitates that parents and providers have an understanding of adolescents' need for confidentiality. This article explores the concepts of confidentiality and consent in the context of teenage development and behaviors and addresses the complexity of the decision-making triad in adolescent sexual health care.

Making Sense of Adolescent Decision-Making: Challenge and Reality 195
Yoram Unguru

Few topics in pediatric bioethics are as vexing as decision-making. Decision-making in pediatrics presents challenges for children, parents, and physicians alike. The related, yet distinct, concepts of assent and consent are central to pediatric decision-making. Although informed consent is largely regarded as a

worthwhile adult principle, assent has been, and continues to be, mired in debate. Controversial subjects include a meaningful definition of assent; how old children should be to assent; who should be included in the assent process; parental permission; how to resolve disputes between children and their parents; the relationship between assent and consent; the quantity and quality of information to disclose to children and their families; how much and what information children desire and need; the necessity and methods for assessing both children's understanding of disclosed information and of the assent process itself; reconciling ethical and legal attitudes toward assent; and finally, an effective, practical, and realistically applicable decision-making model.

Adolescent Brain Development and the Mature Minor Doctrine

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Tomas J. Silber

The medical rights of minors have been questioned, especially due to information on adolescent brain development and studies on adolescent decision-making. This chapter briefly introduces the mature minor doctrine (MMD) and its history, justification, and practice and then presents some of the objections to the MMD. The article then highlights new knowledge about adolescent brain development (ABD) and what this may contribute to this debate and describes "hot cognition" and "cold cognition." It concludes by alerting the reader to the danger of making inappropriate use of the discoveries of brain science and proposing a prudent approach to adolescent consent and confidentiality, one that incorporates the new knowledge on ABD without "turning back the clock" on the medical rights of minors.

Adolescent Refusal of Lifesaving Treatment: Are We Asking the Right Questions?

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Douglas S. Diekema

In life-threatening situations, whether and under what conditions a minor should be allowed to refuse a lifesaving intervention is an important question. This article addresses the issue of whether adolescents, as a rule, possess capacity of sufficient quality that it should be respected even in the case of life-altering medical decisions. After reviewing the traditional approach to determining when adolescents should have their decisions respected, an approach that focuses on establishing capacity under a traditional informed consent model, the article reviews our evolving understanding of adolescent brain development and explores the implications for adolescent decision-making capacity. The author argues that a demonstration of understanding and mature reasoning abilities is not sufficient to establish decision-making capacity and that most minors do not possess fully mature decision-making capacity. Finally, the author suggests an approach to adolescent decision-making that is more reflective of the developing state of the adolescent brain.

The Aftermath of Adolescent Suicide: Clinical, Ethical, and Spiritual Issues 229
Gustavo A. Girard and Tomas J. Silber

The aftermath of an adolescent's suicide can be devastating to family, friends, and treating professionals, yet not much has been written on this subject. In this article, we briefly develop a conceptualization of suicide and a typology of suicide and the physicians' attitudes toward suicide. This is followed with a more detailed review of the aftermath of suicide (focusing on the suicide griever) and the impact of suicide on clinicians. The work ends with discussion of research data and the role of spirituality as well as an outline of therapeutic interventions.

**Adolescent Mothers of Critically Ill Newborns:
Addressing the Rights of Parent and Child** 240
Mark R. Mercurio

Despite recent declines, the teen birth rate in the United States remains markedly higher than in other developed countries. Infants born to teen mothers are more likely to be preterm than those born to adult mothers and thus more likely to end up in the newborn intensive care unit (NICU). Critically ill newborns are not infrequently born to teen mothers, including those in early adolescence. The focus of this chapter is the mechanism of decision-making on behalf of those newborns and the role of the early adolescent mother as surrogate decision-maker. It is argued that the current standard in many US hospitals, and likely elsewhere, is suboptimal and inadequately addresses the rights and needs of both mother and newborn.

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Lainie Friedman Ross

Current professional recommendations discourage health care providers from providing heterozygote carrier testing and predictive genetic testing for adult-onset conditions to minors. These recommendations are based on theoretical concerns that the harms outweigh the benefits. Although empirical data are scant, the emerging evidence suggests that the risks of harms are less than predicted and that there may be some significant benefits for testing adolescents, particularly when the adolescent and parent(s) agree. To ethically respond to requests for genetic testing of adolescents, pediatricians should evaluate the goals of testing, the familial implications of the results, and whose consent is needed.

Cancer Therapy and the Preservation of Adolescent Fertility 265
Edwin N. Forman and Rosalind Ekman Ladd

The increasing survival of adolescents with cancer, achieved through intensive therapy, is often associated with sterility. For most teenagers, the ability to have biological children is psychologically and socially important. Methods of pre-

servicing fertility, some standard and other experimental, have proliferated, but their use raises ethical issues. This review poses three hypothetical cases, describes the preservation methods, and identifies and analyzes the ethical issues. The discussion asks what needs to be told, who decides what to do, when can a pediatrician refuse to follow a family's choice, and what is the pediatrician's role as advocate for adolescents.

Nondisclosure of HIV Status in Adolescence

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Hans M.L. Spiegel

A marked decline of disclosure age for HIV positive youth is greatly influenced by the increase in long-term survival due to the introduction of highly active antiretroviral therapy (HAART) and the concomitant reduction in social stigma. Nevertheless, there are still significant numbers of young adolescents that are receiving treatment without having their HIV positive status disclosed to them. This chapter reviews studies of caregiver and health care provider preferences and hurdles for disclosure, as well as cultural patterns that strongly influence how and by whom HIV diagnosis disclosure is being provided. Disclosure of HIV infection status to young adolescents and symptomatic children is strongly recommended. All adolescents should know their HIV status and should be fully informed and counseled about all aspects of their health, including their sexual behavior. Physicians should encourage adolescents to involve their parents in their care.

