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edited by LeRoy Walters, Tamar Joy Kahn and Doris Mueller Goldstein

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Georgetown University
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**NATIONAL REFERENCE CENTER FOR BIOETHICS LITERATURE**

**LIBRARY CLASSIFICATION SCHEME**
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PERIODICAL LITERATURE AND ESSAYS

Sample Entry

ENHANCEMENT¹

Baylis, Françoise; Robert, Jason Scott.² The inevitability of genetic enhancement technologies.³ Bioethics⁴ 2004 February⁵; 18(1): 1-26⁶. NRCBL: 4.5; 1.2; 15.1; 3.2; 4.2; 9.3.1.⁷ SC: an.⁸

Abstract: We outline a number of ethical objections to genetic technologies aimed at enhancing human capacities and traits. We then argue that, despite the persuasiveness of some of these objections, they are insufficient to stop the development and use of genetic enhancement technologies. We contend that the inevitability of the technologies results from a particular guiding worldview of humans as masters of the human evolutionary future, and conclude that recognising this worldview points to new directions for ethical thinking about genetic enhancement technologies.¹⁴

1. Subject heading: ENHANCEMENT
2. Author(s): Baylis, Françoise; Robert, Jason Scott.
3. Title of article: The inevitability of genetic enhancement technologies.
4. Title of journal: Bioethics
5. Date of publication: 2004 February
6. Volume and issue number (if available): 18(1)
7. Pagination: 1-26
8. NRCBL Classification Numbers: 4.5; 1.2; 15.1; 3.2; 4.2; 9.3.1.
9. SC (Subject Captions): an
10. Identifiers: corporate names, geographics, etc. (optional)
11. Note: additional information (optional)
12. Conference: conference information (optional)
13. Comments: information about related publications (optional)
14. Abstract: We outline a number of ethical objections to genetic technologies aimed at enhancing human capacities and traits. We then argue that, despite the persuasiveness of some of these objections, they are insufficient to stop the development and use of genetic enhancement technologies. We contend that the inevitability of the technologies results from a particular guiding worldview of humans as masters of the human evolutionary future, and conclude that recognising this worldview points to new directions for ethical thinking about genetic enhancement technologies. (optional)
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OF
BIOETHICS
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INTRODUCTION
INTRODUCTION

The Field of Bioethics

Bioethics can be defined as the systematic study of value questions that arise in health care delivery and in biomedicine. Specific bioethical issues that have recently received national and international attention include euthanasia, assisted suicide, new reproductive technologies, cloning, human experimentation, genetic engineering, abortion, informed consent, acquired immunodeficiency syndrome (AIDS), organ donation and transplantation, and managed care and other concerns in the allocation of health care resources.

As this list of topics suggests, the field of bioethics includes several dimensions. The first is the ethics of the professional patient relationship. Traditionally, the accent has been on the duties of health professionals—duties that, since the time of Hippocrates, have frequently been delineated in codes of professional ethics. In more recent times the rights of patients have also received considerable attention. Research ethics, the study of value problems in biomedical and behavioral research, constitutes a second dimension of bioethics. During the 20th century, as both the volume and visible achievements of such research have increased, new questions have arisen concerning the investigator-subject relationship and the potential social impact of biomedical and behavioral research and technology. In recent years a third dimension of bioethics has emerged—the quest to develop reasonable public policy guidelines for both the delivery of health care and the allocation of health care resources, as well as for the conduct of research.

No single academic discipline is adequate to discuss these various dimensions of bioethics. For this reason bioethics has been, since its inception in the late 1960s, a cross-disciplinary field. The primary participants in the interdisciplinary discussion have been physicians and other health professionals, biologists, psychologists, sociologists, lawyers, historians, and philosophical and religious ethicists.

During the past thirty-two years there has been a rapid growth of academic, professional, and public interest in the field of bioethics. One evidence of this interest is the establishment of numerous research institutes and teaching programs in bioethics, both in the United States and abroad. Professional societies, federal and state legislatures, and the courts have also turned increasing attention to problems in the field. In addition, there has been a veritable explosion of literature on bioethical issues.

The literature of bioethics appears in widely scattered sources and is reported in diverse indexes which employ a bewildering variety of subject headings. This annual Bibliography is the product of a unique information retrieval system designed to identify the central issues of bioethics, to develop a subject classification scheme appropriate to the field, and to provide comprehensive, cross-disciplinary coverage of current English-language materials on bioethical topics.

Volume 31 of the Bibliography contains one year’s worth of the literature garnered by this comprehensive information system. Specifically, it includes all of the citations that were acquired by the National Reference Center for Bioethics Literature (NRCBL) in 2004 and selected for indexing for the bioethics subset of the U.S. National Library of Medicine’s PubMed/MEDLINE journal database and for NLM’s LOCATORplus book database.

The Table of Contents for this volume includes a list of subject headings under which the citations are arranged. Most citations are listed once, under their primary subject heading. Classification numbers at the end of each citation represent additional topics covered by the publication. These classification numbers are drawn from the NRCBL’s Classification Scheme, which is reproduced on the inside front cover.
BIBLIOGRAPHY OF BIOETHICS

The Scope of the Bibliography

This thirty-first volume of the Bibliography of Bioethics includes materials which discuss the ethical aspects of the following major topics and subtopics:

BIOETHICS, MEDICAL ETHICS, AND PROFESSIONAL ETHICS
Codes of Ethics
Commissions
Ethicists and Ethics Committees
Nursing Ethics and Philosophy
Philosophy of Medicine
Quality and Value of Life
Religious Perspectives

DEATH AND DYING
Advance Directives
Assisted Suicide
Attitudes to Death
Capital Punishment
Determination of Death
Euthanasia and Allowing to Die
Terminal Care

GENETICS
Behavioral Genetics
Eugenics
Gene Therapy
Genetic Counseling
Genetic Research
Genetic Screening
Genome Mapping
Patents
Recombinant DNA Research

HEALTH CARE AND PUBLIC HEALTH
AIDS
Care for Specific Groups
Health, Concept of
Mental Health, Concept of
Health Care
Health Care Economics
Health Care Quality
Right to Health Care
Organ and Tissue Donation and Transplantation
Public Health
Resource Allocation
Telemedicine

MENTAL HEALTH THERAPIES
Behavior Control
Electroconvulsive Therapy
Involuntary Commitment
Psychopharmacology
Psychotherapy

PROFESSIONAL PATIENT RELATIONSHIP
Confidentiality
Informed Consent
Treatment Refusal
Truth Disclosure

REPRODUCTION AND REPRODUCTIVE TECHNOLOGIES
Abortion
Cloning
Contraception
Population Policy
Reproductive Technologies
Sex Determination

RESEARCH
Animal Experimentation
Behavioral Research
Biomedical Research
Human Experimentation
Research Ethics and Scientific Misconduct

SOCIOCY OF MEDICINE
Cultural Pluralism
Journalism and Publishing
Medical Education
Professional-Professional Relationship

WAR AND HUMAN RIGHTS ABUSES
International Human Rights
Torture, Genocide, and War Crimes
War and Terrorism

This volume of the Bibliography cites 7,379 documents (primarily in English) that discuss ethical and related public policy aspects of the topics and subtopics listed above. Documents cited in this volume include journal and newspaper articles, laws, court decisions, monographs, and chapters in books. Most of the documents listed were published since 2003. In the Periodical Literature and Essays section, for example, 3,976 of the 6,348 entries were published in 2004, 1,372 in 2003, and 371 in 2002; therefore, 90 per cent of the literature cited in Section I was published since 2002.

A cross-disciplinary monitoring system has been devised in an effort to secure documents falling within the subject-matter scope outlined above. Among the reference tools and databases the staff searches for pertinent citations are the following:

AGRICOLA
All England Law Reports (subject index)
ATLA RELIGION DATABASE

Choice
Cumulative Index to Nursing and Allied Health Literature (CINAHL)
In addition, the Bibliography staff directly monitors 200 journals and newspapers for articles falling within the scope of bioethics. Those preceded by an asterisk (*) have given permission for abstracts to be included in this volume. It is important to note that the journal articles cited in this volume are actually drawn from many more journals than those listed below.

Academic Medicine
*Accountability in Research
Agriculture and Human Values
AIDS and Public Policy Journal
America
*American Journal of Bioethics
American Journal of Human Genetics
*American Journal of Law and Medicine
American Journal of Nursing
American Journal of Psychiatry
*American Journal of Public Health
Annals of Health Law
*Annals of Internal Medicine
APA Newsletter on Philosophy and Medicine
*Archives of Internal Medicine
Assia, Jewish Medical Ethics
ATLA: Alternatives to Laboratory Animals
*Bioethics
Bioethics Forum
BMC Medical Ethics [electronic resource]
*BMJ (British Medical Journal)
British Journal of Nursing
Bulletin of Medical Ethics
Business Ethics Quarterly
Business and Professional Ethics Journal
*Cambridge Quarterly of Healthcare Ethics
Canadian Medical Association Journal
Cerebrum
*Christian Bioethics
Christian Century
Community Genetics
Conservative Judaism
Criminal Justice Ethics
Death Studies
Decisions; Journal of the Federation Internationale des Associations Medicales Catholiques
DePaul Journal of Health Care Law

Mental and Physical Disability Law Reporter
Month in Review (GAO reports and other publications)
New Titles in Bioethics
PAIS INTERNATIONAL
PHILOSOPHER’S INDEX
POPLINE
ProQuest
PsycInfo
Social Sciences Index
SOCIOLICAL ABSTRACTS
Specialty Law Digest: Health Care
Tarlton Law Library
UMI ProQuest Digital Dissertations
WorldCat
BIBLIOGRAPHY OF BIOETHICS

Human Research Report
Humane Health Care [electronic resource]
Hypatia
International Digest of Health Legislation [online]
International Journal of Applied Philosophy
*International Journal of Bioethics (Journal International de Bioethique)
International Journal of Health Services
International Journal of Law and Psychiatry
International Journal of Technology Assessment in Health Care
IRB: Ethics and Human Research
Issues in Ethics
Issues in Law and Medicine
Issues in Medical Ethics
Issues in Science and Technology
*JAMA
JONA’s Healthcare Law, Ethics, and Regulation
Journal of Advanced Nursing
Journal of Applied Animal Welfare Science
Journal of Applied Philosophy
Journal of Biolaw and Business
*Journal of Clinical Ethics
Journal of Contemporary Health Law and Policy
Journal of Ethics
Journal of General Internal Medicine
Journal of Genetic Counseling
Journal of Halacha and Contemporary Society
Journal of Health Care Law and Policy
*Journal of Health Politics, Policy and Law
Journal of Information Ethics
Journal of Intellectual Disability Research
Journal of Law and Health
Journal of Law and Religion
*Journal of Law, Medicine and Ethics
Journal of Legal Medicine
*Journal of Medical Ethics
Journal of Medical Genetics
*Journal of Medical Humanities
*Journal of Medicine and Philosophy
Journal of Moral Education
Journal of Nursing Administration
Journal of Nursing Law
Journal of Palliative Care
Journal of Professional Nursing
Journal of Psychiatry and Law
Journal of Public Health Policy
Journal of Religion and Health
Journal of Religious Ethics
Journal of Social Philosophy
Journal of the American Academy of Psychiatry and the Law
Journal of the American College of Dentists
Journal of the American Geriatrics Society
Journal of the American Medical Women’s Association
Journal of the Society of Christian Ethics
Journal on Medical Ethics
Judaism
*Kennedy Institute of Ethics Journal
*Lancet
Law and the Human Genome Review (Revista de Derecho y Genoma Humano)
Legal Medical Quarterly
Linacre Quarterly
Literature and Medicine
Medical Ethics & Bioethics (Medicinska Etika & Bioetika)
Medical Humanities
Medical Humanities Review
Medical Law International
Medical Law Review
Medical Trial Technique Quarterly
Medicine and Law
Medicine, Conflict and Survival
Medicine, Health Care and Philosophy
Mental Retardation [0047-6765]
*Milbank Quarterly
Minnesota Medicine
Monash Bioethics Review
*National Catholic Bioethics Quarterly
*Nature
Nature Biotechnology
Nature Genetics
Nature Medicine
NCEHR Communiqué (National Council on Ethics in Human Research)
New Atlantis
*New England Journal of Medicine
New Genetics and Society
New Review of Bioethics
New Scientist
New York Times
*New Zealand Bioethics Journal
Newsweek
Notre Dame Journal of Law, Ethics and Public Policy
*Nursing Ethics
Omega: Journal of Death and Dying
Online Journal of Issues in Nursing
Origins
Perspectives in Biology and Medicine
Perspectives on the Professions: Ethical & Policy Issues
Pharos
*Philosophy and Public Affairs
Philosophy and Public Policy Quarterly
Politics and the Life Sciences
Princeton Journal of Bioethics
Professional Ethics: A Multidisciplinary Journal
Professional Ethics Report
Protecting Human Subjects
Psychiatric Services
Public Affairs Quarterly
Res Publica
Responsive Community
Review of Metaphysics
INTRODUCTION

Romanian Journal of Bioethics (Revista Romana de Bioetica)  *Theoretical Medicine and Bioethics
*Science  Time
Science and Engineering Ethics  Today's Christian Doctor
Science as Culture  Tradition
Science, Technology, and Human Values  UNOS Update
Sh'ma  Update (Loma Linda University Ethics Center)
Social Justice Research  U.S. News and World Report
Social Philosophy and Policy  Virtual Mentor: Ethics Journal of the American Medical
*Social Science and Medicine  Association [electronic resource]
Social Theory and Practice  Washington Post
Society and Animals  Women's Health Issues
Studies in Christian Ethics  Yale Journal of Health Policy, Law, and Ethics

All documents cited by the Bibliography are in the collection of the NRCBL. For information on ordering photocopies, contact the NRCBL at the Kennedy Institute of Ethics, Georgetown University, Box 571212, Washington, DC 20057-1212; telephone +202-687-3885 or 888-BIO-ETHX (U.S. and Canada); email: bioethics@georgetown.edu; Web: http://bioethics.georgetown.edu.

Arrangement of the Bibliography

This volume of the Bibliography of Bioethics is divided into five parts:
1. Introduction
2. Section I: Periodical Literature and Essays — Subject Entries
3. Section II: Periodical Literature and Essays — Author Index
4. Section III: Monographs — Subject Entries
5. Section IV: Monographs — Title Index.

Sections 2 and 4 constitute the core of the Bibliography.

Section 1: Periodical Literature and Essays — Subject Entries

This Section, one of the two main parts of the Bibliography, contains usually one entry for each of the documents selected by the bioethics information retrieval system during the preceding year. In Volume 31 of the Bibliography, entries for 6,846 documents have been included in the Section. The format of these documents is as follows:

<table>
<thead>
<tr>
<th>Type of Document</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Journal articles</td>
<td>5,167</td>
</tr>
<tr>
<td>Essays in books</td>
<td>741</td>
</tr>
<tr>
<td>Newspaper articles</td>
<td>339</td>
</tr>
<tr>
<td>Unpublished documents</td>
<td>3</td>
</tr>
<tr>
<td>Pamphlets and similar materials</td>
<td>91</td>
</tr>
<tr>
<td>Legal documents</td>
<td>7</td>
</tr>
</tbody>
</table>

Section I is organized under 74 major subject headings, of which 13 are further divided by subheadings. Each subheading is separated from the major subject term by a slash.

Readers of the Bibliography should first scan the alphabetic list of subject headings in the Table of Contents to determine where citations of interest to them are likely to be found.

Section I includes cross references of two types. See cross references lead the reader from terms that are not used as subject headings to terms that are used. See also cross references suggest additional subject headings where the reader may find citations of related interest.

Citations appear alphabetically by author, with anonymous citations at the top of the section, sorted alphabetically by title. Entries with both corporate and personal authors are sorted by the corporate author. As explained below, the citations are accompanied by NRCBL Classification Scheme numbers as well as, in some cases, Subject Captions denoting approach or content. Subject Capture definitions can be found on page footers. Abstracts are included in this volume. In addition, several optional fields in Section I provide additional information: identifiers (such as persons, places, organizations, acronym equivalents), conference information, comments regarding related publications, and general notes.
BIBLIOGRAPHY OF BIOETHICS

Fourteen data elements may appear in an entry for a journal article. A sample subject heading and entry for a journal article follow:

**ENHANCEMENT**

Baylis, Françoise; Robert, Jason Scott. The inevitability of genetic enhancement technologies. Bioethics 2004 February; 18(1): 1-26. NRCBL: 4.5; 1.2; 15.1; 3.2; 4.2; 9.3.1. SC: an.

Abstract: We outline a number of ethical objections to genetic technologies aimed at enhancing human capacities and traits. We then argue that, despite the persuasiveness of some of these objections, they are insufficient to stop the development and use of genetic enhancement technologies. We contend that the inevitability of the technologies results from a particular guiding worldview of humans as masters of the human evolutionary future, and conclude that recognising this worldview points to new directions for ethical thinking about genetic enhancement technologies.

The sample entry presented above displays the format and elements which appear in a journal article, the most prevalent publication type. The title field may be augmented by terms in square brackets which indicate additional aspects of the document, such as: letter, editorial, and news. The complete NRCBL Classification Scheme can be found on the inside front cover, and the Subject Captions equivalents are on alternating footers in Section I. The inside back cover displays the Subject Heading Key for Section II, leading the reader from the primary, i.e. first, NRCBL number to the corresponding Subject Heading(s) in Section I. Most citations appear only once in this volume.

Section II: Periodical Literature and Essays — Author Index

Citations in the Author Index are followed by the primary NRCBL Classification Number (Subject). Citations that have no personal or corporate author are listed at the end of the Author Index for Periodical Literature and Essays under ANONYMOUS. The two-page SUBJECT HEADING KEY FOR SECTION II appears on the inside back cover; it provides subject heading equivalents in Section I for the subject numbers appearing at the end of each citation in Section II.

Section III: Monographs — Subject Entries

These records have been derived from the annual publication of the NRCBL’s New Titles in Bioethics, and cite monographs added to the collection in 2004 that cover bioethics and related areas of ethics and applied ethics. The NRCBL Classification Scheme (reproduced in full on the inside front cover) provides the arrangement for these citations. The Monographs section
INTRODUCTION

includes 1,029 records for books, reports, audiovisuals, special issues of journals, and new periodical subscriptions. Only subject headings actually occurring in Volume 31 are included on this list.

The monograph citations are arranged according to the primary subject category of the volume, and then, under subject category, by author, editor, producer, or title. Each citation in the Section usually appears only once. Classification numbers at the end of each citation represent additional bioethics topics covered by the publication. Monograph entries also include acquisition information, especially important for the so-called “gray literature.” Monographs in foreign languages are included in the Bibliography.

Section IV: Monographs — Title Index

This Section provides a title index to all the entries in the Monographs Section. The title is followed by the subject section and author within which the complete citation can be found.

The Bibliography of Bioethics: History and Current Availability on the World Wide Web

Through December 2000, the entries in all of the annual volumes of the Bibliography of Bioethics were available online in BIOETHICSLINE®, a database produced for the National Library of Medicine (NLM) by the Bioethics Information Retrieval Project at the Kennedy Institute of Ethics, Georgetown University. As of 2001, NLM incorporated its subject-oriented databases into two large databases, PubMed/MEDLINE for journal articles and related documents, and LOCATORplus for books and related documents.

Bibliographic records in the BIOETHICSLINE® database were retrospectively converted to PubMed or LOCATORplus records based on publication type. The Bioethics Information Retrieval Project now selects and indexes bioethics-related journal articles, newspaper articles, court decisions, and laws directly for PubMed/MEDLINE and books, book chapters, audiovisual materials, and unpublished documents for LOCATORplus. This effort is funded by a contract with NLM, with additional support from the National Human Genome Research Institute.

Citations from the Bibliography of Bioethics are available on the World Wide Web via the National Library of Medicine’s PubMed/MEDLINE and LOCATORplus databases, where they are indexed with NLM’s Medical Subject Headings (MeSH) indexing vocabulary, and via the ETHX on the Web and Genetics and Ethics databases, maintained by NRCBL. Access to the NLM and NRCBL databases, along with searching information, is available through the Web gateway of the Kennedy Institute of Ethics at http://bioethics.georgetown.edu. In addition, a comprehensive NRCBL publication provides advice for database searchers: Bioethics Searchers Guides: Using Databases of the National Library of Medicine and National Reference Center for Bioethics Literature. (See “Distribution” paragraph below for ordering information.)

Acknowledgments

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July 20, 2005
SECTION I:
PERIODICAL LITERATURE
AND ESSAYS

SUBJECT ENTRIES
**SECTION I: PERIODICAL LITERATURE AND ESSAYS**

**SUBJECT ENTRIES**

**ABORTION**

*See also GENETIC SCREENING*


**Britt, David W.; Evans, Wendy J.; Mehta, Shilpi S.; Evans, Mark I.** Framing the decision: determinants of how women considering multifetal pregnancy reduction as a pregnancy-management strategy frame their moral dilemma. *Fetal Diagnosis and Therapy* 2004 May-June; 19(3): 232-240. NRCBL: 12.1; 14.1. SC: em.

**Chavkin, Wendy.** Access denied, science denied [editorial]. *American Journal of Public Health* 2004 August; 94(8): 1298-1299. NRCBL: 12.1; 11.1; 9.5.6; 5.3.

**Dommergues, Marc.** Termination of pregnancy for fetal neurological abnormalities. *Child’s Nervous System* 2003 August; 19(7-8): 600-604. NRCBL: 12.1; 15.2; 12.5.3; 9.7.


**Grimes, David A.; Creinin, Mitchell D.** Induced abortion: an overview for internists. *Annals of Internal Medicine* 2004 April 20; 140(8): 620-626. NRCBL: 12.1; 7.1. Abstract: Internists care for many women who have had abortions and many who will seek abortions in the future. Each year, about 2% of all women of reproductive age have an abortion. Women having abortions tend to be young, white, unmarried, and early in pregnancy. Most abortions are done by suction curettage under local anesthesia in a freestanding clinic. However, medical abortion is growing in popularity as a nonsurgical alternative. The regimen approved by the U.S. Food and Drug Administration specifies mifepristone, 600 mg orally, followed 2 days later by misoprostol, 400 microg orally (within 49 days from last menses). Recent studies have recommended alternative approaches, such as mifepristone, 200 mg orally, followed in 1 to 3 days by misoprostol, 800 microg vaginally (up to 63 days). Medical abortion can be provided by a broader variety of physicians than can surgical abortion. The overall case-fatality rate for abortion is less than 1 death per 100,000 procedures. Infection, hemorrhage, acute hematometra, and retained tissue are among the more common complications. Referral back to the original abortion provider for management is advisable. Overall, induced abortion does not lead to late sequelae, either medical or psychiatric. Of importance, no link exists between induced abortion and later breast cancer. For physicians who are asked to help with a referral, the National Abortion Federation and Planned Parenthood Federation of America have helpful Web sites and networks of high-quality clinics. The cost of abortion (currently about $372 dollars at 10 weeks) has decreased in recent decades. Provision of ongoing contraception and encouragement of emergency contraception can reduce unintended pregnancies and the need for abortion.


**Joffe, Carole; Weitz, Tracy A.** Normalizing the exceptional: incorporating the “abortion pill” into mainstream medicine. *Social Science and Medicine* 2003 June; 56(12): 2353-2366. NRCBL: 12.1; 9.7; 5.2.