Treatment of Anorexia Nervosa against the Patient's Will:

Ethical Considerations

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Tomas J. Silber

By the nature of their illness, many if not most patients with anorexia nervosa are treated against their will. This article explores the issue of patient autonomy and right to treatment refusal in the light of justified paternalism as well as a more enriched understanding of autonomy in the context of relationships. A summary follows on the research on patients' perceptions and response to involuntary treatment. The conclusion addresses the importance of human values intrinsic to the quality of a clinical relationship as determinant for patient recovery and professional satisfaction.

Iatrogenesis: Ethical and Legal Aspects

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Tomas J. Silber and Mary Anne Hilliard

This article describes iatrogenic events, giving examples that range from individual error to systemic malfunctions. It then goes on to analyze individual and system responsibilities in the disclosure of iatrogenic events. A discussion follows on the physician's responsibility, professional integrity, "duty to warn," and transparency as they relate to error disclosure, including

an examination of the role of apology and repair in the setting of iatrogenesis. It concludes by considering the moral and legal operational implications of iatrogenic events and the building of a culture of safety.

**Health Rights, Health Ethics, and Adolescence:
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Evelyn Eisenstein and Irene Anne Jillson

This article presents a discussion of the human rights declarations that address adolescent health, including reference to specific articles in the declarations that address this population; examples of ethical issues related to health that are faced by adolescents, their families, and providers who care for them; and ethical principles and frameworks that can serve as a basis for consideration of these issues. The article also includes examples of circumstances that pose ethical dilemmas for clinicians and adolescent clients and their families.

**Sexual Exploitation and Trafficking of the Young and Vulnerable:
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Abigail English

Sexual exploitation and trafficking of the young and vulnerable has devastating consequences for their physical and emotional development, health, and well-being. The horrific treatment they suffer bears the hallmarks of evil made manifest. Governments have enacted laws pursuant to international treaties, conventions, and protocols. Nonprofit and nongovernmental organizations (NGOs) are working to prevent young people from being exploited and trafficked, to identify victims, and to provide services to survivors. Progress in addressing the problem is haltingly slow in relation to its magnitude. The prevalence and persistence of this phenomenon is an ethical, legal, and human rights disgrace.

**Law, Ethics, and Clinical Discretion: Recurring and Emerging Issues
in Adolescent Health Care** 321
Amy T. Campbell and Abigail English

Varied stakeholders are involved in adolescent health care, with many looking to law to provide clear-cut answers on who can control decisions and when. However, law allows for much clinician discretion, carving out space for contextual sensitivity and clinical determination of maturity. A triad model of decision-making is very often the most appropriate clinical and ethical course. Law's aim is ideally not to impede, but rather to support clinical and ethical wisdom. Drawing on cases in this volume, it is argued that law should not and typically does not, when accurately interpreted and applied, stand in clinicians' way.

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Preface

Ethical and Legal Issues in Adolescent Medicine

This issue of *Adolescent Medicine: State of the Art Reviews (AM:STARs)* focuses on a variety of ethical and legal issues that practitioners may encounter during the delivery of adolescent health care. A panel of authors has been assembled that not only explores these issues, but also provides us with sound reasoning and proposed solutions. Plantz and Lantos forcefully address the issue of conscientious objection in their article “Conscience, Clinical Ethics, and Emergency Contraception,” and Padon and Baren deal thoroughly with the reproductive rights of teenagers in “Achieving a Decision-Making Triad in Adolescent Sexual Health Care.” Unguru analyzes how we deal with assent in his thought-provoking article “Making Sense of Adolescent Decision-Making: Challenge and Reality,” and Silber reflects on the contribution of neuroscience to the debate in “Adolescent Brain Development and the Mature Minor Doctrine.” Tragedy is often the harbinger of philosophical inquiry, a concept Diekema covers in his compelling article “Adolescent Refusal of Lifesaving Treatment: Are We Asking the Right Questions?” Girard and Silber share their experiential thoughts in “The Aftermath of Adolescent Suicide: Clinical, Ethical, and Spiritual Issues,” and Mercurio approaches his topic with wisdom and compassion in “Adolescent Mothers of Critically Ill Newborns: Addressing the Rights of Parent and Child.” A classical question in bioethics asks whether what can be done, should be done, and Friedman Ross offers a systematic approach to answering this question in “Ethical and Policy Issues Raised by Heterozygote Carrier Identification and Predictive Genetic Testing of Adolescents.” Forman and Ladd delve into new territory in their article “Cancer Therapy and the Preservation of Adolescent Fertility.” The moral dilemmas posed by particular clinical issues are the subject of Spiegel’s careful review “Nondisclosure of HIV Status in Adolescence” and Silber’s “food for thought” article on “Treatment of Anorexia Nervosa against the Patient’s Will: Ethical Considerations.” Dealing with macroethics, Silber and Hilliard address medical errors in “Iatrogenesis: Ethical and Legal Aspects.” The wider societal issues that impact adolescent health care are confronted head on by Eisenstein and Jillson in “Health Rights, Health Ethics, and Adolescence: Addressing Current Challenges, Ensuring a Just Future,” and by English in “Sexual Exploitation and Trafficking of the Young and Vulnerable: Reflections on a Legal, Ethical, and Human Rights Disgrace.” The volume ends with legal considerations by Campbell and English about many of the ethical issues explored in this volume in their article “Law, Ethics, and Clinical Discretion: Recurring and

Emerging Issues in Adolescent Health Care.” These articles provide the reader with content that is timely and that will withstand the test of time. We appreciate the opportunity to share this *AM:STARs* issue with a community of practitioners devoted to protecting and enhancing the health of adolescents.

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