**Kirklin, Deborah.** The role of medical imaging in the abortion debate [editorial]. *Journal of Medical Ethics* 2004 October; 30(5): 426. NRCBL: 12.1; 15.2; 5.1.


**Macklin, Ruth.** Abortion controversies: ethics, politics and religion. *In: Baird, David T.; Grimes, David A.; Van Look, Paul F.A., eds. Modern Methods of Inducing Abor-


ABORTION/LEGAL ASPECTS


Abstract: The debate over abortion is still controversial as ever. As one of every four people in the world is of the Muslim religion, it is important to learn more about the Islamic point of view toward this dilemma in medical ethics. The first part of this paper gives a general view of the sources of Islamic law and discusses modern developments in Islamic medical ethics regarding abortion. The second part focuses on the legal aspects of abortion in different Islamic states, dealing with the need to supply solutions to women who for different reasons wish to abort and at the same time enact laws that would not contradict Islamic principles. A study of three Muslim states (Egypt, Kuwait and Tunisia) demonstrates three different approaches toward legalizing abortion—a conservative approach, a more lenient approach, and a liberal one—all within Islamic oriented states. This leads to a conclusion that a more liberal attitude regarding abortion is possible in Islamic states, as long as traditional principles are taken into account.


Abstract: This paper addresses legal protection of individual choices to obtain abortion services, to decline to perform abortions on grounds of religious objection, and to participate in these procedures. It considers legal duties to respect women as...
decision-makers in their own lives, including when they decide to continue pregnancy. The choice to decline participation in abortions is an aspect of religious freedom available to physicians, nurses, and, for instance, pharmacists, but not artificial legal persons such as hospital and clinic corporations. Refusal does not extend to ancillary functions such as serving meals, routine pre-operative and post-operative care of abortion patients or typing abortion referral letters. Physicians practising in proximate care must be trained in appropriate medical management of incomplete and threatened abortion even when they would refuse to apply such techniques to induce abortion.


Fletcher, Ruth. Legal forms and reproductive norms. Social and Legal Studies 2003 June; 12(2): 217-241. NRCBL: 12.4.2; 9.5.5; 7.1; 1.1. SC: le.


Latkovic, Mark S. Pro-life nurses and cooperation in abortion: ordinary care or extraordinary intervention? National Catholic Bioethics Quarterly 2004 Spring; 4(1): 89-102. NRCBL: 12.4.3; 4.1.3; 12.3.


Mikolajczyk, Rafael T. Recent experiences with legal restrictions and the incidence of abortion in Poland. Linacre Quarterly 2004 August; 71(3): 245-253. NRCBL: 12.4.1. SC: le.


Place, Michael D. Conscience clauses and Catholic health care. Origins 2003 September 11; 33(14): 225, 227-229. NRCBL: 12.4.3; 9.1; 1.2; 9.2; 12.3.


Shotorbani, Solmaz; Zimmerman, Frederick J.; Bell, Janice F.; Ward, Deborah; Assefi, Nassim. Attitudes and intentions of future health care providers toward abortion provision. Perspectives on Sexual and Reproductive
Health 2004 March-April; 36(2): 58-63. NRCBL: 12.4.3; 7.2; 12.5.2. SC: em.


Teklehaimanot, K.I.; Smith, C. Hord. Rape as a legal indication for abortion: implications and consequences of the medical examination requirement. Medicine and Law: World Association for Medical Law 2004; 23(1): 91-102. NRCBL: 12.4.2; 9.5.5; 1.3.5. SC: le. Abstract: A number of countries adopt abortion laws recognizing rape as a legal ground for access to safe abortion service. As rape is a crime, these abortion laws carry with them criminal and health care elements that in turn result in the involvement of legal and medical expertise. The most common objective of the laws should be providing safe abortion services to women survivors of rape. Depending on purposes of a given abortion law, the laws usually require women to undergo a medical examination to qualify for a legal abortion. Some abortion laws are so vague as to result in uncertainties regarding the steps health personnel must follow in conducting medical examination. Another group of abortion laws do not leave room for regulation and remain too rigid to respond to changing socio-economic circumstances. Still others require medical examination as a prerequisite for abortion. As a result, a number of abortion laws remain on the books. The paper attempts to analyze legal and practical issues related to medical examination in rape cases.


Wilde, Marshall L. Air Force women’s access to abortion services and the erosion of 10 U.S.C., section 1093. William and Mary Journal of Women and the Law 2003 Spring; 9(3): 351-412. NRCBL: 12.4.2; 18.5.8; 9.5.5. SC: le.

ABORTION/ MORA L AND RELIGIOUS ASPECTS


Gibson, Susanne. The problem of abortion: essentially contested concepts and moral autonomy. Bioethics 2004 June; 18(3): 221-233. NRCBL: 12.3; 10; 1.1; 4.4. SC: an. Abstract: When one thinks about the ethics of abortion, one inevitably thinks about rights, since it is in terms of the concept of rights that much of the debate has been conducted. This is true of overtly feminist as well as non-feminist accounts. Indeed, some early feminist writers—Judith Jarvis Thomson and Mary Ann Warren, for example—employ a model of rights that is in-
distinguishable, or virtually indistinguishable, from that of their non-feminist counterparts. However, more recent feminist writers have developed a different understanding of ‘a woman’s right to choose.’ In this paper, I will begin by outlining the non-feminist debate over the moral permissibility of abortion. I will suggest that this debate is irresolvable, since at its heart is an ‘essentially contested concept’, that of personhood. I will then consider the way in which some feminist writers have attempted to reconceive the terms of the abortion debate and suggest an expanded account of women’s right to abortion, drawing on the work of Susan Sherwin. Finally, I will argue that there is a further element to a ‘woman’s right to choose’ that expands on and provides a conceptual link between feminist and non-feminist understanding of abortion.


ABORTION/ SOCIAL ASPECTS


Appelbaum, Judith C.; Morrison, Jill C. Hospital mergers and the threat to women’s reproductive health services: applying the antitrust laws. New York University Review of Law and Social Change 2001; 26: 1-36. NRCBL: 12.5.1; 9.5.5; 9.1. SC: le.


Bassett, Chris; Lehane, Mike; Chivers, Lesley; Hopkins, Sue. Who needs to know? Should parents have a legal right to be informed if a child of 14 is being counselled about an abortion? Nursing Standard 2004 June 16-22; 18(40): 22-23. NRCBL: 12.5.3; 9.5.7; 8.4. SC: cs.


Kade, Kristy; Kumar, Divya; Polis, Chelsea; Schaffer, Kate. Effect of nurses’ attitudes on hospital-based abortion procedures in Massachusetts. Contraception 2004 January; 69(1): 59-62. NRCBL: 12.5.2; 8.1. SC: em.


Madhok, Bindu; Raj, Selva J. Lower income Hindu women’s attitude towards abortion: a case study in urban India. International Journal of Applied Philosophy 2004 Spring; 18(1): 123-137. NRCBL: 12.5.2; 12.3; 12.4.2.


ADVERTISE DIRECTIVES

See also DEATH AND DYING; TREATMENT REFUSAL

Do living wills affect the setting where people die in the United States? *Annals of Internal Medicine* 2004 July 20; 141(2): 1-40. NRCBL: 20.5.4; 9.5.2; 20.3.1. SC: em.


Bravo, Gina; Dubois, Marie-France; Pâquet, Mariane. Advance directives for health care and research: prevalence and correlates. *Alzheimer Disease and Associated Disorders* 2003 October-December; 17(4): 215-222. NRCBL: 20.5.4; 17.1; 9.5.2. SC: em. Identifiers: Canada.


Cantor, Michael D.; Pearlman, Robert A. Advance care planning in long-term care facilities. *Journal of the American Medical Directors Association* 2004 March-April; 5(2, Supplement): S72-S80. NRCBL: 20.5.4; 9.5.1; 9.5.2.


Cross, Laura L. Legal issues in end-of-life care in Oklahoma. *Oklahoma City University Law Review* 2002 Fall; 27(3): 921-937. NRCBL: 20.5.4; 8.3.3; 20.5.1. SC: le.

Degenholtz, Howard B.; Rhee, YongJoo; Arnold, Robert M. Brief communication: the relationship between having a living will and dying in peace. *Annals of Internal Medicine* 2004 July 20; 141(2): 113-117. NRCBL: 20.5.4; 9.5.2; 20.3.1. SC: em. Abstract: Living wills, a type of advance directive, are promoted as a way for patients to document preferences for life-sustaining treatments should they become incompetent. Previous research, however, has found that these documents do not guide decision making in the hospital. OBJECTIVE: To test the hypothesis that people with living wills are less likely to die in a hospital than in their residence before death. DESIGN: Secondary analysis of data from a nationally representative longitudinal study. SETTING: Publicly available data from the Asset and Health Dynamics Among the Oldest Old (AHEAD) study. PATIENTS: People older than 70 years of age living in the community in 1993 who died between 1993 and 1995. MEASUREMENTS: Self-report and proxy informant interviews conducted in 1993 and 1995. RESULTS: Having a living will was associated with lower probability of dying in a hospital for nursing home residents and people living in the community. For people living in the community, the probability of in-hospital death decreased from 0.65 (95% CI, 0.58 to 0.71) to 0.52 (CI, 0.42 to 0.62). For people living in nursing homes, the probability of in-hospital death decreased from 0.35 (CI, 0.23 to 0.49) to 0.13 (CI, 0.07 to 0.22). LIMITATIONS: Retrospective survey data do not contain detailed clinical information on whether the...
Living wills were consulted. Conclusion: Living wills are associated with dying in place rather than in a hospital. This implies that previous research examining only people who died in a hospital suffers from selection bias. During advance care planning, physicians should discuss patients’ preferences for location of death.

**Dimond, Bridgit.** The refusal of treatment: living wills and the current law in the UK. *British Journal of Nursing* 2004 October 14-27; 13(18): 1104-1106. NRCBL: 20.5.4; 8.3.4. SC: le. Identifiers: Great Britain.


**Douglas, Rebecca; Brown, Hazel N.** Patients’ attitudes toward advance directives. *Journal of Nursing Scholarship* 2002; 34(1): 61-65. NRCBL: 20.5.4; 9.5.2.


**Dubler, Nancy Neveloff.** Legal principles and decision-making. *Sh’ma* 2004 May; 34(611): 16. NRCBL: 20.5.4; 20.5.1; 1.2.

**Dyer, Clare.** Living wills will have to specify treatments that patient is refusing [news]. *BMJ: British Medical Journal* 2004 May 1; 328(7447): 1035. NRCBL: 20.5.4.

**Emanuel, Ezekiel J.; Fagerlin, Angela; Schneider, Carl.** Living wills: are durable powers of attorney better? [letter and reply]. *Hastings Center Report* 2004 November-December; 34(6): 5-7. NRCBL: 20.5.4. SC: le.

**Emanuel, Linda L.** Advance directives and advancing age [editorial]. *Journal of the American Geriatrics Society* 2004 April; 52(4): 641-642. NRCBL: 20.5.4; 9.5.2.


Abstract: The introduction describes Alzheimer’s Disease and the statement portion of the document begins with the heading, “My Last Wishes (In the event of irreversible cognitive decline).”

**Fagerlin, Angela; Schneider, Carl E.** Enough — the failure of the living will. *Hastings Center Report* 2004 March-April; 34(2): 30-42. NRCBL: 20.5.4. SC: le; an.


**Guyatt, Gordon; Cook, Deborah; Weaver, Bruce; Rocker, Graeme; Dodek, Peter; Sjokvist, Peter; Hamielec, Cindy; Puksa, Serge; Marshall, John; Foster, Debra; Levy, Mitchell; Varon, Joseph; Thorpe, Kevin; Fisher, Malcolm; Walter, Stephen.** Influence of perceived functional and employment status on cardiopulmonary resuscitation directives. *Journal of Critical Care* 2003 September; 18(3): 133-141. NRCBL: 20.5.4. SC: em. Identifiers: Australia; Canada; Sweden; United States.


**Hardin, Steven B.; Yusufaly, Yasmin A.** Difficult end-of-life treatment decisions — do other factors trump advance directives? *Archives of Internal Medicine* 2004 July 26; 164(14): 1531-1533. NRCBL: 20.5.4; 20.5.1. Abstract: BACKGROUND: Advance directives are widely promoted as a means to plan for patients’ “decisional incapacity, yet there is little evidence of their effectiveness. We devised a study to assess physicians’ compliance with hypothetical advance directives and further examine their clinical reasoning. METHODS: The study consisted of an analysis of a mailed written survey containing 6 hypothetical cases of seriously ill patients. Each case contained an explicit advance directive with potential conflict between the directive and (1) prognosis, (2) the wishes of family or friends, or (3) quality of life. Data were collected on the clinical treatment decisions made by physicians and the reasons for those decisions. Study participants were all internal medicine faculty and resident physicians from a single academic institution. RESULTS: A total of 47% analyzable surveys (117/250) were returned. Decisions by faculty and residents were not consistent with the advance directive in 65% of cases. This inconsistency was similar for faculty and residents (68% and 61%, respectively; P.05). When physicians made decisions inconsistent with the advance directive, they were more likely to list reasons other than the directive for their decisions (89%; P001). CONCLUSIONS: Internists frequently made treatment decisions that were not consistent with an explicit ad-
Advance directive. In difficult clinical situations, internists appear to consider other factors such as prognosis, perceived quality of life, and the wishes of family or friends as more determinative than the directive. Future work needs to explore the generalizability of these findings and examine how strictly patients desire their advance directives to be followed.


Hickman, Susan E.; Hammes, Bernard J.; Tolle, Susan W.; Moss, Alvin H.; Fagerlin, Angela; Schneider, Carl. A viable alternative to traditional living wills [letter and reply]. *Hastings Center Report* 2004 September-October; 34(5): 4-6. NRCBL: 20.5.4.

Hildén, Hanna-Mari; Louhiala, Pekka; Honkasalo, Marja-Liisa; Palo, Jorma. Finnish nurses’ views on end-of-life discussions and a comparison with physicians’ views. *Nursing Ethics* 2004 March; 11(2): 165-178. NRCBL: 20.5.4; 7.1; 20.5.1. SC: em. Identifiers: Finland.

Abstract: This study investigated Finnish nurses’ experiences and views on end-of-life decision making and compared them with physicians’ views. For this purpose, a questionnaire was sent to 800 nurses, of which 51% responded. Most of the nurses had a positive attitude towards and respect for living wills, more often than physicians. Most also believed that a will had an effect on discussion with physicians. Almost all of the nurses considered it their responsibility to talk to physicians about respecting living wills. Do-not-resuscitate (DNR) orders were often interpreted to imply partial or complete palliative (symptom-oriented) care, which may cause confusion. Half of the nurses reported that a DNR decision was discussed always or often with a patient who was able to communicate; physicians were more positive in this respect. Surprisingly, many nurses (44%) stated that active treatment continued too long. Two-thirds thought that their opinions were taken into account sufficiently, even though only half believed that, in general, they had some impact.


Kahana, Boaz; Dan, Amy; Kahana, Eva; Kercher, Kyle. The personal and social context of planning for end-of-life care. *Journal of the American Geriatrics Society* 2004 July; 52(7): 1163-1167. NRCBL: 20.5.4; 9.5.2.


Kessler, Daniel P.; McClellan, Mark B. Advance directives and medical treatment at the end of life. *Journal of Health Economics* 2004 January; 23(1): 111-127. NRCBL: 20.5.4; 9.3.1; 9.5.2; 20.4.1. SC: em; le. Identifiers: Medicare.


Laakkonen, Marja-Liisa; Pitkala, Kaisu H.; Strandberg, Timo E.; Berglind, Salla; Tilvis, Reijo S. Living will, resuscitation preferences, and attitudes towards life in an aged population. *Gerontology* 2004 July-August; 50(4): 247-254. NRCBL: 20.5.4; 20.3.1. Identifiers: Finland.


Lo, Bernard; Steinbrook, Robert. Resuscitating advance directives. *Archives of Internal Medicine* 2004 July 26; 164(14): 1501-1506. NRCBL: 20.5.4. SC: le. Abstract: Advance directives have not fulfilled their promise of facilitating decisions about end-of-life care for incompetent patients. Many legal requirements and restrictions concerning advance directives are counterproductive. Requirements for witnessing or notarizing advance directives make it difficult for patients to complete a written directive during a physician visit. State laws that establish a hierarchy of family surrogates for incompetent patients who have not appointed a proxy are inflexible and may not apply to common clinical situations. Advance directives would be more useful if they emphasized discussing end-of-life care with physicians rather than completing a legal document. State laws should be revised to encourage patients to discuss advance directives with physicians and to complete them during an office visit. Such patient-physician discussions about end-of-life care can lead to more informed patient decisions. Procedures for written advance directives should be simplified. Patients should be able to designate health care proxies through oral statements to physicians. These reforms will encourage discussions between patients and physicians about advance directives and may lead to more informed decisions near the end of life.


Morrison, R. Sean; Meier, Diane E. High rates of advance care planning in New York City’s elderly population. *Archives of Internal Medicine* 2004 December 13-27; 164(22): 2421-2426. NRCBL: 20.5.4; 9.5.4. SC: em.


Phipps, Etienne J.; True, Gala; Murray, Geneva F. Community perspectives on advance care planning: report from the Community Ethics Program. *Journal of Cultural Diversity* 2003 Winter; 10(4): 118-123. NRCBL: 20.5.4; 20.3.1; 20.4.1; 21.7. SC: em.


Schwartz, Carolyn; Lennes, Inga; Hammes, Bernard; Lapham, Carrie; Bottner, Wayne; Ma, Yunsheng. Honoring advance care planning intervention using qualitative analysis: the Living Well interview. *Journal of Palliative Medicine* 2003 August; 6(4): 593-603. NRCBL: 20.5.4; 8.1; 4.4.


Srebnik, Debra S.; Russo, Joan; Sage, Julie; Peto, Tracy; Zick, Ellen. Interest in psychiatric advance direc-


van Delden, J.J.M.; Laurie, G. The unfeasibility of requests for euthanasia in advance directives [article and commentary]. *Journal of Medical Ethics* 2004 October; 30(5): 447-452. NRCBL: 20.5.4; 1.1; 20.5.1. SC: an; cs; le.

Wreen, Michael J. Hypothetical autonomy and actual autonomy: some problem cases involving advance directives. *Journal of Clinical Ethics* 2004 Winter; 15(4): 319-333. NRCBL: 20.5.4; 1.1; 8.3.3. SC: cs.

**ADVISORY COMMITTEES ON BIOETHICS**

See BIOETHICS AND MEDICAL ETHICS/COMMISSIONS

**AGED** See CARE FOR SPECIFIC GROUPS/AGED; HUMAN EXPERIMENTATION/SPECIAL POPULATIONS/AGED AND TERMINALLY ILL

**AIDS**


Bayer, Ronald. AIDS and the making of an ethics of public health. *In*: Valdiserri, Ronald O., ed. Dawning An-
de Bruyn, Maria. Safe abortion for HIV-positive women with unwanted pregnancy: a reproductive right. *Reproductive Health Matters* 2003 November; 11(22): 152-161. NRCBL: 9.5.6; 9.5.5; 12.4.2; 12.5.1; 21.1.


Garber, Mandy; Hunt, Susan C.; Arnold, Robert M. Can an HIV-positive woman be forced to take medicine to protect her fetus? *Medical Ethics Newsletter [Lahey Clinic]* 2004 Fall; 11(3): 3, 12. NRCBL: 9.5.6; 9.5.5; 9.5.8; 8.3.4.


Honig, Judy; Jurgrau, Andrea. Mandatory newborn HIV testing. *Journal of Nursing Law* 1999; 6(1): 33-38. NRCBL: 9.5.6; 9.5.5; 9.5.8; 8.3.4; 8.3.2.


Abstract: Robert Veatch has proposed a model of the doctor-patient relationship that has as its foundation the sharing of values between the doctor and the patient. This paper uses qualitative research conducted with six doctors involved in the long term, specialised care of HIV positive patients in South Australia to explore the practical application of Veatch’s value sharing model in that setting. The research found that the doctors in this study linked “values” with sexual identity such that they defined value sharing in part, as a shared set of values and beliefs about sexual identity and practices. They voluntarily identified themselves as either homosexual or heterosexual and they regarded the relation between their own sexual identity and that of their patients as important for the provision of quality care. None of the doctors thought that value sharing, in the way they defined it, was essential to the clinical relationship, but the homosexual doctors attributed a greater degree of importance to it than their heterosexual colleagues.


MacQueen, Kathleen M.; Shapiro, Katharine; Karim, Quarraisha Abdool; Sugarman, Jeremy. Ethical challenges in international HIV prevention research. *Accountability in Research* 2004 January-March; 11(1): 49-61. NRCBL: 9.5.6; 18.2; 18.3; 21.1.

Abstract: Members of an HIV-prevention research network were asked to describe ethical challenges faced in their work. Major themes included acceptable standards of care for participants, defining research of relevance to host countries, reducing risks related to stigma, designing research that meets local needs without contributing to an inadequate status quo, and ensuring informed consent for complex research with potentially vulnerable participants. The challenges are interrelated and highlight the need for innovative, practical strategies to be incorporated into the planning, design, and conduct of HIV prevention trials. Research in applied ethics to support decision-making about HIV prevention research is needed, along with ethics training, mechanisms to support community-wide benefit from research, and expanded dialog on ethics surrounding HIV prevention and public health research.


Maticka-Tynadle, Eleanor. Dilemmas for obtaining consent when working with children in high AIDS prevalence regions. NCEHR Communiqué CNERH 2004 Spring; 12(2): 27-28. NRCBL: 9.5.6; 18.3; 8.3.2; 18.5.2.

McGrath, Janet W.; George, Kathleen; Svilar, Grace; Ihler, Elizabeth; Mafigiri, David; Kabugo, Michael; Mugisha, Emmanuel. Knowledge about vaccine trials and willingness to participate in an HIV/AIDS vaccine study in the Ugandan military. Journal of Acquired Immune Deficiency Syndromes 2001; 27: 381-388. NRCBL: 9.5.6; 9.7; 18.2; 18.5.9.


Abstract: This paper contrasts biomedical and epidemiological approaches to the diagnosis and treatment of disease, and uses Collingwood’s “principle of the relativity of causes” to show how different approaches focus on different causal factors reflecting different interests. By distinguishing between the etiology of a disease and an epidemic, the paper argues that, from an epidemiological perspective, poverty is an important causal factor in the African AIDS epidemic and that emphasizing this should not be considered incompatible with recognizing the causal necessity of HIV for the AIDS disease.

Muula, Adamson S.; Mfutso-Bengo, Joseph M. Important but neglected ethical and cultural considerations in the fight against HIV/AIDS in Malawi. Nursing Ethics 2004 September; 11(5): 479-488. NRCBL: 9.5.6; 1.1; 8.4.

Abstract: Southern African countries have the highest HIV infection rates in the world. In most of the countries in the region, the rate among adults is at least 10%. The fight against HIV/AIDS has mostly been inadequate owing to the lack of proper consideration of ethical and cultural issues. In this article, the authors discuss the ethical and cultural dilemmas concerning HIV/AIDS, with Malawi as a case in point. It is argued that increasing financial resources alone, as exemplified by the Global Fund to Fight AIDS, Tuberculosis and Malaria initiative, without proper attention to ethical issues, morals and appropriate legal obligations, are unlikely to reduce the spread of HIV in southern Africa.


Sengupta, Sohini; Lo, Bernard. U.S. pregnant women’s perceptions of universal, routine prenatal HIV testing. AIDS and Public Policy Journal 2003 Winter; 18(3-4): 83-97. NRCBL: 9.5.6; 9.5.5; 9.5.8; 9.5.1; 7.1; 17.1. SC: em.

Sheldon, Tony. Patients can be made to have HIV test to protect doctor [news]. BMJ: British Medical Journal 2004 February 7; 328(7435): 304. NRCBL: 9.5.6; 9.1; 1.3.5.


Surlis, Siobhan; Hyde, Abbey. HIV-positive patients’ experiences of stigma during hospitalization. Journal of the Association of Nurses in AIDS Care 2001 November-December; 12(6): 68-77. NRCBL: 9.5.6; 8.1; 7.1; 4.1.3.


Van Casteren, Viviane; Devroey, Dirk; Sasse, André; Wallyn, Solvejg. An 8 year nationwide prospective registration of non-consent HIV testing in Belgium. *Journal of Public Health* 2004 March; 26(1): 72-76. NRCBL: 9.5.6; 8.3.1. SC: cm.


**AIDS/LEGAL ASPECTS**


Christie, Timothy. HIV serostatus disclosure: legal, scientific and ethical considerations. *Health Law in Canada* 2002 February; 22(3): 70-76. NRCBL: 9.5.6; 8.4; 8.2; 1.1. SC: le.


Goldring, Douglas S. The Law and ACTG Protocol 076: do the slings and arrows of mandatory HIV testing penetrate a woman’s right to privacy. *Lincoln Law Review* 1999; 25/26: 1-23. NRCBL: 9.5.6; 9.5.5; 9.5.8; 8.3.4. SC: le.


Kelly, Kristin. Obtaining informed consent prior to prenatal HIV testing: the value of persuasion and the threat of coercion. *AIDS and Public Policy Journal* 2003 Winter; 18(3-4): 98-111. NRCBL: 9.5.6; 8.3.1; 9.5.7; 9.5.1; 15.2. SC: an; le.


Webber, David W. HIV testing during pregnancy: the value of optimizing consent. *AIDS and Public Policy Journal* 2003 Winter; 18(3-4): 77-82. NRCBL: 9.5.6; 8.3.1; 9.5.5; 9.5.8; 9.1; 7.1. SC: le.


**ALLOCATION** See RESOURCE ALLOCATION; ORGAN AND TISSUE TRANSPLANTATION/ALLOCATION

**ALLOWING TO DIE** See EUTHANASIA AND ALLOWING TO DIE

**ANIMAL EXPERIMENTATION**


Animal research is a source of human compassion, not shame [editorial]. *Lancet* 2004 September 4-10; 364(9437): 815-816. NRCBL: 22.2; 22.1. Identifiers: Stop Huntingdon Animal Cruelty; Victims of Animal Rights Extremism.


The fewer the better — we can never stop all animal testing, but there are other things we can do. *New Scientist* 2004 August 7-13; 183(2459): 3. NRCBL: 22.2.


Re-homing primates: the consequences of zero-tolerance to primate research [news]. *ATLA: Alternatives to Laboratory Animals* 2004 September; 32(3): 153-154. NRCBL: 22.2; 21.1; 5.3.

**American College of Toxicology.** American College of Toxicology: policy statement on the use of animals in toxicology. *International Journal of Toxicology* 2004 January-February; 23(1): 1 p. NRCBL: 22.2; 6.

**American College of Toxicology. Animals in Research Committee.** American College of Toxicology: policy statement on the use of animals in toxicology. *International Journal of Toxicology* 2003 July-August; 22(4): 1 p preceding 261. NRCBL: 22.2.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.


Babcock, George F. Common problems encountered by IACUCs — one chair’s perspective. Contemporary Topics in Laboratory Animal Science 2004 May; 43(3): 70-71. NRCBL: 22.2; 5.3.

Bakhle, Y.S. Missing evidence that animal research benefits humans — evidence is all around us. BMJ: British Medical Journal 2004 April 24; 328(7446): 1017. NRCBL: 22.2.

Balls, Michael. Progressing toward the reduction, refinement and replacement of laboratory animal procedures: thoughts on some encounters with Dr. Iain Purchase. Toxicology In Vitro 2004 April; 18(2): 165-170. NRCBL: 22.2; 2.2.


Bennett, B. Taylor; Conlee, Kathleen M.; Rollin, Bernard E.; Rowan, Andrew N.; Short, Charles E.; Toth, Linda A.; Wolfe, Thomas L. Pain and distress in research animals: a panel of experts debates the issues. Lab Animal 2002 January; 31(1): 34-42. NRCBL: 22.2; 22.1.


Capaldo, Theodora. The psychological effects on students of using animals in ways that they see as ethnically, morally or religiously wrong. ATLA: Alternatives to Laboratory Animals 2004 June; 32(Supplement 1B): 525-531. NRCBL: 22.2; 7.2; 1.3.3. SC: em. Conference: The Three Rs at the Beginning of the 21st Century, New Orleans, Louisiana, 11-15 August 2002, Fourth World Congress on Alternatives and Animal Use in the Life Sciences.


SECTION I

ANIMAL EXPERIMENTATION


Guittin, Pierre; Decelle, Thierry. Future improvements and implementation of animal care practices within the animal testing regulatory environment. *ILAR Journal* 2002; 43(Supplement): S80-S84. NRCBL: 22.2; 22.1.


Lekan, Todd. Integrating justice and care in animal ethics. *Journal of Applied Philosophy* 2004; 21(2): 183-195. NRCBL: 22.1; 1.1. SC: an. Abstract: In this paper I argue that the stand off between justice and care approaches to animal ethics presents us with a false dilemma. We should take justice’s focus on reasoning from principles, and care’s use of sympathetic awareness, as two integrated deliberative capacities necessary for the consideration of arguments for extending moral concern to animals. Such an integrated approach rests on a plausible account of the psychology of moral deliberation. I develop my argument as follows. Section I summarizes the nature of the debate between justice and care approaches to animal ethics, focusing on Brian Luke’s arguments against justice approaches. Section II provides pro-justice rebuttals to Luke’s objections. These rebuttals, while largely successful against Luke’s objections, do not account for the intuition that sympathy does play a central epistemological role in animal ethics. Section III explains how sympathy cognitively simulates the perspective of the other, and thus can play an epistemological role in animal ethics. I argue that the abilities to simulate the perspective of the other and to reason from moral principles can complement each other. In section IV, I argue that though it may not be desirable to use both sympathy and reasoning from principles in all moral delibera-
tion, it is a desirable aim when offering, and considering, moral arguments for what I will term the “extensionist project” of extending over moral concern to animals. I make this idea plausible by elucidating the claim that arguments for this project are best thought of as second-order deliberations about our first-order deliberative life.


Pound, Pandora; Erbahi, Shah; Sandercok, Peter; Bracken, Michael B.; Roberts, Ian. Where is the evidence that animal research benefits humans? Much animal research into potential treatments for humans is wasted because it is poorly conducted and not evaluated through systematic reviews. *BMJ: British Medical Journal* 2004 February 28; 328(7438): 514-517. NRCBL: 22.2.

Preece, Rod. Darwinism, Christianity, and the great vivisection debate. *Journal of the History of Ideas* 2003 July; 64(3): 399-419. NRCBL: 22.2; 1.2; 3.2.

SECTION I

ANIMAL EXPERIMENTATION

ana, 11-15 August 2002, Fourth World Congress on Alternatives and Animal Use in the Life Sciences.


Richmond, Jon. Refinement, reduction, and replacement of animal use for regulatory testing: future improvements and implementation within the regulatory framework. ILAR Journal 2002; 43(Supplement): S63-S68. NRCBL: 22.2; 22.1.


Schuppli, Catherine A.; Fraser, David; McDonald, Michael. Expanding the three Rs to meet new challenges in humane animal experimentation. ATLA: Alternatives to Laboratory Animals 2004 November; 32(5): 525-532. NRCBL: 22.2.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme  
See inside front cover for terms.
ARTIFICIAL INSEMINATION AND SURROGATE MOTHERS  SECTION I

Stephens, Martin L.; Conlee, Kathleen; Alvino, Gina; Rowan, Andrew N. Possibilities for refinement and reduction: future improvements within regulatory testing. *ILAR Journal* 2002; 43(Supplement): S74-S79. NRCBL: 22.2; 21.1.


ARTIFICIAL INSEMINATION AND SURROGATE MOTHERS

See also REPRODUCTIVE TECHNOLOGIES


Chen, Melody. Wombs for rent: an examination of prohibitory and regulatory approaches to governing preconception arrangement. *Health Law in Canada* 2003 February; 23(3): 33-50. NRCBL: 14.2; 2.4; 4.4; 1.3.5. SC: le.


Orenstein, Peggy. The other mother: K. provided the eggs, her lover the womb, and for nearly six years the two women raised the twin girls thus conceived. But when the women broke up, K. learned how fragile the definition of motherhood could be. *New York Times Magazine* 2004 July 25; p. 24-29. NRCBL: 14.2; 10. SC: po; le.


Zhou, Ling Jing. Provision of assisted reproductive technology for single women in China: a new challenge. *Medicine and Law: World Association for Medical Law* 2004; 23(2): 433-451. NRCBL: 14.2; 14.4; 9.5.5; 13.3. SC: le. Abstract: Following the enactment of the Jilin Regulation, single women, for the first time, are allowed to access assisted reproductive services in China. This paper is intended to analyze the arguments over whether single women are entitled to access assisted reproductive services, in relation to Chinese legal, ethical and social characteristics.

**ARTIFICIAL NUTRITION AND HYDRATION**

See EUTHANASIA AND ALLOWING TO DIE

**ASSISTED REPRODUCTIVE TECHNOLOGIES**

See REPRODUCTIVE TECHNOLOGIES

**ASSISTED SUICIDE**

See also EUTHANASIA AND ALLOWING TO DIE


Angell, Marcia. The quality of mercy. *In: Quill, Timothy E.; Battin, Margaret P., eds. Physician-Assisted Dying: The Case for Palliative Care and Patient Choice. Balti-
more, MD: Johns Hopkins University Press; 2004: 15-23. NRCBL: 20.7; 20.4.1; 4.4; 20.5.1.

Arnold, Elizabeth Mayfield; Artin, Katherine Abbott; Person, Judi Lund; Griffith, Devin L. Consideration of hastening death among hospice patients and their families. *Journal of Pain and Symptom Management* 2004 June; 27(6): 523-532. NRCBL: 20.7; 20.5.1; 20.3.1; 20.3.3. SC: em.


Abstract: In this essay I shall describe and analyse the current debate on physician assisted suicide in contemporary German Protestant church and theology. It will be shown that the Protestant (mainly Lutheran) Church in Germany together with her Roman Catholic sister church has a specific and influential position in the public discussion: The two churches counting the majority of the population in Germany among their members tend to “organize” a social and political consensus on end-of-life questions. This cooperation is until now very successful: Speaking with one voice on end-of-life questions, the two churches function as the guardians of a moral consensus which is appreciated even by many non-believers. Behind this joint service to society the lines of the theological debate have to be re-discovered. First it will be argued that a Protestant reading of the joint memorandum has to be based on the concept of individual conscience. The crucial questions are then: Whose conscience has the authority to decide? and: Can the physician assisted suicide be desired faithfully? Prominent in the current debate are Ulrich Eibach as a strict defender of the sanctity of life, and on the other side Walter Jens and Hans Kung, who argue for a right to physician assisted suicide under extreme conditions. I shall argue that it will be necessary to go beyond this actual controversy to the works of Gerhard Ebeling and Karl Barth for a clear and instructive account of conscience and a theological analysis of the concepts of life and suicide. On the basis of their considerations, a conscience-related approach to physician assisted suicide is developed.

Basta, Lofty L. Ethical issues in the management of geriatric cardiac patients: a terminally ill colleague asks for a prescription for barbiturates to commit suicide at the time of need. *American Journal of Geriatric Cardiology* 2004 March-April; 13(2): 92-94. NRCBL: 20.7; 20.5.1. SC: cs; le.


Bosshard, Georg; Ulrich, Esther; Bär, Walter. 748 cases of suicide assisted by a Swiss right-to-die organisation. *Swiss Medical Weekly* 2003; 133: 310-317. NRCBL: 20.7; 20.5.1; 7.1.


**SECTION I**

**ASSISTED SUICIDE**


Cherry, Mark J. Why physician-assisted suicide perpetuates the idolatry of medicine. *Christian Bioethics* 2003 August-December; 9(2-3): 245-271. NRCBL: 20.7; 20.5.1; 8.1; 1.2; 4.4; 7.1. Abstract: Adequate response to physician-assisted suicide and euthanasia depends on fundamental philosophical and theological issues, including the character of an appropriate philosophically and theologically anchored anthropology, where the central element of traditional Christian anthropology is that humans are created to worship God. As I will argue, Christian morality and moral epistemology must be nested within and understood through this background Christian anthropology. As a result, I will argue that physician-assisted suicide and euthanasia can only be one-sidedly and inadequately appreciated through rational appeal to central values, such as “human dignity” and “self determination”, or through “sola scriptura” biblical interpretation, or individual judgments of conscience. Adequately addressing physician-assisted suicide and euthanasia will depend on a more fundamental spiritual-therapeutic approach. This cluster of moral, epistemological, anthropological, and bioethical claims will be explored by drawing on the texts of St. Basil the Great, St. Maximos the Confessor, and St. Isaac the Syrian. Their reflections on medicine, the human good, and its relationship to worship, spiritual therapy, and God will be used as a basis to indicate a broader philosophical perspective, which will be needed to avoid a one-sided, incomplete approach to the challenges of physician-assisted suicide and euthanasia. Medical morality, I argue, is best understood within categories that transcend the right, the good, the just, and the virtuous; namely, the holy.


Abstract: In 2002 Diane Pretty went to the European Court of Human Rights to gain a ruling about assisted suicide. In the course of this she argued that the right to life implied a right to die. This paper will consider, from an ethical rather than a legal point of view, how the right to life might imply (or not) a right to die, and whether this includes either a right that others shall help us die, or a right against non-interference if others are willing to help us. It does this by comparing the right to the right to conceptions of property rights. This is not because I think human life is property, but because some of our ways of talking and thinking about our control over our own lives seem to be similar to our thoughts about our control over our own property. The right to life has traditionally been taken as a negative right, that is a right that others not deprive us of life. Pretty’s argument, however, seems to be moving towards a positive right, not just to remain alive, but to be enabled in doing what we want to with our lives, and thus disposing of them if we so choose. The comparison with property rights suggests that the right to die only applies if our lives are ours absolutely, and may itself be modified by the suggestion that suicide harms all of us by devaluing human life in general.


Delkeskamp-Hayes, Corinna. Euthanasia, physician assisted suicide, and Christianity’s positive relationship to the world. *Christian Bioethics* 2003 August-December; 9(2-3): 163-185. NRCBL: 20.7; 20.5.1; 8.1; 1.2; 1.1. Abstract: This essay addresses the problem of communication between Christianity and the secular world in an area where the latter tends to oppose the moral norms endorsed by the former. How, in the interest of missionary outreach (and with which understandings of what such outreach involves) can the language barriers be bridged? Whereas the Roman Catholic natural law tradition posits a neutral common ground of (traditional or
hermeneutical) rationality between Christianity and the world, an Ebeling- and Barth-modified Lutheranism engages in an argument ad hominem by seizing upon an admitted deficiency within that world, and by recommending Christianity for mending that deficiency. Both positions differ from the Evangelical claim that since that which the world politically values is derived from Christianity, it must remain subject to Christianity’s moral legislation. An entirely different approach to the communication- and outreach-problem is taken by Orthodox Christianity: The gulf which separates it from the world is acknowledged, and the possibility of trans-gulf-traffic is referred to God’s grace. It is only this latter model, however, which preserves Christianity’s theological terms (such as “Scripture”, “law”, and “holiness”) from common-ground-securing, deficiency-mending, or authority-imposing secularizing, and thus from compromising that very theological context into which communicative outreach endeavors were to invite.


Fadem, Pamela; Minkler, Meredith; Perry, Martha; Blum, Klaus; Moore, Leroy F.; Rogers, Judi; Williams, Lee. Attitudes of people with disabilities toward death with dignity legislation: broadening the dialogue. Journal of Health Politics, Policy and Law 2003 December; 28(6): 977-1001. NRCBL: 20.7; 20.5.1; 8.1; 17.1; 9.5.1.

Fickling, David. A happy ending? Lancet 2004 September 4-10; 364(9437): 831-832. NRCBL: 20.7; 20.5.1; 8.1; 20.3.1. SC: cs.


Fletcher, David B. Holy dying, assisted dying?: an Anglican perspective on physician-assisted suicide. Ethics and Medicine 2004 Spring; 20(1): 35-42. NRCBL: 20.7; 20.5.1; 8.1; 1.2; 1.1.


Ganzini, Linda; Dobscha, Steven K. Clarifying distinctions between contemplating and completing physician-assisted suicide. Journal of Clinical Ethics 2004 Summer; 15(2): 119-122. NRCBL: 20.7; 20.3.1; 20.3.2; 20.3.3; 20.5.1. Identifiers: Oregon Death with Dignity Act.


Gill, Carol J. Depression in the context of disability and the “right to die”. Theoretical Medicine and Bioethics 2004; 25(3): 171-198. NRCBL: 20.7; 20.5.1; 9.5.1; 4.3; 4.4; 8.3.4.
SECTION I

ASSISTED SUICIDE

Abstract: Arguments in favor of legalized assisted suicide often center on issues of personal privacy and freedom of choice over one’s body. Many disability advocates assert, however, that autonomy arguments neglect the complex sociopolitical determinants of despair for people with disabilities. Specifically, they argue that social approval of suicide for individuals with irreversible conditions is discriminatory and that relaxing restrictions on assisted suicide would jeopardize, not advance, the freedom of persons with disabilities to direct the lives they choose. This paper examines the idea promoted by some proponents of assisted suicide that it is reasonable to be depressed about one’s diminished quality of life in cases of irreversible illness or disability and, therefore, such depression should not call into question the individual’s competence to request assistance in dying. The concept of rational depression is defined and examined in the context of four real-life cases involving individuals with disabilities who requested assistance in dying: a set of criteria commonly applied to decision-making to determine rationality; and research bearing on the emotional status of people with disabilities. It is concluded that although disability is associated with particular socially mediated stressors, there is no theoretical or empirical evidence to indicate that depression and its role in the “right to die” is dynamically different, more natural, or more reasonable for disabled people than for non-disabled people.


Haider-Markel, Donald P.; Joslyn, Mark R. Just how important is the messenger versus the message? The case of framing physician-assisted suicide. Death Studies 2004 April; 28(3): 243-262. NRCBL: 20.7; 20.5.1; 8.1. SC: em.

Hermann, Donald H.J. The question remains: are there terminally ill patients who have a constitutional right to physician assistance in hastening the dying process. DePaul Journal of Health Care Law 1997 Spring; 1(3): 445-493. NRCBL: 20.7; 20.5.1; 8.1. SC: le.


Irwin, Michael. Am I breaking the law again? BMJ: British Medical Journal 2004 June 12; 328(7453): 1440. NRCBL: 20.7; 1.3.5; 20.5.1. SC: le.


Jones, Robert P. Cultural bias and liberal neutrality: reconsidering the relationship between religion and liberalism through the lens of the physician-assisted suicide debate. Journal of the Society of Christian Ethics 2002 Fall; 22: 229-263. NRCBL: 20.7; 1.1; 1.2; 20.5.1; 21.7.


Lerner, Barron H. A calculated departure: for someone in good health, can suicide ever be a rational choice? Wash-
ASSISTED SUICIDE

SECTION I


Magnusson, Roger S. “Underground euthanasia” and the harm minimization debate. *Journal of Law, Medicine and Ethics* 2004 Fall; 32(3): 486-495. NRCBL: 20.7; 20.5.1; 9.8; 20.3.2.

Magnusson, R.S. Euthanasia: above ground, below ground. *Journal of Medical Ethics* 2004 October; 30(5): 441-446. NRCBL: 20.7; 20.5.1. SC: an; le.


Meyskens, Frank L., Jr; Fetting, John H. Pulling the trigger. *Journal of Clinical Oncology* 2004 September 1; 22(17): 3644-3645. NRCBL: 20.7; 20.5.1; 4.4; 8.1.

Mitchell, K. Physician commitment in end of life care — perspectives from New Zealand and the Netherlands. *Social Science and Medicine* 2004 August; 59(4): 775-785. NRCBL: 20.7; 8.1; 20.4.1; 20.3.2; 20.5.1. SC: em; cs.


Abstract: Discussions in Germany regarding appropriate end-of-life decision-making have been heavily influenced by the liberalization of access to physician-assisted suicide and voluntary active euthanasia in the Netherlands and Belgium. These discussions disclose conflicting moral views regarding the propriety of physician-assisted suicide and euthanasia, threatening conflicts within not only the medical profession, but also the mainline churches in Germany, whose membership now entertains views regarding end-of-life decision-making at odds with traditional Christian doctrine. On the surface, there appears to be a broad consensus supporting the hospice movement and condemning physician-assisted suicide and euthanasia. The German Supreme Court has held that treatment decisions should, in absence of known patients’ wishes, be made in light of commonly shared values, unless these violate the principle of “in dubio pro vita”. The Roman Catholic church and the Evangelical Lutheran church in Germany have developed an advance directive for treatment choices at the end of life, while condemning physician-assisted suicide and euthanasia. This stance is in tension with the strong emerging support for physician-assisted suicide and euthanasia, a development that promises to open up foundational disagreements within mainline German Christianity regarding the appropriate approach to intentionally terminating human life.
SECTION I

Assisted Suicide


Plaut, W. Gunther; Washofsky, Mark; Friedman, Joan S.; Lilienthal, David; Rhiens, Richard S.; Weiss, Faendra L.; Schiff, Daniel; Zemer, Moshe. On the treatment of the terminally ill. *CCAR Journal: A Reform Jewish Quarterly* 1997 Spring; 44(2): 11-35. NRCBL: 20.7; 20.5.1; 4.4; 1.2.


Rich, Karen L.; Butts, Janie B.; Büchner, Günter; Chi-Tim, Lui; Rassool, G. Hussein. Rational suicide: uncertain moral ground [discussion]. *Journal of Advanced Nursing* 2004 May; 46(3): 270-283. NRCBL: 20.7; 20.5.1; 4.1.1; 4.1.3; 8.1.


Thun der, James M. Quiet killings in medical facilities: detection and prevention. *Issues in Law and Medicine* 2003 Spring; 18(3): 211-237. NRCBL: 20.7; 20.5.1; 20.2.1; 1.3.5; 9.5.2. SC: le.


**ATTITUDES TO DEATH** See DEATH AND DYING/ATTITUDES TO DEATH

**BEHAVIOR CONTROL**

See also CARE FOR SPECIFIC GROUPS/MENTALLY DISABLED; ELECTROCONVULSIVE THERAPY; INVOLUNTARY COMMITMENT; MENTAL HEALTH THERAPIES; PSYCHOPHARMACOLOGY; PSYCHOTHERAPY


Donovan, Abigail; Plant, Robert; Peller, Allyson; Siegel, Lesley; Martin, Andrés. Two-year trends in the use of seclusion and restraint among psychiatrically hospitalized youths. *Psychiatric Services* 2003 July; 54(7): 987-993. NRCBL: 17.3; 9.5.7; 17.7.

Donovan, Abigail; Siegel, Leslie; Zera, Gary; Plant, Robert; Martin, Andrés. Seclusion and restraint reform: an initiative by a child and adolescent psychiatric hospital. *Psychiatric Services* 2003 July; 54(7): 958-959. NRCBL: 17.3; 9.5.7; 17.7.


Shapiro, Michael H.; Spece, Roy G.; Dresser, Rebecca; Clayton, Ellen Wright. Control of mind and behavior: selected problems. In: their: Cases, Materials and Problems on Bioethics and Law. 2nd ed. St. Paul, MN: Thomson/West; 2003: 317-540. NRCBL: 17.3; 8.3.3; 8.3.4. SC: le.


BEHAVIORAL GENETICS


DeCamp, Matthew; Sugarman, Jeremy. Ethics in behavioral genetics research. Accountability in Research 2004 January-March; 11(1): 27-47. NRCBL: 15.6; 18.4; 18.2; 1.3.7. Abstract: As research in behavioral genetics uncovers the genetic contribution to human behavior, it will undoubtedly further our understanding of normal human variation in many behavioral traits, such as personality, intelligence, and sexuality. This research also shows great potential for the diagnosis, treatment, and prevention of mental illnesses. Recent findings underscore this potential and document the increasing validity of research methods — methods that in the past have led to mistaken inferences about genes “for” violent behavior and homosexuality. Although all research with human subjects requires adequate attention to its ethical aspects, certain ethical issues involved with behavioral genetics are particularly acute and deserve careful attention. This article reviews these selected major ethical issues arising in (1) the conduct of behavioral genetics research; and (2) the application of its research findings. While some of the ethical concerns in the latter category are likely to be of substantial importance and animate considerable popular concern, they currently fall outside the realm of traditional research review. Determining how to deal with these concerns should be a focus of future scholarly work.


Abstract: A short review is given of the Nuffield Council’s report on behavioural genetics. This review is used as an entry point to a discussion of the factors that influence the presentation of behavioural genetics in the media and in the popular scientific press. It is argued that our interest in formulating narrative explanations of our individual lives puts pressure on publishers and editors to present behavioural genetics in a selective, misleading way. Some other influences on presentation are discussed and it is suggested that the Nuffield report is particularly useful in so far as it lacks these distorting influences.


BEHAVIORAL RESEARCH
See also BIOMEDICAL RESEARCH


DePrince, Anne P.; Allard, Carolyn B.; Oh, Hannah; Freyd, Jennifer J. What’s in a name for memory errors? Implications and ethical issues arising from the use of the term “false memory” for errors in memory for details. Ethics and Behavior 2004; 14(3): 201-233. NRCBL: 18.4; 1.3.9; 17.1; 7.1. SC: em.


Flicker, Sarah; Haans, Dave; Skinner, Harvey. Ethical dilemmas in research on Internet communities. Qualitative Health Research 2004 January; 14(1): 124-134. NRCBL: 18.4; 1.3.12; 2.1.


BIOETHICS AND MEDICAL ETHICS
See also CODES OF ETHICS; NURSING ETHICS AND PHILOSOPHY; PROFESSIONAL ETHICS


Abstract: The American Society for Bioethics and Humanities debated for several years about whether it should adopt positions and, if so, on what range of issues. The membership recently approved an amendment to its bylaws permitting the Society to adopt positions on matters related to academic freedom and professionalism but not on substantive moral and policy issues. This resolution is problematic for a number of reasons, including the lack of a categorical difference between these types of claims and the Society’s inability to speak on behalf of patients and research subjects. The implementation of the amendment also raises several issues. The Society will need...
to refrain from speaking too specifically and to articulate the responsibilities of its members. If the Society fails to address these concerns, it runs the risk of denigrating its public image and that of the profession.

Antommaria, Armand H. Matheny. Do as I say, not as I do — why bioethicists should seek informed consent for some case studies. Hastings Center Report 2004 May-June; 34(3): 28-34. NRCBL: 2.1; 8.3.1; 8.4; 1.3.7. SC: cs.


Blackburn, Elizabeth. Bioethics and the political distortion of biomedical science [opinion]. New England Journal of Medicine 2004 April 1; 350(14): 1379-1380. NRCBL: 2.1; 1.3.5; 21.1; 5.3.

Blustein, Jeffrey; Fleischman, Alan R. Urban bioethics: adapting bioethics to the urban context. Academic Medicine 2004 December; 79(12): 1198-1202. NRCBL: 2.1; 21.7; 7.1; 16.1; 9.2; 9.5.4.


Abstract: The field of bioethics is increasingly coming into contact with empirical research findings. In this article, we ask what role empirical research can play in the process of ethical clarification and decision-making. Ethical reflection almost always proceeds in three steps: the description of the moral question, the assessment of the moral question and the evaluation of the decision-making. Empirical research can contribute to each step of this process. In the description of the moral object, first of all, empirical research has a role to play in the description of morally relevant facts. It plays a role in answering the “reality-revealing questions” (what, why, how, who, where and when), in assessing the consequences and in proposing alternative courses of action. Secondly, empirical research plays a role in assessing the moral question. It must be acknowledged that research possesses “the normative power of the factual,” which can also become normative by suppressing other norms. However, inductive normativity should always be balanced out by a deductive form of normativity. Thirdly, empirical research also has a role to play in evaluating the decision-making process. It can rule out certain moral choices by pointing out the occurrence of certain unexpected consequences or effects. It can also be useful, however, as a sociology of bioethics in which the discipline of bioethics itself becomes an object of research.


Curtis, Hilary; Parker, Michael J. Getting ethics into practice: Tuskegee was bad enough [letter and reply]. *BMJ: British Medical Journal* 2004 August 28; 329(7464): 513. NRCBL: 2.1.


Fangerau, H. Finding European bioethical literature: an evaluation of the leading abstracting and indexing services. *Journal of Medical Ethics* 2004 June; 30(3): 299-303. NRCBL: 2.1; 1.3.12. SC: em. Abstract: OBJECTIVES: In this study the author aimed to provide information for researchers to help them with the selection of suitable databases for finding medical ethics literature. The quantity of medical ethical literature that is indexed in different existing electronic bibliographies was ascertained. METHOD: Using the international journal index Ulrich’s Periodicals Directory, journals on medical ethics were identified. The electronic bibliographies indexing these journals were analysed. In an additional analysis documentalists indexing bioethical literature were asked to name European journals on medical ethics. The bibliographies indexing these journals were examined. RESULTS: Of 290 journals on medical ethics 173 were indexed in at least one bibliography. Current Contents showed the highest coverage with 66 (22.8%) journals indexed followed by MEDLINE (22.1%). By a combined search in the top ten bibliographies with the highest coverage, a maximum coverage of 45.2% of all journals could be reached. All the bibliographies showed a tendency to index more North American than European literature. This result was verified by the supplementary analysis of a sample of continental European journals. Here EMBASE covered the highest number of journals (20.6%) followed by the Russian Academy of Sciences Bibliographies (19.2%). CONCLUSION: A medical ethics literature search has to be carried out in several databases in order to reach an adequate collection of literature. The databases one wishes to combine should be carefully chosen. There seems to be a regional bias in the most popular databases, favouring North American periodicals compared with European literature on medical ethics.

Farmer, Paul; Campos, Nicole Gastineau. New malaise: bioethics and human rights in the global era. *Journal of...

Guyer, Ruth Levy; Moreno, Jonathan D. Slouching toward policy: lazy bioethics and the perils of science fiction. American Journal of Bioethics [Online]. 2004 Fall; 4(4): W14-W17. NRCBL: 2.1; 14.5; 20.5.1; 1.3.7; 14.1; 15.4; 5.3.

Abstract: Too much contemporary bioethical discourse is weak on science, lastly citing and adopting science fiction scenarios rather than science facts in the framing of analyses and policies. We challenge bioethicists to take more seriously the role of providing informed insight into and oversight over contemporary science and its implications and applications. Bioethicists must work harder to understand the fast-changing truths and limits of basic science, and they must incorporate only appropriate and authentic science into their discourse, just as they did in the past when addressing the quandaries of clinical medicine. The field of bioethics is not so old and entrenched that its future is assured. Bioethicists must make themselves useful to society in order to deserve and retain the public’s trust. They can best do this by ensuring that decision making and public policy are grounded in facts, not fictions and fantasies.


Holm, Soren; Harris, John. Free speech, democracy, and eugenics — attempts to stifle debate in medical ethics must be strongly resisted. Journal of Medical Ethics 2004 December; 30(6): 519. NRCBL: 2.1; 15.1; 15.5.


BIOETHICS AND MEDICAL ETHICS

SECTION I


Lane, Melissa. Bioethics, health, and inequality. Lancet 2004 September 18-24; 364(9439): 1017-1019. NRCBL: 2.1; 9.1; 21.1; 15.3; 14.3; 19.5; 9.3.1; 14.5.


Levitt, Mairi; Williams, Garrath. Thirty years of bioethics: all grown up now? New Review of Bioethics 2003 November; 1(1): 3-5. NRCBL: 2.1; 1.3.7.


Lysaught, M. Therese. Respect: or, how respect for persons became respect for autonomy. Journal of Medicine and Philosophy 2004 December; 29(6): 665-680. NRCBL: 2.1; 2.2; 2.4; 8.1; 18.1; 18.5.4. SC: an.

Abstract: This article provides an intellectual archeology of how the term “respect” has functioned in the field of bioethics. I argue that over time the function of the term has shifted, with a significant turning point occurring in 1979. Prior to 1979, the term “respect” connoted primarily the notion of “respect for persons” which functioned as an umbrella which conferred protection to autonomous persons and those with compromised autonomy. But in 1979, with the First Edition of Principles of Biomedical Ethics by Beauchamp and Childress, and the report of the Ethical Advisory Board (EAB) of the (then) Department of Health, Education, and Welfare entitled Research on In Vitro Fertilization, usage shifts from “respect for persons” to “respect for autonomy.” Two results: 1) those with compromised autonomy are no longer protected by the canons of “respect” but rather the less over-riding canons of beneficence; and 2) the term “respect” functions increasingly as a rhetorical device in public bioethics discourse.


McConnaughy, Scott A.; Bayley, Carol; Clark, Peter A.; Gallagher, John A.; Heyl, Jennifer; Tuohy, John F.; Carney, Chris; Finan, John Jr.; Statuto, Rich; Westhoff, Lola; Wolf, Laura. Who cares about ethics? Health Progress 2004 May-June; 85(3): 15-22. NRCBL: 2.1; 4.2; 1.3.2.


Abstract: The nature and limits of the physician’s professional responsibilities constitute core topics in clinical ethics. These responsibilities originate in the physician’s professional role, which was first examined in the modern English-language literature of medical ethics by two eighteenth-century British physician-ethicists, John Gregory and Thomas Percival. The papers in this annual clinical ethics number of the Journal explore the physician’s professional responsibilities in the areas of surgical ethics, matters of conscience, and managed care.


Abstract: Ethicists differ considerably in their reasons for using empirical data. This paper presents a brief overview of four traditional approaches to the use of empirical data: “the prescriptive applied ethicists,” “the theorists,” “the critical applied ethicists,” and “the particularists.” The main aim of this paper is to introduce a fifth approach of more recent date (i.e. “integrated empirical ethics”) and to offer some methodological directives for research in integrated empirical ethics. All five approaches are presented in a table for heuristic purposes. The table consists of eight columns: “view on distinction descriptive-prescriptive sciences,” “location of moral authority,” “central goal(s),” “types of normativity,” “use of empirical data,” “method,” “interaction empirical data and moral theory,” and

SC (Subject Caption): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
“cooperation with descriptive sciences.” Ethicists can use the table in order to identify their own approach. Reflection on these issues prior to starting research in empirical ethics should lead to harmonization of the different scientific disciplines and effective planning of the final research design. Integrated empirical ethics (IEE) refers to studies in which ethicists and descriptive scientists cooperate together continuously and intensively. Both disciplines try to integrate moral theory and empirical data in order to reach a normative conclusion with respect to a specific social practice. IEE is not wholly prescriptive or wholly descriptive since IEE assumes an interdependence between facts and values and between the empirical and the normative. The paper ends with three suggestions for consideration on some of the future challenges of integrated empirical ethics.


Abstract: In a recent issue of this Journal Kim Atkins argued that Thomas Nagel’s argument regarding a bat’s phenomenal experience is important for understanding the value placed on patient autonomy in medical ethics. In this reply to her paper, I demonstrate that Atkin’s argument (a) is based on her misinterpretations of Nagel’s argument, and (b) can be established without appealing to such a controversial assumption as that which she makes.

Nuffield Council on Bioethics. Nuffield Council on Bioethics 1992-99. London: Nuffield Council, 2000 December; 28 p. [ISBN: 0-9522701-7-X]. NRCBL: 2.1; 2.4; 15.3; 19.5; 19.1; 22.1; 17.1; 18.5.6; 15.2; 1.3.11; 8.3.1; 8.3.3; 8.3.2; 8.4.

Parker, Michael J. Getting ethics into practice: clinicians need to be able to analyse and justify their day to day value judgments [editorial]. *BMJ: British Medical Journal* 2004 July 17; 329(7458): 126. NRCBL: 2.1; 7.2; 9.6.


Abstract: Public intellectuals have long played a role in American culture, filling the gap between the academic elite and the educated public. According to some commentators, the role of the public intellectual has undergone a steady decline for the past several decades, being replaced by the academic expert. The most notable cause of this decline has been both the growth of the academy in the twentieth century, which has served to concentrate intellectual activity within its confines, and the changing nature of the media, which has framed the way in which information is conveyed to the public. We argue that although bioethics has developed primarily within the academic tradition and utilized the role of expert when dealing with the public, bioethicists are well suited to don the mantle of the public intellectual. Indeed, because they address issues in medicine and science of great relevance for the general public, bioethicists have a duty to revitalize the tradition of public intellectuals as a necessary complement to the important, but narrower role of expert.


Abstract: What is the status of empirical contributions to bioethics, especially to clinical bioethics? Where is the empirical approach discussed in bioethics related to the ongoing debate about principlism versus casuistry? Can we consider an integrative model of research in medical ethics and which empirical methodology could then be valuable, the quantitative or the qualitative? These issues will be addressed in the first, theoretical part of the paper. The concept of the “embedded researcher” presented in this article was stimulated by the two questions, (1) how can we safeguard that our research will yield valid and meaningful results to practice? and (2), how can we convince clinical colleagues that medical ethics offers relevant contributions to the analysis and solution of problems? One tentative answer has been our effort to elaborate a coherent methodological research approach in the field of end-of-life issues integrating qualitative and quantitative as well as casuistic methodologies. This development is characterized in the second part describing the ECOPE Study (short title “Ethical Conditions Of Passive Euthanasia.” The achievements and limitations of the suggested approach of the “embedded researcher” are discussed referring to 3 examples of our joint studies about ethical issues concerning (1) critical decision-making in neonatology (2) limitation of treatment in intensive care (3) problems with doctor-patient conversation at the end-of-life in oncology. Conclusions from our studies are put to discussion in the final part of the paper about how to further develop research in the field of end-of-life care and, maybe, clinical bioethics as a whole.

Rennie, John. Five ways to kill the biotech industry (and one to help it prosper). *CQ: Cambridge Quarterly of
Healthcare Ethics 2004 Spring; 13(2): 185-192. NRCBL: 2.1; 5.1; 5.3; 1.3.7.


Simpson, Christy. Challenges for health regions — meeting both rural and urban ethics needs: a Canadian perspective. HEC (Healthcare Ethics Committee) Forum 2004 December; 16(4): 219-221. NRCBL: 2.1; 9.1.


Abstract: In this paper I argue for the universality of morality as against and in spite of the plurality and inevitable relativity of human cultures. Universalisability is the litmus test of moral authenticity whereas culture tends to impose an egocentric predicament. I argue equally for the equality of cultures qua cultures and of the importance of different cultural perspectives, given the limitations of each and every particular culture, in a balanced and wholesome appreciation of moral issues, particularly issues of cross-cultural relevance. I then try to anchor my reflections on a few topical ethical issues of cross-cultural relevance which have been the subject of controversy in recent times.


Williams, John R. The promise and limits of international bioethics: lessons from the recent revision of the Declaration of Helsinki. Journal International de Bioethique / In-


BIOETHICS AND MEDICAL ETHICS/COMMISSIONS


Change the record [editorial]. Nature Biotechnology 2004 April; 22(4): 361. NRCBL: 2.4; 18.5.4; 14.5; 18.6.


Check, Erika. Bush sacks outspoken biologist from ethics council [news]. Nature 2004 March 4; 428(6978): 4. NRCBL: 2.4; 1.3.5. Identifiers: President’s Council on Bioethics; George Bush; Elizabeth Blackburn.


Doeffinger, Richard M. President’s Council on Bioethics: reproduction and responsibility. National Catholic Bioethics Quarterly 2004 Autumn; 4(3): 461-469. NRCBL: 2.4; 14.1; 14.4; 14.5; 18.5.4; 18.2.

Dresser, Rebecca; Blackburn, Elizabeth H. Bioethics, science, and politics [letter and reply]. New England Journal of Medicine 2004 July 15; 351(3): 298-300. NRCBL: 2.4; 18.5.4; 19.1; 19.5; 15.1.

Dzur, Albert W.; Levin, Daniel. The “nation’s conscience”: assessing bioethics commissions as public forums. Kennedy Institute of Ethics Journal 2004 December; 14(4): 333-360. NRCBL: 2.4; 2.2; 1.1; 7.1.


Holden, Constance. Researchers blast U.S. bioethics panel shuffle [news]. Science 2004 March 5; 303(5663): 1447. NRCBL: 2.4; 5.3. Identifiers: United States; Elizabeth Blackburn; William F. May.


International Colloquium of Catholic Bioethics Institutes. Globalization and the culture of life consensus statement. National Catholic Bioethics Quarterly 2004 Spring; 4(1): 151-158. NRCBL: 2.4; 21.1; 1.2; 9.5.2; 9.5.10; 20.4.1; 20.5.1; 20.7.


Keim, Brandon. Beyond politics — the strange saga of the President’s Council on Bioethics. *GeneWatch* 2004 May-June; 17(3): 6-10. NRCBL: 2.4; 18.5.4; 19.5; 15.1; 15.5; 4.4.


Saunders, Williams L. Washington Insider. *National Catholic Bioethics Quarterly* 2004 Winter; 4(4): 671-677. NRCBL: 2.4; 18.5.4; 1.3.9; 1.2; 14.5; 12.3; 12.4.4.


Taylor, Sandra D.; Otłowski, Margaret F.; Barlow-Stewart, Kristine K.; Treloar, Susan A.; Stranger, Mark; Chenoweth, Kellie. Investigating genetic discrimination in Australia: opportunities and challenges in the early stages. *New Genetics and Society* 2004 August; 23(2): 225-239. NRCBL: 2.4; 15.3; 9.1; 9.3.1; 16.3. SC: le.


Weed, Matthew. Ethics, regulation, and biomedical research. *Kennedy Institute of Ethics Journal* 2004 December; 14(4): 361-368. NRCBL: 2.4; 5.3; 1.3.9; 1.3.5.


BIOETHICS AND MEDICAL ETHICS/ EDUCATION

See also MEDICAL EDUCATION

Response from Dundee Medical Student Council to “media misinterpretation” [letter]. *Journal of Medical Ethics* 2004 August; 30(4): 380. NRCBL: 2.3; 1.3.3; 1.3.9. Identifiers: Scotland.


Ber, Rosalie; Grunfeld, Gershon B.; Alroy, Gideon. A multidisciplinary forum for ethics in medicine: our seven years experience. *Israel Medical Association Journal* 2000 December; 2(12): 954-956. NRCBL: 2.3; 7.2.

Bertolami, Charles N. Why our ethics curricula don’t work. *Journal of Dental Education* 2004 April; 68(4): 414-425. NRCBL: 2.3; 7.2; 4.1.1. SC: an.


Caplan, Arthur L. Power failure — how the President’s Council on Bioethics lost its credibility and what this
means for the future of ethical debate in America and Europe about advances in biomedicine. Unpublished Document 2004 May: 19 pages [published in Die Zeit 2004; (20) in German]. NRCBL: 2.3; 2.1; 5.3; 21.1. Identifiers: German title of the article is “Säuberung im Ethikrat”.


Fleetwood, Janet; Vaught, Wayne; Feldman, Debra; Gracely, Edward; Kassutto, Zach; Novack, Dennis. MedEthEx online: a computer-based learning program in medical ethics and communication skills. Teaching and Learning in Medicine 2000 Spring; 12(2): 96-104. NRCBL: 2.3; 1.3.12. SC: em.


Abstract: We study the decisions taken in five real cases by 178 doctors working in hospital emergency services and compare their decisions with those proposed a reference group composed of professionals with a master’s degree in bioethics. The findings of our study point to an increased ability to take difficult decisions in critical situations involving the use of life-support measures in the emergency room. The group of professionals chosen as “gold standard”, despite lacking the training and clinical preparation of emergency doctors, made decisions that were technically very close to the most suitable. In this respect, an adequate ethical training facilitated the taking of decisions that required the involvement of personally held values, underlining the need for such training in the case of professionals who will work in hospital emergency services.


Abstract: The unprecedented progress in bio-medical sciences and technology during the last few decades has resulted in great transformations in the concepts of health and disease, health systems and healthcare organisation and practices. Those changes have been accompanied by the emergence of a broad range of ethical dilemmas that confront health professionals more frequently. The classical Hippocratic ethical principles, though still retaining their relevance and validity, have become insufficiently adequate in an increasing range of problems and situations. Healthcare that has been practised for centuries on the basis of a direct doctor-patient relationship has been increasingly transformed into a more complex process integrating the health-team, the patient (healthcare seeker) and the community. Systematic review of the specialised literatures revealed that Healthcare Ethics education has become a basic requirement for any training programme for health professionals, and should cover the different stages of undergraduate, postgraduate and continuing education. Both theoretical foundations and practical skills are required for the appropriate ethical reasoning, ethical attitude and decision-making abilities. There is growing evidence that physicians’ professional and moral development is not only determined by the formal curriculum of ethics; rather more, it is determined by the moral environment of the professional practice, the ‘hidden curriculum’ which deserves serious consideration by medical education.


Ladas, Spiros D. 1(st) European symposium on ethics in gastroenterology and digestive endoscopy — Kos, Greece, 27-29 of June, 2002. Endoscopy 2002 September; 34(9): 759-763. NRCBL: 2.3; 8.3.1; 8.4; 9.5.2; 18.3. SC: em.


Abstract: Beginning with an exemplary case study, this paper diagnoses and analyses some important strategies of evasion and factors of hindrance that are met in the teaching of medical ethics to undergraduate medical students. Some of these inhibitions are inherent to ethical theories; others are connected with the nature of medicine or cultural trends. It is argued that in order to avoid an attitude of evasion in medical ethics teaching, a philosophical theory of emotions is needed that is able to clarify on a conceptual level the ethical importance of emotions. An
approach is proposed with the help of the emotion theory Martha Nussbaum works out in her book Upheavals of Thought. The paper ends with some practical recommendations.


Roff, S.; Preece, P. Helping medical students to find their moral compasses: ethics teaching for second and third year undergraduates. Journal of Medical Ethics 2004 October; 30(5): 487-489. NRCBL: 2.3; 7.2.

Abstract: The paper describes a two week course that has been offered as a special study module to intermediate level (second and third year) undergraduate medical students at Dundee University Medical School for the past five years. The course requires students to research the various aspects of ethical dilemmas that they have identified themselves, and to “teach” these issues to their colleagues in a short PowerPoint presentation as well as to prepare an extended 3000 word essay discussion. The course specifically asks students not to disclose their own ethical positions, as these are probably still in formation and the objective is to promote critical thinking capacity in ethical and moral issues as a prelude to the development of practical skills in dealing with clinical problems. The course is easy to resource for the school and has received universally high evaluations from the students since its inception.


Smith, Morton E. A structured curriculum on ethics for ophthalmology residents is not valuable. Archives of Ophthalmology 2002 July; 120(7): 965. NRCBL: 2.3; 7.2.


Wayne, Diane B.; Muir, J. Cameron; DaRosa, Debra A. Developing an ethics curriculum for an internal medicine residency program: use of a needs assessment. Teaching and Learning in Medicine 2004 Spring; 16(2): 197-201. NRCBL: 2.3; 7.2. SC: cs; em.


Baker, Robert. The co-evolution of bioethics, computing and cyberspace: an archaeological perspective. *API Newsletters* 2002 Spring; 01(2 Revised): 13-18. NRCBL: 2.2; 1.3.12; 2.3.


Abstract: The Newman programs established at secular colleges and universities provided an opportunity for intellectual, spiritual, and social growth among the Catholic student population. As a young physician and junior medical faculty member, Andre Hellegers took part in the early organization and ongoing work of Carroll House, the Newman Center at the Johns Hopkins Medical Institutions. Hellegers’ experience at Carroll House enabled him to develop a clear blueprint of an academic center of excellence for the scientific, theological, and philosophical exploration of the many problems that he had seen and foresaw in medicine. That center would become Georgetown’s Kennedy Institute of Ethics.


Moreno, Jonathan D. Bioethics and the national security state. Journal of Law, Medicine and Ethics 2004 Summer; 32(2): 198-208. NRCBL: 2.2; 21.2; 18.3; 18.5.8; 21.3; 16.2.


**BIOETHICS AND MEDICAL ETHICS/LEGAL ASPECTS**


Elkin, Sandy. Bioethics commentary [opinion]. *New Zealand Bioethics Journal* 2004 February; 5(1): 4-8. NRCBL: 2.1; 9.5.5; 8.4; 20.5.1; 14.1; 2.4. SC: le.

English, Veronica; Mussell, Rebecca; Sheather, Julian; Sommerville, Ann. Ethics briefings. *Journal of Medical Ethics* 2004 February; 30(1): 117-118. NRCBL: 2.1; 9.5.6; 9.1; 12.4.1; 14.1. SC: le.


Schneider, Carl E. Benumbed. Hastings Center Report 2004 January-February; 34(1): 9-10. NRCBL: 2.1; 1.3.5; 1.1; 17.1; 8.3.1; 8.3.4. SC: le.


Taylor, Sandra D.; Otłowski, Margaret F.; Barlow-Stewart, Kristine K.; Treloar, Susan A.; Stranger, Mark; Chenoweth, Kellie. Investigating genetic discrimination in Australia: opportunities and challenges in the early stages. New Genetics and Society 2004 August; 23(2): 225-239. NRCBL: 2.4; 15.3; 9.1; 9.3.1; 16.3. SC: le.


BIOETHICS AND MEDICAL ETHICS/ PHILOSOPHICAL PERSPECTIVES


Almond, Brenda. Setting bioethics in context. Journal of Applied Philosophy 1999; 16(3): 297-299. NRCBL: 2.1; 1.1; 14.1; 10; 7.1; 12.1; 20.5.1; 20.7.


Belkin, Gary S. Moving beyond bioethics: history and the search for medical humanism. Perspectives in Biology and Medicine 2004 Summer; 47(3): 372-385. NRCBL: 2.1; 4.1.2; 1.1; 7.1.


Abstract: This paper examines the Japanese notion of relationality, that is, the idea that the individual is defined primarily within a web of relationships. Furthermore, it proposes that this relationality provides an ontological basis for morality, particularly the critical need for achieving consensus. This need for consensus is evident in the dispute over brain death. It was also conspicuous in the long-standing debate regarding heart transplantation. By reviewing key features of relationality, the study also demonstrates that the Japanese approach toward consensus reflects certain cultural values such as the importance of nemawashi. This inquiry thereby evokes the brain death and heart transplantation controversy in order to illustrate the critical need for consensus in the decision-making process.


Engelhardt, H. Tristram, Jr. Moral philosophy and theology: why is there so little difference for Roman Catholics? *Christian Bioethics* 2003 August-December; 9(2-3): 315-329. NRCBL: 2.1; 1.2; 7.1; 1.1; 20.7; 20.5.1; 8.1.

Abstract: The cardinal question in Christian moral theory and bioethics is whether the knowledge that Christians have (1) by grace and (2) by revelation (e.g., regarding the character of human and cosmic history as reaching from creation through the Incarnation and the Redemption to the Second Coming and the restoration of all things) makes a crucial contribution to understanding morality, as for example issues such as the good death and the morality of physician-assisted suicide and euthanasia. This article argues that such a contribution is made by grace and revelation. The reduction of Roman Catholic moral theology and bioethics to secular bioethics is explored, as well as the necessity of the unique knowledge possessed by Christians for adequate end-of-life decision-making.


Gross, Michael L. Speaking in one voice or many? The language of community. *CQ: Cambridge Quarterly of Healthcare Ethics* 2004 Winter; 13(1): 28-33. NRCBL: 2.1; 1.3.1; 1.1; 21.5; 4.1.2; 21.7; 21.1.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms.


Abstract: The term “community” in ethics and bioethics traditionally has been used to designate either a specific kind of moral relationship available to rational agents or, in contrast, the context in which any sense of rational agency can even be understood. I argue that bioethics is better served when both “selves” and “community” are expressed through a more processive language that highlights the functional character of such concepts. In particular, I see the turn to “processive” community in bioethics as a turn towards method, contextualization, and narrative. In clinical practice, such a processive account demands that bioethics concentrate on methods of developing healthy dialogue and deeper understanding from within the problematic situation rather than trying to “fix” problems using ethical tools developed from outside the present situation. “Community,” I argue, is in and of the interactive processes of inquiry itself. Such inquiry, such “communiting,” requires that we engage individual patients in context; it demands more than simply gaining their permission or mere consent; it demands developing a supportive environment for participation.


Holm, Søren. If you have said A, you must also say B: is this always true? *CQ: Cambridge Quarterly of Healthcare Ethics* 2004 Spring; 13(2): 179-184. NRCBL: 2.1; 1.1. Identifiers: Charity.


Malm, Heidi. “Do this, it could save your life!” and other problematic claims in preventive medicine. *APA Newsletters* 2002 Spring; 01(2 Revised): 3-9. NRCBL: 2.1; 1.1; 9.1; 15.2; 5.2.

Merry, Michael S. Libertarian bioethics and religion: the case of H. Tristram Engelhardt, Jr. Bioethics 2004 September; 18(5): 387-407. NRCBL: 2.1; 1.1; 1.3.5; 1.2.

Abstract: This paper is a critique of certain moral perspectives that are found in the second edition of Engelhardt’s Foundation of Bioethics. These views are spelled out in explicit detail in his second edition, and follow on the heels of a profound religious conversion. Engelhardt is an eminent bioethicist with strong religious convictions that overlay much of his writing. The author wishes to question some of the conclusions that Engelhardt reaches as they touch upon moral frameworks, pluralism, and a ‘secular’ bioethics.


Orr, Robert D. Beyond justice. Bioethics Forum 1999 Summer; 15(2): 5-10. NRCBL: 2.1; 1.1; 4.1.2.

Reeves, Diane. Virtue ethics cannot be the answer! A reply to Peter Toon. British Journal of Medical Practice 2002 November; 52(484): 960-961. NRCBL: 2.1; 1.1; 8.3.1.


Schneider, Carl E. Benumbed. Hastings Center Report 2004 January-February; 34(1): 9-10. NRCBL: 2.1; 1.3.5; 1.1; 17.1; 8.3.1; 8.3.4. SC: te.


Solbakk, Jan Helge. Therapeutic doubt and moral dialogue. Journal of Medicine and Philosophy 2004 February; 29(1): 93-118. NRCBL: 2.1; 1.1. SC: an. Abstract: This paper aims at analysing the problem of remainder and regret in moral conflicts. Four different approaches are subject of investigation: a moral-theoretical strategy aimed at consistency; a narrative approach of moral coherence and open consensus; Plato’s moral methodology of dialogue and aporetic resolution of moral conflicts and finally, an approach deduced from Greek tragedy of emotional resolution of moral conflicts. A central argument is that since there exists no theoretically convincing way of solving the problem of remainder and regret, the attention should instead be directed towards finding alternative ways of coping with this problem. The three last approaches subject of investigation attempt—each in their own way—to do this. Teaching medical ethics to medical students and the burning issue of medical fallibility is used to demonstrate the relevance of these forms of resolution in a medical context.


Turner, Leigh. Bioethics in pluralistic societies. Medicine, Health Care and Philosophy: A European Journal 2004; 7(2): 201-208. NRCBL: 2.1; 21.7; 1.1. Abstract: Contemporary liberal democracies contain multiple cultural, religious, and philosophical traditions. Within these societies, different interpretive communities provide divergent
models for understanding health, illness, and moral obligations. Bioethicists commonly draw upon models of moral reasoning that presume the existence of shared moral intuitions. Principist bioethics, case-based models of moral deliberation, intuitionist frameworks, and cost-benefit analyses all emphasise the uniformity of moral reasoning. However, religious and cultural differences challenge assumptions about common modes of moral deliberation. Too often, bioethicists minimize or ignore the existence of multiple traditions of moral inquiry. Careful consideration of the presence of multiple horizons for moral deliberation generates challenging questions about the capacity of bioethicists to effectively resolve complex cases and social policy disputes.


van der Scheer, Lieke; Widdershoven, Guy. Integrated empirical ethics: loss of normativity? Medicine, Health Care and Philosophy: A European Journal 2004; 7(1): 71-79. NRCBL: 2.1; 1.1; 17.1; 8.3.4. SC: an; em. Abstract: An important discussion in contemporary ethics concerns the relevance of empirical research for ethics. Specifically, two crucial questions pertain, respectively, to the possibility of inferring normative statements from descriptive statements, and to the danger of a loss of normativity if normative statements should be based on empirical research. Here we take part in the debate and defend integrated empirical ethical research: research in which normative guidelines are established on the basis of empirical research and in which the guidelines are empirically evaluated by focusing on observable consequences. We argue that in our concrete example normative statements are not derived from descriptive statements, but are developed within a process of reflection and dialogue that goes on within a specific praxis. Moreover, we show that the distinction in experience between the desirable and the undesirable precludes relativism. The normative guidelines so developed are both critical and normative: they help in choosing the right action and in evaluating that action. Finally, following Aristotle, we plead for a return to the view that morality and ethics are inherently related to one another, and for an acknowledgment of the fact that moral judgments have their origin in experience which is always related to historical and cultural circumstances.


BIOETHICS AND MEDICAL ETHICS/ RELIGIOUS PERSPECTIVES


Cahill, Lisa Sowle. Realigning Catholic priorities: bioethics and the common good. America 2004 September 13; 191(6): 11-13. NRCBL: 2.1; 1.2; 12.2; 12.3; 18.5.4; 4.4.


Engelhardt, H. Tristram, Jr. Moral philosophy and theology: why is there so little difference for Roman Catholics? Christian Bioethics 2003 August-December; (9-2-3): 315-329. NRCBL: 2.1; 1.2; 7.1; 1.1; 20.7; 20.5.1; 8.1. Abstract: The cardinal question in Christian moral theory and bioethics is whether the knowledge that Christians have (1) by grace and (2) by revelation (e.g., regarding the character of human and cosmic history as reaching from creation through the Incarnation and the Redemption to the Second Coming and the restoration of all things) makes a crucial contribution to understanding morality, as for example issues such as the good death and the morality of physician-assisted suicide and euthanasia. This article argues that such a contribution is made by grace and revelation. The reduction of Roman Catholic moral theology and bioethics to secular bioethics is explored, as well as the necessity of the unique knowledge possessed by Christians for adequate end-of-life decision-making.


International Colloquium of Catholic Bioethics Institutes. Globalization and the culture of life consensus statement. National Catholic Bioethics Quarterly 2004 Spring; 4(1): 151-158. NRCBL: 2.4; 21.1; 1.2; 9.5.2; 9.5.10; 20.4.1; 20.5.1; 20.7.


Merry, Michael S. Libertarian bioethics and religion: the case of H. Tristram Engelhardt, Jr. Bioethics 2004 September; 18(5): 387-407. NRCBL: 2.1; 1.1; 1.3.5; 1.2. 
Abstract: This paper is a critique of certain moral perspectives that are found in the second edition of Engelhardt’s Foundation of Bioethics. These views are spelled out in explicit detail in his second edition, and follow on the heels of a profound religious conversion. Engelhardt is an eminent bioethicist with strong religious convictions that overlay much of his writing. The author wishes to question some of the conclusions that Engelhardt reaches as they touch upon moral frameworks, pluralism, and a ‘secular’ bioethics.


Orr, Robert D. Personal and professional integrity in clinical medicine. Update: Loma Linda University Center for Christian Bioethics 1992 December; 8(4): 1-7. NRCBL: 2.3; 7.2; 8.1; 1.2.


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Ryan, Maura A. Beyond a western bioethics? Theological Studies 2004 March; 65(1): 158-177. NRCBL: 2.1; 1.2; 9.1; 9.5.6; 15.10; 21.1.


Weingarten, Michael. Jewish medical ethics and halakah [editorial]. Israel Medical Association Journal 2002 September; 4(9): 725-726. NRCBL: 2.1; 1.2; 8.2; 8.1.


BIOLOGICAL WARFARE See WAR AND TERRORISM

BIOMEDICAL RESEARCH

See also BEHAVIORAL RESEARCH; HUMAN EXPERIMENTATION/GENETIC RESEARCH


Bucchi, Massimino; Nerini, Federico. Why are people hostile to biotechnologies? Science 2004 June 18; 304(5678): 1749. NRCBL: 5.1; 21.1; 1.3.7. SC: em.


Daly, Bernard M. Transhumanism: toward a brave new world? America 2004 October 25; 191(12): 18-20. NRCBL: 5.1; 5.3; 11.1; 12.4.4.

Dyer, Clare. Human Tissue Bill is modified because of research needs [news]. BMJ: British Medical Journal 2004 June 26; 328(7545): 1518. NRCBL: 5.1; 19.5; 8.4.

Elam, Mark. Contemporary science communication as a world of political invention. Science as Culture 2004 June; 13(2): 229-258. NRCBL: 5.2; 4.4; 9.4.


Gold, E. Richard; Adams, Wen; Castle, David; Cleret de Langavant, Ghislaine; Cloutier, L. Martin; Daar, Abdallah S.; Glass, Amy; Smith, Pamela J.; Bernier, Louise. The unexamined assumptions of intellectual property — adopting an evaluative approach to patenting biotechnological innovation. Public Affairs Quarterly 2004 October; 18(4): 299-344. NRCBL: 5.1; 5.3; 13.9; 15.8; 11. SC: an; le.


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Vossenkuhl, W. Knowledge matters. Acta Neurochirurgica 2004 Supplement; 89: 3-7. NRCBL: 5.1; 5.2.


Welsh, S.; Hassiotis, A.; O’Mahoney, G.; Deahl, M. Big brother is watching you — the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties. Aging and Mental Health 2003 September; 7(5): 372-375. NRCBL: 5.1; 8.4; 9.5.2; 9.5.3.

BIOMEDICAL RESEARCH/ RESEARCH ETHICS AND SCIENTIFIC MISCONDUCT

See also MISCONDUCT

All above board: openness is the only option if science is to maintain its integrity [editorial]. New Scientist 2004 March 6-12; 181(2437): 3. NRCBL: 1.3.9.

Conflicts at the NIH (cont.) [editorial]. Nature 2004 July 1; 430(6995): 1. NRCBL: 1.3.9; 1.3.5. Identifiers: National Institutes of Health.


Going public: should scientists let the public help them decide how government research funds are spent? Yes they should, because the consequences are to be welcomed, not feared [editorial]. Nature 2004 October 21; 431(7011): 883. NRCBL: 1.3.9; 15.1.

How, where, and when should trial data be reported? [editorial]. Lancet 2004 November 13-19; 364(9447): 1730. NRCBL: 1.3.9; 1.3.7.

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Ashar, Bimal H.; Miller, Redonda G.; Getz, Kelly J.; Powe, Neil R. Prevalence and determinants of physician participation in conducting pharmaceutical-sponsored


Baylis, Françoise. Response to Mary Rowell [opinion]. *Journal of Medical Ethics* 2004 February; 30(1): 51-52. NRCBL: 1.3.9; 9.6; 7.3; 18.2.

Baylis, Françoise. The Olivieri debacle: where were the heroes of bioethics? *Journal of Medical Ethics* 2004 February; 30(1): 44-49. NRCBL: 1.3.9; 9.6; 7.3; 2.1; 18.2.

Abstract: All Canadian bioethicists need to reflect on the meaning and value of their work, to see more clearly how the ethics of bioethics is being undermined from within. In the case involving Dr. Olivieri, the Hospital for Sick Children, the University of Toronto, and Apotex Inc, there were countless opportunities for bioethical heroism. And yet, no bioethics heroes emerged from this case. Much has been written about the hospital’s and the university’s failures in this case. But what about the deafening silence from the Canadian bioethics community? Given the duty of bioethicists to “speak truth to power”, this silence is troubling. To date, nothing has been written about the silence. This article is intended as a partial remedy. As well, the article pays tribute to heretofore unsung heroes among Dr. Olivieri’s research colleagues.

Bell, Jeffrey G.; Brady, Mark; Copeland, Larry J. The ethics of reporting and disseminating results of clinical research trials. *Cancer* 2004 March 15; 100(6): 1107-1109. NRCBL: 1.3.9; 18.6.


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Boyd, Elizabeth A.; Lipton, Shira; Bero, Lisa A. Implementation of financial disclosure policies to manage conflicts of interest: how seven University of California campuses deal with their research relationships. *Health Af-

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms. 65
articles with protocols, 62% of trials had at least 1 primary outcome that was changed, introduced, or omitted. Eighty-six percent of survey responders (42/49) denied the existence of unreported outcomes despite clear evidence to the contrary.

CONCLUSIONS: The reporting of trial outcomes is not only frequently incomplete but also biased and inconsistent with protocols. Published articles, as well as reviews that incorporate them, may therefore be unreliable and overestimate the benefits of an intervention. To ensure transparency, planned trials should be registered and protocols should be made publicly available prior to trial completion.


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Clamon, Joseph B. The search for a cure: combating the problem of conflicts of interest that currently plagues biomedical research. Iowa Law Review 2003 October; 89(1): 235-271. NRCBL: 1.3.9; 7.3.


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Dayton, Leigh. Hall found guilty of lesser misconduct [news]. Science 2004 January 16; 303(5656): 298. NRCBL: 1.3.9; 1.3.7; 5.1. Identifiers: University of New South Wales (UNSW); Bruce Hall.


Drazen, Jeffrey M.; Curfman, Gregory D. Public access to biomedical research [editorial]. New England Journal of Medicine 2004 September 23; 351(13): 1343. NRCBL: 1.3.9; 1.3.7; 1.3.12; 18.2; 5.1.

DuBois, James M. Is compliance a professional virtue of researchers? Reflections on promoting the responsible conduct of research. Ethics and Behavior 2004; 14(4): 383-395. NRCBL: 1.3.9; 1.3.1; 18.2.

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Eisenberg, Rebecca S.; Nelson, Richard R. Public vs. proprietary science: a fruitful tension? Academic Medicine 2002 December; 77(12, part 2): 1392-1399. NRCBL: 1.3.9; 5.3; 15.8; 7.1.

Faunce, T.; Bolsin, S.; Chan, W.-P. Supporting whistleblowers in academic medicine: training and respecting the courage of professional conscience. Journal of Medical Ethics 2004 February; 30(1): 40-43. NRCBL: 1.3.9; 7.2; 7.3.

Abstract: Conflicts between the ethical values of an organisation and the ethical values of the employees of that organisation can often lead to conflict. When the ethical values of the employee are considerably higher than those of the organisation the potential for catastrophic results is enormous. In recent years several high profile cases have exposed organisations with ethical weaknesses. Academic medical institutions have exhibited such weaknesses and when exposed their employees have almost invariably been vindicated by objective inquiry. The mechanisms that work to produce such low ethical standards in what should be exemplary organisations are well documented and have been highlighted recently. The contribution of elements of medical training in eroding ethical standards of medical students have also been emphasised recently and strategies proposed to reduce or reverse this process. The ability to rapidly change the ethical and professional culture of graduate
medical trainees may help to deal with some of the perceived problems of declining ethical standards in academic medicine.


Abstract: The Toronto experience suggests that there may be several general lessons for academic health sciences complexes to learn from the Olivieri/Apotex affair (OAA) regarding the ethics, independence, and integrity of clinical research sponsored by for profit enterprises. From a local perspective, the OAA occurred when there already was a focus on the complex and changing relationships among the University of Toronto, its medical school, the fully affiliated teaching hospitals, and off campus faculty because of intertwined interests and responsibilities. The OAA became a catalyst that accelerated various systemic reforms, particularly concerning academic/industry relations. In this article, the evolving governance framework for the Toronto academic health sciences complex is reviewed and these policy and process reforms discussed. These reforms have created collaborative activity among research ethics boards and contract research offices of the partner institutions, and allowed the joint university/hospital ethics centre to play a role in governance and policy, while respecting the missions and mandates of the involved institutions. Although few of the policies are dramatically innovative, what is arguably novel is the elaboration of an overarching governance framework that aims to move ethics to a central focus in the academic complex. Time alone will tell how sustainable and effective these changes are.

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**Gould, Paula.** Creative Commons ponders share options [news]. Nature 2004 November 11; 432(7014): 137. NRCBL: 1.3.9; 5.3.


**Hensley, Scott; Abboud, Leila.** Medical research has ‘Black Hole’: negative results often fail to get published in journals; some blame drug industry. Wall Street Journal 2004 June 4; 243(109): p. B3. NRCBL: 1.3.9; 1.3.7; 9.7. SC: po.

**Holmes, David R., Jr.; Firth, Brian G.; James, Astrid; Winslow, Ron; Hodgson, Patricia K.; Gamble, Gail L.; Popp, Richard L.; Harrington, Robert A.** Conflict of interest. American Heart Journal 2004 February; 147(2): 228-237. NRCBL: 1.3.9; 1.3.7; 7.3; 5.3; 9.3.1; 9.7.


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**Jobanputra, Paresh.** Structural and symptomatic efficacy of glucosamine and chondroitin: relevant financial interest? Archives of Internal Medicine 2004 February 9; 164(3): 338-339. NRCBL: 1.3.9; 9.7; 1.3.7.


**Kaiser, Jocelyn.** House committee slams NIH’s plan on consulting [news]. Science 2004 May 21; 304(5674): 1091. NRCBL: 1.3.9; 5.3. Identifiers: National Institutes of Health.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.


Krisberg, Kim. New NIH panel to examine possible conflicts of interest [news]. *Nation's Health* 2004 March; 34(2): 7. NRCBL: 1.3.9; 7.3.


Leo, Jonathan. Multiple comparisons in drug efficacy studies: scientific or marketing principles? [editorial]. *Ethical Human Psychology and Psychiatry* 2004 Spring; 6(1): 3-6. NRCBL: 1.3.9; 9.7; 18.4; 18.5.2; 18.5.1.


Lowe, Gordon D.O.; Murray, Gordon D.; Finlayson, Niall D. Britain's failure to tackle research misconduct: UK bodies are now working together to set up panel on misconduct [letter]. *BMJ: British Medical Journal* 2004 January 24; 328(7433): 229-230. NRCBL: 1.3.9.


Abstract: CIOMS has been criticised for not adequately consulting stakeholders about its revised ethical guidelines regarding medical research. Political and logistical issues that arise in democratic processes and open exchange of information probably contributed to this exclusion. What might CIOMS have done to be more inclusive and attain broader consensus on its proposed revisions? Consensus is dynamic, and evolves as a community digests new information and perspectives. Engaging the public (and particularly the stakeholders) in discussion about the revisions would have generated broader consensus.

SC (Subject Caption): an=analytical cs=case studies em=empirical le=legal po=popular rv=review

Remuzzi, Giuseppe; Schieppati, Arrigo; Boissel, Jean-Pierre; Garattini, Silvio; Horton, Richard. Independent clinical research in Europe [opinion]. *Lancet* 2004 November 6-12; 364(9446): 1723-1726. NRCBL: 1.3.9; 5.3; 9.7; 9.3.1; 21.1.


Abstract: According to some estimates, less than 10% of the world’s biomedical research funds are dedicated to addressing problems that are responsible for 90% of the world’s burden of disease. This paper explains why this disparity exists and what should be done about it. It argues that the disparity exists because: 1) multinational pharmaceutical and biotechnology companies do not regard research and development investments on the health problems of developing nations to be economically lucrative; and 2) governmental agencies that sponsor biomedical research face little political pressure to allocate funds for the problems of developing nations. This paper argues that developed nations have an obligation to address disparities related to biomedical research funding. To facilitate this effort, developed countries should establish a trust fund dedicated to research on the health problems of developing nations similar to the Global AIDS Fund.


Abstract: Although medical centres have established boards, special committees, and offices for the review and redress of breaches in ethical behaviour, these mechanisms repeatedly prove themselves ineffective in addressing research misconduct within the institutions of academic medicine. As the authors see it, institutional design: (1) systematically ignores serious ethical problems, (2) makes whistleblowers into institutional enemies and punishes them, and (3) thereby fails to provide an ethical environment. The authors present and discuss cases of academic medicine failing to address unethical behaviour in academic science and, thereby, illustrate the scope and seriousness of the problem. The Olivieri/Apotex affair is just another instance of academic medicine’s dereliction in a case of scientific fraud and misconduct. Instead of vigorously supporting their facially member in her efforts to honestly communicate her findings and to protect patients from the risks associated with the use of the study drug, the University of Toronto collaborated with the Apotex company’s “stalling tactics,” closed down Dr Olivieri’s laboratory, harassed her, and ultimately dismissed her. The authors argue that the incentives for addressing problematic behaviour have to be revised in order to effect a change in the current pattern of response that occurs in academic medicine. An externally imposed realignment of incentives could convert the perception of the whistleblower, from their present caste as the enemy within, into a new position, as valued friend of the institution. The authors explain how such a correction could encourage appropriate reactions to scientific misconduct from academic medicine.

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Rowell, Mary. The Olivieri debacle: where were the heroes of bioethics? A reply [opinion]. *Journal of Medical Ethics* 2004 February; 30(1): 50. NRCBL: 1.3.9; 9.6; 7.3; 18.2.

Sade, Robert M.; McKneally, Martin. Responsibilities of investigators [editorial]. *Journal of Thoracic and Cardiovascular Surgery* 2002 May; 123(5): 837-838. NRCBL: 1.3.9; 1.3.7; 5.3.

Savla, Ushma. When did everyone become so naughty? [editorial]. *Journal of Clinical Investigation* 2004 April; 113(8): 1072. NRCBL: 1.3.9; 1.3.7.


Abstract: No discussion of academic freedom, research integrity, and patient safety could begin with a more disquieting pair of case studies than those of Nancy Olivieri and David Healy. The cumulative impact of the Olivieri and Healy affairs has caused serious self examination within the biomedical research community. The first part of the essay analyses these recent academic scandals. The two case studies are then placed in their historical context—context being the transformation of the norms of science through increasingly close ties between research universities and the corporate world. After a literature survey of the ways in which corporate sponsorship has biased the results of clinical drug trials, two different strategies to mitigate this problem are identified and assessed: a regulatory approach, which focuses on managing risks associated with industry funding of university research, and a more radical approach, the sequestration thesis, which counsels the outright elimination of corporate sponsorship. The reformist approach is criticised and the radical approach defended.

Schülenk, Udo. Professional responsibilities of biomedical scientists in public discourse. *Journal of Medical Ethics* 2004 February; 30(1): 53-60. NRCBL: 1.3.9; 9.5.6; 5.1; 7.3; 21.1.

Abstract: This article describes how a small but vocal group of biomedical scientists propagates the views that either HIV is not the cause of AIDS, or that it does not exist at all. When these views were rejected by mainstream science, this group took its views and arguments into the public domain, actively campaigning via newspapers, radio, and television to make its views known to the lay public. I describe some of the harmful consequences of the group’s activities, and ask two distinct ethical questions: what moral obligations do scientists who hold such minority views have with regard to a scientifically untrained lay audience, and what moral obligations do mainstream newspapers and government politicians have when it comes to such views. The latter question will be asked because the “dissidents” succeeded for a number of years in convincing the South African government of the soundness of their views. The consequences of their stance affected millions of HIV infected South Africans severely.


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BIOMEDICAL RESEARCH/ SOCIAL CONTROL OF SCIENCE AND TECHNOLOGY


**Amsden, Guy W.** Industry sponsorship in research and publishing: who is really to blame for perceived bias? [editorial]. *Annals of Pharmacotherapy* 2004 April; 38(4): 714-716. NRCBL: 5.3; 1.3.7; 1.3.9; 9.7.


**Benkler, Yochai.** Commons-based strategies and the problems of patents. *Science* 2004 August 20; 305(5687): 1110-1111. NRCBL: 5.3.


**Campbell, Eric G.; Moy, Beverly; Feibelmann, Sandra; Weissman, Joel S.; Blumenthal, David.** Institutional academic industry relationship: results of interviews with university leaders. *Accountability in Research* 2004 April-June; 11(2): 103-118. NRCBL: 5.3. SC: em.

**Check, Erika.** Universities fear repercussions as NIH tunes conflicts policy [news]. *Nature* 2004 October 14; 431(7010): 725. NRCBL: 5.3; 1.3.9. Identifiers: National Institutes of Health.

**Döring, Ole.** Chinese researchers promote biomedical regulations: what are the motives of the biopolitical dawn in China and where are they heading? *Kennedy Institute of Ethics Journal* 2004 March; 14(1): 39-46. NRCBL: 5.3; 18.5.4; 18.6; 14.4; 15.1. SC: le. Abstract: In the past five years, China has experienced increased efforts to regulate activities in biomedical research and practice. Background is provided on some of the key developments in Chinese bioethics especially in relation to genetics, stem cells, cloning, and reproductive medicine. This background sets the stage for a document entitled “Ethical Guidelines for Human Embryo Stem Cell Research,” proposed by the Bioethics Committee of the Southern China National Human Gene Research Center, Shanghai, which is reprinted in this volume of the Kennedy Institute of Ethics Journal.

**Doubleday, Robert.** Knowledge and the governance of biotechnology. *Notizie di Politeia* 2001; 17(62): 22-33. NRCBL: 5.3; 15.7; 5.2; 21.1. SC: an; le.

**Etzioni, Amitai.** Think global, act global. *New Scientist* 2004 September 11-17; 183(2464): 16. NRCBL: 5.3; 1.3.5; 21.1.

**Finland. National Advisory Board on Research Ethics (TENK); National Advisory Board on Health Care Ethics (ETENE); Cooperation Group for Laboratory Animal Sciences (KYTO); National Advisory Board for Biotechnology (BTNK); Board for Gene Technology (GTLK).** Ethical evaluation of research in Finland: Report. Helsinki: House Snellman, Ltd., 2002, 12 p. [Online]. Available: http://www.etene.org/dokumentit/EthicEval.pdf [29 December 2004]. NRCBL: 5.3; 18.2; 2.1; 22.2; 15.1.

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**Hughes, Greg; Ram Mohan, Sonali; Emanuel, Linda.** Corporate citizenship: managing relationships with professionals and government. *AIDS and Public Policy Journal* 2003 Winter; 18(3-4): 61-76. NRCBL: 5.3; 1.3.2; 9.5.6; 9.7; 7.1. SC: cs.


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Lemmens, Trudo. Piercing the veil of corporate secrecy about clinical trials. *Hastings Center Report* 2004 September-October; 34(5): 14-18. NRCBL: 5.3; 1.3.7; 1.3.12; 9.7.


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Mathews, Anna Wilde; Burton, Thomas M. After Medtronic lobbying push, the FDA had a change of heart: agency squelches an article raising doubts about safety of device to repair artery. Threat of “criminal sanction”. *Wall Street Journal* 2004 July 9; p. A1, A7. NRCBL: 5.3; 9.7. SC: po.


Mitrovetski, O.; Nicol, D.; Piper, T. Are patents for methods of medical treatment contrary to the *ordre public* and morality or “generally inconvenient”? [article and commentary]. *Journal of Medical Ethics* 2004 October; 30(5): 470-477. NRCBL: 5.3; 9.1. SC: an; le. Abstract: “No one has advanced a just and logical reason why reward for service to the public should be extended to the inventor of a mechanical toy and denied to the genius whose patience, foresight, and effort have given a valuable new [discovery] to mankind” (Katopis CJ. Patents v patents: policy implications of recent patent legislation. *St John’s Law Review* 1997;71:329).

The law around the world permits the granting of patents for drugs, medical devices, and cosmetic treatment of the human body. At the same time, patentability for a method of treatment of the same body is denied in some countries on various public policy grounds. Is there any logical justification for this distinction? Are methods of medical treatment not as vital to the health or even to the life of a patient as drugs or medical devices? Why is a cosmetic result patentable and a curative result not?

Norris, John W. Industry and academic medicine: a dangerous liaison? [editorial]. *Canadian Journal of Neurological Sciences* 2004 February; 31(1): 5-6. NRCBL: 5.3; 1.3.2; 9.7; 18.6.


Petsko, Gregory A. For the good of the state. *Genome Biology* 2003; 4(12): 121. NRCBL: 5.3; 1.3.9.

Prendergast, Mary M.; Abramovits, William; Boguniewicz, Mark; Lebwohl, Mark; Tokar, Michael; Tong, Kuo B. Look beyond financial conflicts of interest in evaluating industry-academia collaborations in burden-of-illness and outcomes research studies in dermatology. *Journal of Investigative Dermatology* 2004 September; 123(3): 452-454. NRCBL: 5.3; 9.5.1.


Abstract: This paper discusses the hazards of regulating controversial biomedical research in light of the emergence of powerful, multi-national biotechnology corporations. Prohibitions on the use of government funds can simply force controversial research into the private sphere, and unilateral or multilateral research bans can simply encourage multi-national companies to conduct research in countries that lack restrictive laws. Thus, a net effect of government regulation is that research migrates from the public to the private sphere. Because private research receives less oversight and external scrutiny than public research, it can threaten the welfare and rights of human subjects, scientific progress and openness, and the quality of the approval process for new biomedical technologies. In order to avoid the harmful effects of government regulation of biotechnology, society should promote meaningful discussion and dialogue among scientists, industry leaders, and the public before resorting to regulatory solutions. Legislative or executive initiatives should be applied with great discretion and care, and should be crafted in such a way that they protect public health and safety, promote scientific progress, and avoid the hazards of privatized research and polarized debates.


Abstract: More than half of the world’s population has no access to essential drugs. More than half of this group of people live in the poorest regions of Africa and Asia. Several factors determine the accessibility of drugs in developing countries. Hardy medicines for tropical diseases are being developed, but even existing drugs are often not available to the patients who need them. One of the important determinants of access to drugs is the working of the patent system. This paper first maps out some facts about the global patent regime that has emerged as a consequence of the conclusion of the WTO-TRIPS Agreement in 1994. Attempts to construct a moral justification of the patent system have been based on three grounds: natural rights, distributive justice, and utilitarian arguments. This paper examines to what extent and on which grounds drug patents can be justified. The final section looks at the so-called ‘Doha Declaration on the TRIPS Agreement and Public Health’, which was adopted by the WTO Ministerial Conference two years ago, recognising the primacy of public health over the interests of patent proprietors.


BIOMEDICAL TECHNOLOGIES See ORGAN AND TISSUE TRANSPLANTATION; REPRODUCTIVE TECHNOLOGIES

BLOOD DONATION AND TRANSFUSION

See also ORGAN AND TISSUE TRANSPLANTATION


Sugarman, Jeremy; Powers, Madison; Fleischman, Alan R. Unraveling the ethical issues in umbilical cord blood banking and use. Cancer Research Therapy and Control 1999; 8: 315-321. NRCBL: 19.4; 9.5.7; 19.1; 8.3.1.


CAPITAL PUNISHMENT


Boisabain, Eugene V.; Duarte, Alexander G.; Blair, Patricia; Stone, T. Howard. ‘Well enough to execute’: the health professional’s responsibility to the death row inmate. CorrectCare 2004 Fall; 18(4): 8. NRCBL: 20.6; 9.2; 9.8; 8.3.4; 1.3.5. SC: 1e.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.


Shaiwitz, Daniel S. Medicate-to-execute: current trends in death penalty jurisprudence and the perils of dual loyalty [comment]. *Journal of Health Care Law and Policy* 2004; 7(1): 149-174. NRCBL: 20.6; 4.1.2; 8.1; 7.3; 8.3.4; 17.4. SC: le.

**CARE FOR SPECIFIC GROUPS**

*See also OCCUPATIONAL HEALTH; TERMINAL CARE*

Barron, Bruce J.; Kim, E. Edmund. Ethical dilemmas in today’s nuclear medicine and radiology practice. *Journal of Nuclear Medicine* 2003 November; 44(11): 1818-1826. NRCBL: 9.5.1; 5.2; 5.3.


Bernstein, Joseph; Perlis, Clifford; Bartolozzi, Arthur R. Normative ethics in sports medicine. *Clinical Orthopaedics and Related Research* 2004 March; (420): 309-318. NRCBL: 9.5.1; 4.1.2; 8.4; 9.5.7. SC: cs; em.

Bernstein, Mark; Bampoe, Joseph. Surgical innovation or surgical evolution: an ethical and practical guide to handling novel neurosurgical procedures. *Journal of Neurosurgery* 2004 January; 100: 2-7. NRCBL: 9.5.1; 9.8; 18.2.

Bernstein, Mark; Hawryluck, Laura. Challenging belief and ethical concepts: the collateral damage of SARS [commentary]. *Critical Care* 2003; 7: 269-271. NRCBL: 9.5.1; 9.4; 9.8; 17.1; 7.1; 9.1. Identifiers: Severe Acute Respiratory Syndrome.


Brown, Phil; Mayer, Brian; Zavestoski, Stephen; Luebbe, Theo; Mandelbaum, Joshua; McCormick, Sabrina. The health politics of asthma: environmental justice and collective illness experience in the United States. *Social Science and Medicine* 2003 August; 57(3): 453-464. NRCBL: 9.5.1; 9.5.10; 18.1; 16.1; 21.1.


SECTION I

CARE FOR SPECIFIC GROUPS


Frank, Arthur W. Emily’s scars — surgical shapings, technoluxe, and bioethics. Hastings Center Report 2004 March-April; 34(2): 18-298. NRCBL: 9.5.1; 5.2; 6.9; 9.5.7; 2.1; 1.1. SC: an.


Gilligan, Timothy. When do we stop talking about curative care? Journal of Palliative Medicine 2004 June; 7(4): 657-660. NRCBL: 9.5.1; 4.2; 8.2; 8.1; 20.4.1.


Hagan, Pat. Falling on deaf ears. New Scientist 2004 August 28-September 3; 183(2462): 36-39. NRCBL: 9.5.1; 9.5.7; 15.1; 1.3.9.

Hamill, M.; McDonald, L.; Brook, G.; Murphy, S. Ethical and legal issues in caring for asylum seekers and refugees in the UK. Bulletin of Medical Ethics 2004 November; (203): 17-21. NRCBL: 9.5.1; 21.1; 9.5.6. Identifiers: Great Britain.


Hartmann, M.; Knoth, H.; Schulz, D.; Knoth, S. Industry-sponsored economic studies in oncology vs studies sponsored by nonprofit organisations. British Journal of Cancer 2003 October; 89(8): 1405-1408. NRCBL: 9.5.1; 7.3; 9.5.3; 1.3.2. SC: em. Identifiers:

Hayashi, Hideaki; Oppenheim, Edward Anthony. ALS patients on TPPV: totally locked-in state, neurologic findings and ethical implications. Neurology 2003 July 8; 61(1): 135-137. NRCBL: 9.5.1; 5.2. SC: em. Identifiers:
amyotrophic lateral sclerosis; tracheostomy positive pressure ventilation.


Hampstead NHS Trust. University College Medical School and the Royal Free.


Holm, Sooren. Irreversible bodily interventions in children [editorial]. *Journal of Medical Ethics* 2004 June; 30(3): 237. NRCBL: 9.5.1; 10; 9.5.5; 9.5.7; 21.7.


Horton, Richard. The lessons of MMR [opinion]. *Lancet* 2004 March 6; 363(9411): 747-749. NRCBL: 9.5.1; 9.7; 1.3.9; 18.5.2; 1.3.7; 9.1; 9.8; 9.1. Identifiers: Measles, mumps, and rubella (MMR); Andrew Wakefield.


Jones, James W.; McCullough, Laurence B.; Richman, Bruce W. The ethics of innovative surgical approaches for well-established procedures. *Journal of Vascular Surgery* 2004 July; 40(1): 199-201. NRCBL: 9.5.1; 5.1; 8.3.1; 18.2. SC: cs.


King, Michael; Smith, Glenn; Bartlett, Annie. Treatments of homosexuality in Britain since the 1950s — an oral history: the experience of professionals. *BMJ: British Medical Journal* 2004 February 21; 328(7437): 429-432. NRCBL: 9.5.1; 10; 17.3; 7.1.


Mussell, R. The development of professional guidelines on the law and ethics of male circumcision. *Journal of Medical Ethics* 2004 June; 30(3): 254-258. NRCBL: 9.5.1; 10; 9.5.7. SC: le. Identifiers: British Medical Association; Great Britain. Conference: symposium on circumcision. Abstract: This paper does not attempt to lay out the arguments relating to male circumcision for non-medical reasons. Rather, the aim is to focus more on the process and the problems of a professional body (in this case the British Medical Association (BMA)) attempting to produce any consensus guidelines for its members on an issue which clearly polarises doctors as much as it divides society as a whole. The legal and ethical considerations of male circumcision are inevitably touched upon here but are not the central issue. In 2003, the BMA published professional guidance on this subject. Some thought this a pointless exercise; others saw it as an initiative which simply failed to go far enough. Reservations centred on the fact that the BMA’s guidance—like that of the statutory body, the General Medical Council—explored the issues without either firmly rejecting or accepting non-therapeutic male circumcision. Was it then a fruitless project or a brave start to grasping the nettle?

Nast, Shauna; Richard, Shawn A.; Martin, Douglas K. Ethical issues related to cardiac report cards. *Canadian Journal of Cardiology* 2004 March 1; 20(3): 325-328. NRCBL: 9.5.1; 8.3.1; 9.4; 9.8.


Abstract: BACKGROUND: Many oncologists believe that patients with cancer who enroll in clinical trials have better outcomes than those who do not enroll. We aimed to assess the empirical evidence that such a trial effect exists. METHODS: We developed a conceptual framework for comparison of trial and non-trial patients. We then did a comprehensive literature search to identify studies that compared outcomes between these groups. We critically evaluated these studies to assess whether they provide valid and generalizable support for a trial effect. FINDINGS: We identified 26 comparisons, from 24 published articles, of outcomes among cancer patients enrolled and not enrolled in clinical trials. 21 comparisons used retrospective cohort designs. 14 comparisons provided some evidence that patients enrolled in trials have improved outcomes. However, strategies to control for potential confounding factors were inconsistent and frequently inadequate. Only eight comparisons restricted non-trial patients to those meeting trial eligibility criteria. Of these, three noted better outcomes in trial patients than in non-trial patients. Children with cancer, patients with haematological malignant disease, and patients treated before 1986 were disproportionately represented in positive studies. INTERPRETATION: Despite widespread belief that enrollment in clinical trials leads to improved outcomes in patients with cancer, there is insufficient data to conclude that such a trial effect exists. Until such data are available, patients with cancer should be encouraged to enroll in clinical trials on the basis of trials’ unquestioned role in improving treatment for future patients.

Piantanida, Nicholas A.; Oriscello, Ralph G.; Pettrone, Frank A.; O’Connor, Francis G. Sudden cardiac death: ethical considerations in the return to play. *Current Sports Medicine Reports* 2004 April; 3(2): 89-92. NRCBL: 9.5.1; 1.1; 1.3.1.

Potter, Robert Lyman. Prisoners as vulnerable persons [opinion]. *Bioethics Forum* 1999 Summer; 15(2): 47-48. NRCBL: 9.5.1; 1.3.5; 9.2; 8.3.4; 8.4; 17.4; 9.6; 17.7.

Reis, Judy Panko; Baumann, Bill. Acquired brain injury: reflections of two professionals with ABI. *Journal of Clinical Ethics* 2004 Winter; 15(4): 308-313. NRCBL: 9.5.1; 4.4; 7.1; 7.3; 8.1.


Abstract: This paper examines the characteristics of infectious diseases that raise special medical and social ethical issues, and explores ways of integrating both current bioethical and classic public health ethics concerns. Many of the ethical issues raised by infectious diseases are related to these diseases' powerful ability to engender fear in individuals and panic in populations. We address the association of some infectious diseases with high morbidity and mortality rates, the sense that infectious diseases are caused by invasion or attack on humans by foreign micro-organisms, the acute onset and rapid course of many infectious diseases, and, in particular, the communicability of infectious diseases. The individual fear and community panic associated with infectious diseases often leads to rapid, emotionally driven decision making about public health policies needed to protect the community that may be in conflict with current bioethical principles regarding the care of individual patients. The discussion includes recent examples where dialogue between public health practitioners and medical-ethicists has helped resolve ethical issues that require us to consider the infected patient as both a victim with individual needs and rights and as a potential vector of disease that is of concern to the community.


Spriggs, M. Compulsory brain scans and genetic tests for boxers — or should boxing be banned? Journal of Medical Ethics 2004 October; 30(5): 515-516. NRCBL: 9.5.1; 15.3; 17.1.


Swiss Academy of Medical Sciences: Restellini, Jean-Pierre; Berner-Chervet, Daphné; Grütter, Peter; Guilod, Olivier; Osterwalder, Joseph; Rameiser, Fritz; Steiner-König, Ursula; Vallotton, André; Vallotton, Michel; Nickel, Dominique. The exercise of medical activities in respect to detained persons: medi-cal-ethical guidelines of the Swiss Academy of Medical Sciences. Swiss Medical Weekly 2004 March 6; 134(9-10): 136-139. NRCBL: 9.5.1; 1.3.5; 6; 8.3.1; 8.4.


Wakefield, Andrew. A statement by Dr. Andrew Wakefield. Lancet 2004 March 6; 363(9411): 823-824. NRCBL: 9.5.1; 9.7; 18.5.2; 18.2.


Zambon, Maria C. Ethics versus evidence in influenza vaccination [opinion]. Lancet 2004 December 18-31; 364(9452): 2161-2163. NRCBL: 9.5.1; 9.6; 5.2; 9.2.

CARE FOR SPECIFIC GROUPS/ AGED

Baggs, Judith Gedney; Mick, Diane J. Collaboration: a tool addressing ethical issues for elderly patients near the end of life in intensive care units. Journal of Gerontological Nursing 2000 September; 26(9): 41-47. NRCBL: 9.5.2; 20.5.1; 8.1; 7.1.

Basta, Lofty L. Ethical issues in the management of geriatric cardiac patients [case study]. *American Journal of Geriatric Cardiology* 2004 May-June; 13(3): 168-170. NRCBL: 9.5.2; 9.5.5; 20.5.4.


Davis, John K. Collective surtee: is it unjust to develop life extension if it will not be possible to provide it to everyone? *Annals of the New York Academy of Sciences* 2004 June; 1019: 535-541. NRCBL: 9.5.2; 9.4; 9.3.1.

Denny, Marilyn. “This is who I am, don’t let them move me.” autonomy in nursing homes. *Quinnipiac Health Law Journal* 1999; 2(2): 203-225. NRCBL: 9.5.2; 1.1; 7.1.


Abstract: Elderly people are a particularly vulnerable group in society and have special health problems. The world population of older people is increasing. People who are 65 years or older constitute 6% of the Turkish population, 90% of whom have chronic health problems. In Turkey, there is a high possibility that elderly people’s requirements are not met by today’s health care system in the way they would wish. They prefer not to be hospitalized when they have health problems. From a wider perspective, various countries are still seeking how to provide the best care for elderly people. Our goal was to characterize home-based care for elderly people using an ethical approach as an area of interest for nurses and other health care professionals now and in the future, both for Turkey specifically and from a global perspective. We studied four case histories and then prepared a composite scenario and a short questionnaire for elderly people living in a specific district of Istanbul to evaluate their expectations from the health care system. We compared our findings with situations in other countries and have proposed some practical solutions. The results showed that these older people preferred to receive nursing care at home instead of in hospital in Turkey, and also in many other countries. In this article we discuss our findings, comparing them with those in the literature, and suggest that there should be nursing care at home with insurance coverage while using a proper ethical approach.


Funnell, Claire. Ethics, the health assessment interview, and the older patient. *Contemporary Nurse* 2000 September-December; 9(3-4): 303-307. NRCBL: 9.5.2; 2.1; 7.2.


Kamel, Hosam K.; Hajjar, Ramzi R. Sexuality in the nursing home, part 2: managing abnormal behavior — legal and ethical issues. *Journal of the American Medical Di-

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.


Mackney, Martin F. “We don’t do that here”: reflections on the Siena experience with dissecting aneurysms of the thoracic aorta in octogenarians. Journal of Thoracic and Cardiovascular Surgery 2001 February; 121(2): 202-203. NRCBL: 9.5.2; 9.8; 20.4.1; 20.5.1.


Slettebø, Åshild; Haugen Bunch, Eli. Solving ethically difficult care situations in nursing homes. Nursing Ethics 2004 November; 11(6): 543-552. NRCBL: 9.5.2; 8.1; 17.3. SC: em. Identifiers: Norway. Abstract: Patients in nursing homes sometimes give accounts of episodes in which they feel their autonomy and/or self-respect...
are violated as a result of the care they receive from nursing staff. In these ethically difficult care situations nurses use strategies such as negotiation, explanation and, in some cases, restraint. This study investigates how nurses apply these strategies to resolve ethical dilemmas in such a way that patients experience respect rather than violation. Critical issues that will be discussed include the definition of ethically difficult care situations in nursing homes and the identification of strategies for resolving such situations. Examples of the use of three strategies are presented. The use of negotiation, restraint and explanation are discussed in order to ensure respect for patients’ autonomy and thus to optimize health care outcomes.


CARE FOR SPECIFIC GROUPS/ FETUSES
See also HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ EMBRYOS AND FETUSES


Chervenak, Frank A.; McCullough, Laurence B. The Cornell University experience. Fetal Diagnosis and Therapy 2003 July-August; 18(4): 217-222. NRCBL: 9.5.8; 2.2; 18.5.4.


Dickens, B.M.; Cook, R.J. Ethical and legal approaches to ‘the fetal patient’. International Journal of Gynecology and Obstetrics 2003 October; 83(1): 85-91. NRCBL: 9.5.8; 9.5.5. SC: le.

Harris, John M. Before birth — after death [editorial]. Journal of Medical Ethics 2004 October; 30(5): 425. NRCBL: 9.5.8; 4.4; 18.5.4; 15.1; 14.5; 14.3; 19.5. Identifiers: Great Britain; European Court of Human Rights.


CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED
See also BEHAVIOR CONTROL; ELECTRO-CONVULSIVE THERAPY; INVOLUNTARY COMMITMENT; MENTAL HEALTH THERAPIES; PSYCHOPHARMACOLOGY; PSYCHOTHERAPY


Abstract: Much debate concerning ‘precedent autonomy’—that is, the authority of former, competent selves to govern the welfare of later, non-competent selves—has assumed a radical discontinuity between selves, and has overlooked the ‘bridging’ role of intimate proxy decision-makers. I consider a recent proposal by Lynn et al. (1999) that presents a provocative alternative, foregrounding an imagined dialogue between the formerly competent patient and her/his trusted others. I consider what standards must be met for such dialogues to have moral force, appealing to narrative and feminist ethics. I then critique the dualistic construction of selves implicit in much of the advance directive literature, noting the continuities of dependence, character, and body, as well as the social dimension of the construction of selves.


Lynch, Christopher. Psychotherapy for persons with mental retardation. Mental Retardation 2004 October; 42(5): 399-405. NRCBL: 9.5.3; 17.2; 8.3.3. SC: rv.


O'Brien, Gerald V. People with cognitive disabilities: the argument from marginal cases and social work ethics. So-
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CARE FOR SPECIFIC GROUPS/ MINORITIES

May receive their care from a subgroup of physicians whose qualifications or resources are inferior to those of the physicians who treat white patients. METHODS: We performed a cross-sectional analysis of 150,391 visits by black Medicare beneficiaries and white Medicare beneficiaries 65 years of age or older for medical “evaluation and management” who were been by 4355 primary care physicians who participated in a biannual telephone survey, the 2000-2001 Community Tracking Study Physician Survey. RESULTS: Most visits by black patients were with a small group of physicians (80 percent of visits were accounted for by 22 percent of physicians) who provided only a small percentage of care to white patients. In a comparison of visits by white patients and black patients, we found that the physicians whom the black patients visited were less likely to be board certified (77.4 percent) than were the physicians visited by the white patients (86.1 percent, P=0.02) and also more likely to report that they were unable to provide high-quality care to all their patients (27.8 percent vs. 19.3 percent, P=0.005). The physicians treating black patients also reported facing greater difficulties in obtaining access for their patients to high-quality subspecialists, high-quality diagnostic imaging, and nonemergency admission to the hospital. CONCLUSIONS: Black patients and white patients are to a large extent treated by different physicians. The physicians treating black patients may be less well trained clinically and may have less access to important clinical resources than physicians treating white patients. Further research should be conducted to address the extent to which these differences may be responsible for disparities in health care.


Bowman, James E. Genetics and African Americans. Seton Hall Law Review 1997; 27(3): 919-936. NRCBL: 9.5.4; 15.3; 15.5; 11.3.


Callender, Clive O.; Miles, Patrice V. Institutionalized racism and end-stage renal disease: is its impact real or illusory? Seminars in Dialysis 2004 May-June; 17(3): 177-180. NRCBL: 9.5.4; 19.3.


Abstract: OBJECTIVES: To draw on narrative interviews with patients with lung cancer and to explore their perceptions and experience of stigma. DESIGN: Qualitative study. SETTING: United Kingdom. PARTICIPANTS: 45 patients with lung can-
Cancer care experienced stigma commonly felt by patients with other types of cancer, but, whether they smoked or not, they felt particularly stigmatised because the disease is so strongly associated with smoking. Interaction with family, friends, and doctors was often affected as a result, and many patients, particularly those who had stopped smoking years ago or had never smoked, felt unjustly blamed for their illness. Those who resisted victim blaming maintained that the real culprits were tobacco companies with unscrupulous policies. Some patients concealed their illness, which sometimes had adverse financial consequences or made it hard for them to gain support from other people. Some indicated that newspaper and television reports may have added to the stigma: television advertisements aim to put young people off tobacco, but they usually portray a dreadful death, which may exacerbate fear and anxiety. A few patients were worried that diagnosis, access to care, and research into lung cancer might be adversely affected by the stigma attached to the disease and those who smoke. CONCLUSION: Patients with lung cancer report stigmatisation with far reaching consequences. Efforts to help people to quit smoking are important, but clinical and educational interventions should be presented with care so as not to add to the stigma experienced by patients with lung cancer and other smoking related diseases.

Chin, Marshall H.; Humikowski, Catherine A. When is risk stratification by race or ethnicity justified in medical care? *Academic Medicine* 2002 March; 77(3): 202-208. NRCBL: 9.5.4; 5.2; 21.7; 15.11.


SECTION I  
CARE FOR SPECIFIC GROUPS/ MINORITIES


Abstract: Studies documenting racial differences in health care use are common in the medical literature. However, observational studies of racial differences in health care use lack a framework for interpreting reports of variations in health care use, leading to various terms, ranging from “variations” to “bias,” that suggest different causes, consequences, and, ultimately, remedies for such variations in treatment. We propose criteria to assess racial differences in health care use by using a clinical equity (equal treatment based on equal clinical need) framework. This framework differentiates between initial reports of racial differences and subsequent classifications of their findings as racial disparities or racial bias in health care use. Racial variations in health care use may be considered disparities after demonstrating that racial differences are not attributable to treatment eligibility, clinical contraindications, patient preferences, or confounding by other clinical factors and are associated with adverse consequences. Racial bias with adverse consequences in health care may be inferred if a racial variation in treatment that has been characterized as a disparity persists after accounting for health care system factors (for example, type of hospital at which the patient was treated). We apply this framework to published reports of racial differences in treatment to determine which studies provide evidence of differences, disparities, and bias. We discuss the use of such a framework in directing policy interventions for alleviating inappropriate racial variations in health care use.

Abstract: A series of court cases litigated by the National Association for the Advancement of Colored People Legal Defense and Education Fund between 1956 and 1967 laid the foundation for elimination of overt discrimination in hospitals and professional associations. The landmark case, Simkins v Moses H. Cone Memorial Hospital (1963), challenged the use of public funds to expand segregated hospital care. The second case, Cypress v Newport News Hospital Association (1967), reaffirmed the federal government’s application of Medicare certification guidelines to force hospitals to open up patient admissions, education programs, and staff privileges to all citizens and physicians. Pursuit of a legal strategy against racist policies was an essential element in a national campaign to eliminate discrimination in health care delivery in the United States.


Abstract: OBJECTIVES: We examined the association between discrimination and mental health service use among a representative sample of Chinese Americans. METHODS: Our data were derived from the 2-wave Chinese American Psychiatric Epidemiological Survey, a strata-cluster survey conducted in 1993 and 1994 in a western American city. RESULTS: Language-based discrimination was associated with higher levels of use of informal services and seeking help from friends and relatives for emotional problems. Negative attitudes toward professional mental health services were associated with greater use of informal services. CONCLUSIONS: The findings suggest that language-based discrimination influences patterns of mental health service use among Chinese Americans. Implications for service providers and policymakers are discussed.


Tolke, Alexia M.; Corbie-Smith, Giselle M.; Branch, William T., Jr. African American patients’ perspectives on medical decision making. *Archives of Internal Medi-

NRCBL: National Reference Center for Bioethics Literature Classification Scheme  
See inside front cover for terms.
CARE FOR SPECIFIC GROUPS/ MINORS


Abstract: One million cases of child maltreatment and twelve hundred child deaths due to abuse and neglect occur per year. But since many cases of abuse and neglect remain either unreported or unsubstantiated due to insufficient evidence, the number of children who are abused, neglected, and killed at the hands of family caregivers is probably higher. One approach to combat child abuse in the U.K. has been the employment of hospital-based covert video surveillance (CVS) to monitor parents suspected of Munchausen Syndrome by Proxy (MSBP). The use of CVS, however, raises concerns about voluntary informed consent, research on human subjects, privacy, and the appropriateness of healthcare providers to conduct CVS. More broadly, the use of CVS raises concerns about the ethical life of healthcare institutions and their moral obligations to the families and communities they serve. The U.K. protocol for CVS is examined in light of these concerns. Three alternative CVS protocols and two procedures for selecting a protocol are then proposed for use in the U.S. The paper concludes that any CVS protocol selected for use by hospitals ought to be selected by means of open and democratic processes that permit community input and, subsequently, the possibility of a consensus on the moral status and scope of CVS.

Berger, Jan Ellen. Consent by proxy for nonurgent pediatric care. *Pediatrics* 2003 November; 112(5): 1186-1195. NRCBL: 9.5.7; 8.3.2; 2.1; 7.2.


Abstract: This paper is written in response to controversial judicial decisions following separation surgery on conjoined twins “Jodie” and “Mary”. The courts, it is argued, seem to have conceptualised the twins as “entangled singletons” requiring medical intervention to render them physically separate and thus “as they were meant to be”, notwithstanding the death of the weaker twin, “Mary”. In contrast, we argue that certain notions, philosophical and biological, of what human beings are intended to be, are problematic. We consider three compelling conceptualisations of conjoined twins and advocate a model that conceives them as two psychologically separate individu-


Abstract: It has been observed that some groups in society tend to report their health to be better than would be expected through more objective measures. The available evidence suggests that while variations in self-assessed measures of health may act as good proxies of mortality and morbidity in homogeneous populations, in some groups, such as the Aboriginal and Torres Strait Islander communities of Australia, these subjective measures may provide a misleading picture. Useful insights into the formation of health perceptions can be drawn from a range of disciplines, in particular, from social comparison theories, models of illness behaviour, survey literature and linguistics. These theories and models help to provide an understanding of the different ways in which illness may be perceived, evaluated and acted upon by different kinds of people. Such considerations can have very direct implications for those planning and evaluating public health programs as well as those responsible for funding such programs.

als who happen to share a body, the sharing of a body being integral to the individuality of each twin. While we reject an “essentialist” view of the conjoined state, a view which might render separation surgery unthinkable in all cases, we nevertheless argue against an “adversarial” interpretation of conjoined twins’ respective best interests. We maintain that the physical entanglement should be regarded as a shared problem rather than one posed by one twin to the other. And if, after deliberation, separation surgery is deemed the “least detrimental alternative” or the “lesser of two evils”, then there should be recognition of what conjoined twins will lose, as well as gain, through separation. The current drive to separate twins at all costs may evoke a deeper unease with bodily configurations that appear to threaten the premium that the Western ethical and legal tradition places on personal sovereignty, and the physical circumscription that such sovereignty assumes.


Caniano, Donna A. Ethical issues in the management of neonatal surgical anomalies. Seminars in Perinatology 2004 June; 28(3): 240-245. NRCBL: 9.5.7; 8.1; 9.5.8; 18.5.2; 20.5.2.


Clark, Peter A. Medical marijuana: should minors have the same rights as adults? Medical Science Monitor 2003 June; 9(6): ET1-ET9. NRCBL: 9.5.7; 1.1; 9.5.9; 9.7. SC: le.

Colapinto, John. The true story of John/Joan. Rolling Stone 1997 December 11; (775): 54, 56-58, 6062, 64, 66, 68, 70-72, 92, 94-97. NRCBL: 9.5.7; 10; 17.1; 9.5.5; 9.5.1.

Diaz, Angela; Neal, Wendy P.; Nucci, Anne T.; Ludmer, Pamela; Bitterman, Jacalyn; Edwards, Sharon. Legal and ethical issues facing adolescent health care professionals. Mount Sinai Journal of Medicine 2004 May; 71(3): 181-185. NRCBL: 9.5.7; 8.3.2; 8.4. SC: le.


Erb, Thomas O.; Schulman, Scott R.; Sugarman, Jeremy. Permission and assent for clinical research in pediatric anesthesia. Anesthesia and Analgesia 2002; 94: 1155-1160. NRCBL: 9.5.7; 8.3.2; 18.2; 18.3; 18.5.2.


Fost, Norman C. America’s gulag archipelago: institutionalization of children. New England Journal of Medicine 2004 December 2; 351(23): 2369-2370. NRCBL: 9.5.7; 9.1; 17.7; 18.5.2; 1.3.9.


Hagger, L.E. The Human Rights Act 1998 and medical treatment: time for re-examination. Archives of Disease in Childhood 2004 May; 89(5): 460-463. NRCBL: 9.5.7; 8.3.2; 8.4. SC: le.


Herxheimer, Andrew; Mintzes, Barbara. Antidepressants and adverse effects in young patients: uncovering the evidence [opinion]. CMAJ/JAMC: Canadian Medical Association Journal 2004 February 17; 170(4): 487-489. NRCBL: 9.5.7; 9.7; 17.4; 1.3.9.

Hickey, Kenneth S.; Lyckholm, Laurie. Child welfare versus parental autonomy: medical ethics, the law, and faith-based healing. Theoretical Medicine and Bioethics 2004; 25(4): 265-276. NRCBL: 9.5.7; 8.3.4; 1.2. Abstract: Over the past three decades more than 200 children have died in the U.S. of treatable illnesses as a result of their parents relying on spiritual healing rather than conventional medical treatment. Thirty-nine states have laws that protect parents from criminal prosecution when their children die as a result of not receiving medical care. As physicians and citizens, we must choose between protecting the welfare of children and maintaining respect for the rights of parents to practice the religion of their choice and to make important decisions for their children. In order to make and defend such choices, it is essential that we as health care professionals understand the history and background of such practices and the legal aspects of previous cases, as well as formulate an ethical construct by which to begin a dialogue with the religious communities and others who share similar beliefs about spiritual healing. In this paper, we provide a framework for these requirements.

NRCBL: National Reference Center for Bioethics Literature Classification Scheme
Hladek, Glenn A. Cochlear implants, the deaf culture, and ethics — a study of disability, informed surrogate consent, and ethocide. *Monash Bioethics Review* 2002 January; 21(1): 29-44. NRCBL: 9.5.7; 9.5.1; 4.2; 4.4; 8.3.3.

Howe, Edmund G. Criteria for deceit. *Journal of Clinical Ethics* 2004 Summer; 15(2): 100-110. NRCBL: 9.5.7; 8.3.2; 8.1; 17.1.


Maradiegue, Ann. Minor’s rights versus parental rights: review of legal issues in adolescent health care. *Journal of Midwifery and Women’s Health* 2003 May-June; 48(3): 170-177. NRCBL: 9.5.7; 8.3.1; 8.3.2; 8.4.

Marcin, J.P.; Pretzlaff, R.K.; Pollack, M.M.; Patel, K.M.; Ruttimann, U.E. Certainty and mortality prediction in critically ill children. *Journal of Medical Ethics* 2004 June; 30(3): 304-307. NRCBL: 9.5.7; 20.1. SC: em. Abstract: OBJECTIVES: The objective of this study is to investigate the relationship between a physician’s subjective mortality prediction and the level of confidence with which that mortality prediction is made. DESIGN AND PARTICIPANTS: The study is a prospective cohort of patients less than 18 years of age admitted to a tertiary Paediatric Intensive Care Unit (ICU) at a University Children’s Hospital with a minimum length of ICU stay of 10 h. Paediatric ICU attending physicians and fellows provided mortality risk predictions and the level of confidence associated with these predictions on consecutive patients at the time of multidisciplinary rounds within 24 hours of admission to the paediatric ICU. Median confidence levels were compared across different ranges of mortality risk predictions. RESULTS: Data were collected on 642 of 713 eligible patients (36 deaths, 5.6%). Mortality predictions greater than 5% and less than 95% were made with significantly less confidence than those predictions % and 95%. Experience was associated with greater confidence in prognostication. CONCLUSIONS: We conclude that a physician’s subjective mortality prediction may be dependent on the level of confidence in the prognosis; that is, a physician less confident in his or her prognosis is more likely to state an intermediate survival prediction. Measuring the level of confidence associated with mortality risk predictions (or any prognostic assessment) may therefore be important because different levels of confidence may translate into differences in a physician’s therapeutic plans and their assessment of the patient’s future.


Orfali, Kristina; Gordon, Elisa J. Autonomy gone awry: a cross-cultural study of parents’ experiences in neonatal intensive care units. *Theoretical Medicine and Bioethics* 2004; 25(4): 329-365. NRCBL: 9.5.7; 20.5.2; 8.1; 21.7. Abstract: This paper examines parents’ experiences of medical decision-making and coping with having a critically ill baby in the Neonatal Intensive Care Unit (NICU) from a cross-cultural perspective (France vs. U.S.A.). Though parents’ experiences in the NICU were very similar despite cultural and institutional differences, each system addresses their needs in a different way. Interviews with parents show that French parents expressed overall higher satisfaction with the care of their babies and were better able to cope with the loss of their child than American parents. Central to the French parents’ perception of autonomy and their sense of satisfaction were the strong doctor-patient relationship, the emphasis on medical certainty in prognosis versus uncertainty in the American context, and the “sentimental work” provided by the team. The American setting, characterized by respect for parental autonomy, did not necessarily translate into full parental involvement in decision-making, and it limited the rapport between doctors and parents to the extent of parental isolation. This empirical comparative approach fosters a much-needed critique of philosophi-

Pinto, Kristina C. Intersections of gender and age in health care: adapting autonomy and confidentiality for the adolescent girl. Qualitative Health Research 2004 January; 14(1): 78-99. NRCBL: 9.5.7; 1.1; 8.4; 9.5.5.

Rehm, Roberta S. Legal, financial, and ethical ambiguities for Mexican American families: caring for children with chronic conditions. Qualitative Health Research 2003 March; 13(5): 689-702. NRCBL: 9.5.7; 9.5.4; 9.2.


Shevill, Michael. Ethical issues in pediatric critical care neurology. Seminars in Pediatric Neurology 2004 June; 11(2): 179-184. NRCBL: 9.5.7; 8.3.2; 9.4; 18.5.2; 20.5.2.


Tuchman, Mendel. Hyperammonemia: are the burdens too grave? Case study [discussion]. Ethics and Intellectual Disability Newsletter 2004 Winter; 8(1): 1, 3. NRCBL: 9.5.7; 4.4; 8.1; 8.3.2; 9.5.3.


CARE FOR SPECIFIC GROUPS/ SUBSTANCE ABUSERS

Beck, Michael; Dietrich, Sandra; Matschinger, Herbert; Angermeyer, Matthias C. Alcoholism: low standing with the public? Attitudes towards spending financial resources on medical care and research on alcoholism. Alcohol and Alcoholism 2003 November-December; 38(6): 602-605. NRCBL: 9.5.9.


Christie, Timothy; Anderson, John F. Drug treatment courts are popular but do they work and are they ethical and appropriate for Canada? Health Law in Canada 2003 May; 23(4): 70-79. NRCBL: 9.5.9; 1.3.5. SC: le.

Cutler, Tony J.; Nye, David A. Combating the ‘safe’ cigarette: ethical, public health issues and regulatory proposals. Health Care Analysis: An International Journal of

Abstract: Regulatory authorities have advised smokers who would not or could not quit smoking to switch to lower tar cigarettes. Smoking such cigarettes was seen as a means of reducing the harm caused by smoking, but not as offering a ‘safe’ smoking option. Correspondingly manufacturers have been required to place tar and nicotine information on packet labels and/or advertisements. This paper explores the possibility that the conventional format for conveying tar and nicotine information could be responsible for the belief, held by a significant proportion of smokers, that some brands of lower tar cigarettes are absolutely ‘safe’. To deal with this situation it is suggested that changes should be made to health warnings, and tar and nicotine communications. Proposed changes to the latter are evaluated in terms of their ethical and public health implications. The authors conclude that brand specific warnings and a classification of cigarettes as either ‘Very Dangerous’ or ‘Dangerous’, is best suited to reconciling consumer needs for information with the public health objectives of reducing the harm caused by smoking.

Geppert, Cynthia M.A. To help and not to harm: ethical issues in the treatment of chronic pain in patients with substance use disorders. Advances in Psychosomatic Medicine 2004; 25: 151-171. NRCBL: 9.5; 9.1; 9.1.1; 2.1; 4.4; 8.1; 9.5.1.


Hall, Wayne; Degenhardt, Louisa. Medical marijuana initiatives — are they justified? How successful are they likely to be? CNS Drugs 2003; 17(10): 689-697. NRCBL: 9.5; 9.7.


Abstract: Tobacco consumption is believed to be one of the world’s greatest preventable health problems. According to the World Health Organisation, 1.1 billion people worldwide are addicted to nicotine with tobacco causing an estimated four million premature deaths every year. The development of a nicotine conjugate vaccine suggests that immunisation may hold promise as a future therapeutic and preventive strategy for tobacco smoking and nicotine addiction. Allowing parents to immunise their children against smoking could be an infringement of children’s right to an open future, however, and is not ethically unproblematic.


Abstract: The use of coercive measures in the care for the addicted has changed over the past 20 years. Laws that have adopted the “dangerousness” criterion in order to secure patients’ rights to non-intervention are increasingly subjected to critique as many authors plead for wider dangerousness criteria. One of the most salient moral issues at stake is whether addicts who are at risk of causing danger to themselves should be involuntarily admitted and/or treated. In this article, it is argued that the dilemma between coercion on the one hand and abandonment on the other cannot be analysed without differentiated perspectives on the key notions that are used in these debates. The ambiguity these notions carry within care practice indicates that the conflict between the prevention of danger and respect for autonomy is not as sharp as the legal systems seem to imply. Some coercive measures need not be interpreted as an infringement of autonomy—rather, they should be interpreted as a way to provide good care.


Abstract: In August 2001, the Israeli Ministry of Health issued its Limitation of Smoking in Public Places Order, categorically forbidding smoking in hospitals. This forced the mental health system to cope with the issue of smoking inside psychiatric hospitals. The main problem was smoking by compulsorily hospitalized psychiatric patients in closed wards. An attempt by a psychiatric hospital to implement the tobacco smoking restraint instruction by banning the sale of cigarettes inside the hospital led to the development of a black market and cases of patient exploitation in return for cigarettes. This article surveys the literature dealing with smoking among psychiatric patients, the role of smoking in patients and the moral dilemmas of taking steps to prevent smoking in psychiatric hospitals. It addresses the need for public discussion on professional caregivers’ dilemmas between their commitment to uphold the law and their duty to act as advocates for their patients’ rights and welfare.


CARE FOR SPECIFIC GROUPS/ WOMEN


Abstract: Tolerance is at the heart of Western liberalism, permitting mutually exclusive ideas and practices to coexist peacefully with one another, without the proponents of the differing ideas and practices killing one another. Yet, nothing challenges tolerance like the practice of sunna, female circumcision, clitorectomy, or genital mutilation. In this essay, I critique the Western critics of the practices, not in order to defend these practices, but rather to show that Western liberalism itself does not offer transcultural and transtemporal principles, for these principles only cohere within the tradition of liberalm. The Western critique of sunna often maps onto the bodies of African women Western symbolic notions of sexual and political freedom, as symbolized in the clitoris. The practices of sunna cohere within the web of beliefs, the tradition, of those who practice them and, thus, are rationally justified within those traditions. I offer Alasdair MacIntyre’s notion of moral inquiry as a guide through the complex world of cultural and moral dialogue between differing traditions.


Carmichael, Mary. Have it your way: redesigning birth. After decades of letting doctors run the show, more women are taking big decisions into their own hands. *Newsweek* 2004 May 10; 143(19): 70, 72. NRCBL: 9.5.5; 9.5.8; 8.1. SC: po.


de Lima Garcias, Gilberto; Schüler-Faccini, Lavinia. Community diagnosis of maternal exposure to risk factors for congenital defects. *Community Genetics* 2003 October; 6(2): 96-103. NRCBL: 9.5.5; 15.3; 9.5.1. SC: em.

Devendra, K.; Arulkumaran, S. Should doctors perform an elective caesarean section on request? *Annals of the Academy of Medicine, Singapore* 2003 September; 32(5): 577-582. NRCBL: 9.5.5; 8.3.1.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme  
See inside front cover for terms.
CARE FOR SPECIFIC GROUPS/WOMEN


Miesfeldt, Susan; Cohn, Wendy F.; Jones, Susan M.; Ropka, Mary E.; Weinstein, Jenine C. Breast cancer survivors’ attitudes about communication of breast cancer risk to their children. *American Journal of Medical Genetics* 2003 May 15; 119C(1): 45-50. NRCBL: 9.5.5; 8.1; 8.2; 15.3. Identifiers: Virginia.


Minkoff, Howard; Powderly, Kathleen R.; Chervenak, Frank; McCullough, Lawrence B. Ethical dimensions of elective primary cesarean delivery. *Obstetrics and Gynecology* 2004 February; 103(2): 387-392. NRCBL: 9.5.5; 8.3.1.


Pfeffer, N. “If you think you’ve got a lump, they’ll screen you.” Informed consent, health promotion, and breast cancer. *Journal of Medical Ethics* 2004 April; 30(2): 227-230. NRCBL: 9.5.5; 8.3.1; 9.1. Identifiers: Great Britain. Abstract: A great deal has been written about information that is or should be provided when seeking consent to medical research and treatment. Relatively little attention has been paid to information describing health promotion interventions. This paper critically examines some information material describing three different methods of encouraging early presentation of breast cancer in the UK: the NHS breast screening programme, breast self examination, and breast awareness. Findings from a content analysis of printed material and a series of focus group discussions that included women who speak little or no English were organised around the Department of Health’s recommendations about the information which should be provided when seeking consent to treatment and research. They exposed inconsistencies, ambiguities, and gaps, which when taken together suggest both compliance and non-compliance are being achieved in the absence of informed consent. The findings also provide a starting point for a discussion about how informed consent to health promotion might be sought.


Scott, Wendy. Maternal foetal conflict and the anaesthetist’s role. In: Draper, Heather; Scott, Wendy E., eds. Eth-


Sinivaara, Maria; Suominen, Tarja; Routasalo, Pirkko; Hupli, Maija. How delivery ward staff exercise power over women in communication. Journal of Advanced Nursing 2004 April; 46(1): 33-41. NRCBL: 9.5.5; 8.1. SC: em. Identifiers: Finland.

Steel, Michael; Smyth, Elizabeth; Vasen, Hans; Eccles, Diana; Evans, Gareth; Møller, Pål; Hodgson, Shirley; Stoppa-Lyonnet, Dominique; Chang-Claude, Jenny; Caligo, Maria; Morrison, Patrick; Haites, Neva. Ethical, social and economic issues in familial breast cancer: a compilation of views from the E.C. Biomed II Demonstration Project. Disease Markers 1999 October; 15(1-3): 125-131. NRCBL: 9.5.5; 15.3; 9.3.1; 9.2.


Tan, Jacinta O.A.; Hope, Tony; Stewart, Anne. Anorexia nervosa and personal identity: the accounts of patients and their parents. International Journal of Law and Psychiatry 2003 September-October; 26(5): 533-548. NRCBL: 9.5.5; 9.5.7; 8.3.4; 8.3.2; 4.4. SC: em.


CARING See NURSING ETHICS AND PHILOSOPHY; PROFESSIONAL PATIENT RELATIONSHIP

CHEMICAL WARFARE See WAR AND TERRORISM

CIVIL COMMITMENT See INVOLUNTARY COMMITMENT

CLINICAL ETHICISTS See ETHICISTS AND ETHICS COMMITTEES

CLINICAL ETHICS See BIOETHICS AND MEDICAL ETHICS; ETHICISTS AND ETHICS COMMITTEES; NURSING ETHICS AND PHILOSOPHY; PROFESSIONAL ETHICS

CLINICAL ETHICS COMMITTEES See ETHICISTS AND ETHICS COMMITTEES

CLINICAL RESEARCH See HUMAN EXPERIMENTATION

CLONING

See also HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ EMBRYOS AND FETUSES; REPRODUCTIVE TECHNOLOGIES


Ethics of therapeutic cloning: a moment of triumph for South Korean science appears to have been marred by doubts about lab practice [editorial]. Nature 2004 May 6; 429(6987): 1. NRCBL: 14.5; 18.5.4; 14.4; 14.6.

The moral case against cloning for biomedical research. Issues in Law and Medicine 2003 Spring; 18(3): 261-274. NRCBL: 14.5; 18.5.4; 4.4.


Time to look to the future — Germany is understandably cautious about embryo research, but the country would benefit from joint European projects [editorial]. Nature 2004 September 23; 431(7007): 385. NRCBL: 14.5; 18.5.4; 15.1; 2.4. Identifiers: Germany; German National Ethics Council.


George, Robert P. Human cloning and embryo research: the 2003 John J. Conley lecture on medical ethics. *Theoret-
SECTION I  CLONING

Abstract: The author, a member of the U.S. President's Council on Bioethics, discusses ethical issues raised by human cloning, whether for purposes of bringing babies to birth or for research purposes. He first argues that every cloned human embryo is a new, distinct, and enduring organism, belonging to the species Homo sapiens, and directing its own development toward maturity. He then distinguishes between two types of capacities belonging to individual organisms belonging to this species, an immediately exercisable capacity and a basic natural capacity that develops over time. He argues that it is the second type of capacity that is the ground for full moral respect, and that this capacity (and its concomitant degree of respect) belongs to cloned human embryos no less than to adult human beings. He then considers and rejects counter-arguments to his position, including the suggestion that the capacity of embryos is equivalent to the capacity of somatic cells, that full human rights are afforded only to human organisms with functioning brains, that the possibility of twinning diminishes the moral status of embryos, that the fact that people do not typically mourn the loss of early embryos implies that they have a diminished moral status, that the fact that early spontaneous abortions occur frequently diminishes the moral status of embryos, and that his arguments depend upon a concept of ensoulment. He concludes that if the moral status of cloned human embryos is equivalent to that of adults, then public policy should be based upon this assumption.


Knight, Jonathan. Biologists fear cloning hype will undermine stem-cell research [news]. Nature 2004 August 19; 430(7002): 817. NRCBL: 14.5; 18.5.4; 19.1; 15.1.


Abstract: The issues of human cloning and stem cell retrieval are inseparable in circumstances in which the rationale of self-preservation may be invoked as a negative right. I apply this rationale to a hypothetical case in which cloning is necessary to preserve the bodily integrity or life of an individual. Self-preservation as moral integrity is examined in a narrower context, i.e., as applicable to those for whom deliberate termination of embryonic life is morally-problematic. This issue is addressed through comparison with two paradigms commonly used in support of clinical practice: the distinction between letting die and killing, and the permissibility of vital organ retrieval after death. Although these paradigms are questionable in their own right, they offer a rationale by which scientists and clinicians may respect the negative right to moral integrity of those with whom they disagree.


Song, Sang-Yong; Hwang, Woo-Suk; Moon, Shin Yong. Stem cell research in Korea [letter and reply]. *Science* 2004 August 13; 305(5686): 944-945. NRCBL: 14.5; 18.5.4; 15.1; 21.1.


SECTION I

CLONING/ LEGAL ASPECTS

2004 March 10; 291(10): 1185-1186. NRCBL: 14.5; 18.5.4; 19.1.


CLONING/ LEGAL ASPECTS


Adams, Nathan A. Creating clones, kids and chimera: liberal democratic compromise at the crossroads. Issues in Law and Medicine 2004 Summer; 20(1): 3-69. NRCBL: 14.5; 15.3; 15.5; 15.8; 4.4; 5.3. SC: le.


Bernier, L.; Grégoire, D. Reproductive and therapeutic cloning, germline therapy, and purchase of gametes and embryos: comments on Canadian legislation governing reproduction technologies. Journal of Medical Ethics 2004 December; 30(6): 527-532. NRCBL: 14.5; 15.1; 15.4; 19.5; 9.3.1. SC: le. Identifiers: Canada. Abstract: In Canada, the Assisted Human Reproduction Act received royal assent on 29 March 2004. The approach proposed by the federal government responds to Canadians’ strong desire for an enforceable legislative framework in the field of reproduction technologies through criminal law. As a result of the widening gap between the rapid pace of technological change and governing legislation, a distinct need was perceived to create a regulatory framework to guide decisions regarding reproductive technologies. In this article the three main topics covered in the new legislation are commented on: cloning, germline therapy, and purchase of gametes and embryos. Some important issues also covered in the new legislation, such as privacy and access to information, data protection, identity of donors, and inspection, will not be addressed.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms. 97


Deech, Ruth Lynn. Clones, ethics and infertility or sex, sheep and statutes. Quinnipiac Health Law Journal 1999; 2(2): 117-134. NRCBL: 14.5; 14.2; 19.5; 5.3; 2.4. SC: le.

Demick, Barbara. South Korea a fertile field for research into cloning. Los Angeles Times 2004 February 17; p. A1, A8. NRCBL: 14.5; 18.5.4; 18.6; 22.2. SC: le.


Hansen, Bart. Embryonic stem cell research: terminological ambiguity may lead to legal obscurity. Medicine and Law: World Association for Medical Law 2004; 23(1): 19-28. NRCBL: 14.5; 18.5.4; 18.6; 15.1. SC: le. Abstract: National regulation on embryonic stem cell research in the European Union is ambiguous, due to a lack of consistent scientific terminology as exemplified by the Dutch Embryos Act. To force a breakthrough in this ethically dubious research topic, a more careful use of terminology would be in the interest of both the scientific community and the lawmakers, in order to avoid terminology becoming associated with research or applications for which it is inappropriate. Therefore I will first clarify the technological possibilities in an age of biological control. Secondly, we will critically analyse the statements of the European Convention on Human Rights and Biomedicine concerning embryo research and cloning. The Convention prohibits human reproductive cloning but does not take a clear position on so-called therapeutic cloning. Finally, we will give an overview of the most recent legislative initiatives within the European Union on this matter.


Johnson, Alissa. Attack of the clones: as cloning technology marches forward, state legislatures are faced with some hard decisions. State Legislatures 2003 April; 29(4): 30-32, 34. NRCBL: 14.5; 5.3; 1.3.5. SC: le.


McBrien, Maureen. Human cloning: beyond the realm of the constitutional right to procreative liberty. Buffalo Pub


Abstract: Reproductive cloning has thrown up new scientific possibilities, ethical conundrums, and legal challenges. An initial question, considered by the English courts in 2003, was whether the technique presently available, that of cell nucleus replacement, falls outside the provisions of the Human Fertilisation and Embryology Act 1990. If it does, the creation and use, including use in research protocols, of human embryos would be unregulated, disclosing a need to consider remedial legislation. The resolution by the courts of this legal question dramatically engages them in a resolution of fundamental ethical dilemmas and discloses the possibilities and limitation of negotiating science policy through the processes of litigation.


Abstract: The perspectives of applying the cloning technology to human reproduction have generated much controversy. Israel was one of the first countries to adopt (in 1998) a law that prohibits reproductive cloning. This is a moratorium for 5 years during which neither cloning of an entire human being nor genetic changes affecting human reproductive cells will be allowed. An aim of the Law is to allow the examination of the moral, legal, and social aspects of these technologies and their implications for human dignity. With the intention of not being an obstacle to the advancement of medical genetics, the Law provides for a yearly report to the Israel Health Minister on the state of scientific knowledge in these technologies. This article reflects the 2002-3 report, relating to scientific issues and bioethical opinions in Israel and in the world on human reproductive cloning, embryonic stem cell research and germ line gene manipulation. In the Jewish tradition, the primary importance of saving lives and helping suffering patients can take precedence over the fears generated by modern genetic and reproductive research. Provided that new technologies are applied for medical indications and respecting human rights and human dignity, it is legitimate to explore their beneficial potential.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.


**COMMISSIONS ON BIOETHICS See BIOETHICS AND MEDICAL ETHICS/COMMISSIONS**

**CODES OF ETHICS**


Abstract: BACKGROUND: Patients today interact with physicians, physician groups, and health plans, each of which may follow distinct ethical guidelines. METHOD: We systematically compared physician codes of ethics with ethics policies at physician group practices and health plans, using the 1998-99 policies of 38 organisations-18 medical associations (associations), nine physician group practices (groups), and 12 health plans (plans)-selected using random and stratified purposive sampling. A clinician and a social scientist independently abstracted each document, using a 397-item health care ethics taxonomy, a reconciled abstraction form was used for analysis. This study focuses on ethics policies regarding professional obligations towards patients, resource allocation, and care for the vulnerable in society. RESULTS: A majority in all three groups mention “fiduciary obligations” of one sort or another, but associations generally address physician/patient relations but not health plan obligations, while plans rarely endorse physicians’ obligations of advocacy, beneficence, and non-maleficence. Except for occasional mentions of cost effectiveness or efficiency, ethical considerations in resource allocation rarely arise in the ethics policies of all three organisational types. Very few associations, groups, or plans specifically endorse obligations to vulnerable populations. CONCLUSIONS: With some important exceptions, we found that the ethics policies of associations, groups, and plans are narrowly focused and often ignore important ethical concerns for society, such as resource allocation and care for vulnerable populations. More collaborative work is needed to build integrated sets of ethical standards that address the aims and responsibilities of the major stakeholders in health care delivery.


**Pepe, Carl J.** Creating and adopting an ACC ethical code of conduct. *Journal of the American College of Cardiology* 2003 December 3; 42(11): 2028-2029. NRCBL: 6; 4.1.2.

**Qidwai, W.** The Hippocratic Oath: has it ceased to be relevant? *Journal of the Pakistan Medical Association* 2004 April; 54(4): 229-231. NRCBL: 6; 2.1.


**CONFIDENTIALITY**


**American Medical Association [AMA]: National Coalition on Adolescent Health Services.** Policy Compendium on Confidential Health Services for Adolescents. Chicago: American Medical Association, 1993 January; 29 p. NRCBL: 8.4; 9.5.7; 8.3.2; 9.5.9; 11.2; 12.1; 17.1. Identifiers: Janet E. Gans, editor.

**Barber, Barry.** The protection of individuals by protecting medical data in EHRs. *Studies in Health Technology and Informatics* 2002; 87: 38-43. NRCBL: 8.4; 1.3.12.


Abstract: INTRODUCTION: The amendments to the Privacy Act (Cth) 1988 came into force on 21st December 2001. These changes expand the impact of the Act to include the private sector and will have considerable consequences upon healthcare delivery in Australia. This paper reports the findings of a survey, which examined the implications of the Act for doctors in private practice. METHOD: Both Government and private agencies were canvassed to seek clarification of various aspects of the Act. Responses were analysed to determine what needed to be done to ensure compliance with the Act and were reviewed in the light of published material provided by commentators. RESULTS: Of twenty-one contacts, only ten responded of which five were Government agencies. Government agencies chose to deflect commentary and did not respond to specific questions. The Medical Defence Organisations (MDOs) provided the most useful commentary, highlighting various ‘grey areas’ of concern. DISCUSSION: Government agencies tasked with the enforcement of the Act were unhelpful in providing useful guidelines to specific questions. MDOs offered guidelines to risk management obviating litigation. This survey emphasised the concept that legislation developed for general purposes required redefinition to be applicable to the medical profession and had the capacity to negatively impact upon patient well-being.


**Brann, Maria; Mattson, Marifran.** Toward a typology of confidentiality breaches in health care communication: an ethic of care analysis of provider practices and patient perceptions. *Health Communication* 2004; 16(2): 229-251. NRCBL: 8.4; 7.3; 9.3.1. SC: em.


**Clough, John D.** A matter of privacy. *Cleveland Clinic Journal of Medicine* 2003 March; 70(3): 166. NRCBL: 8.4; 1.1.
English, Abigail; Ford, Carol A. The HIPAA privacy rule and adolescents: legal questions and clinical challenges. Perspectives on Sexual and Reproductive Health 2004 March-April; 36(2): 80-86. NRCBL: 8.4, 9.5.7. SC: le.


Fletcher, Jonathan; Marriott, Joanna; Phillips, David. Data protection, informed consent, and research — interpretation of legislation should reflect patients’ views [letter]. BMJ: British Medical Journal 2004 June 12; 328(7453): 1437. NRCBL: 8.4; 18.2; 1.3.12.


Harrison, John; Booth, Nick. Applying new thinking from the linked and emerging fields of digital identity and privacy to information governance in health informatics. *Informatics in Primary Care* 2003; 11(4): 223-228. NRCBL: 8.4; 1.3.12; 8.1.


Kachigian, Claudia; Felthous, Alan R. Court responses to Tarasoff statutes. *Journal of the American Academy of Psychiatry and the Law* 2004; 32(3): 263-273. NRCBL: 8.4; 17.2; 4.3; SC: le; rv.

Kaiser, Jocelyn. Privacy rule creates bottleneck for U.S. biomedical researchers [news]. *Science* 2004 July 9; 305(5681): 168-169. NRCBL: 8.4; 1.3.12; 5.3; 18.2; SC: le.


Leeman, Cavin P.; Appelbaum, Paul S. Confidentiality and the duty to warn of possible harm [letter and reply]. *American Journal of Psychiatry* 2004 March; 161(3): 583. NRCBL: 8.4; 4.3; 17.2.


Lucassen, Anneke M.; Parker, Michael; Wheeler, Robert. Role of next of kin in accessing health records of deceased relatives. *BMJ: British Medical Journal* 2004 April 17; 328(7445): 952-953. NRCBL: 8.4; 1.3.12; 8.3.3; 15.2.


CONFIDENTIALITY


Peto, Julian; Fletcher, Olivia; Gilham, Clare. Data protection, informed consent, and research — medical research suffers because of pointless obstacles. *BMJ: British Medical Journal* 2004 May 1; 328(7447): 1029-1030. NRCBL: 8.4; 8.3.1; 18.2; 7.1.


Rawdon, Suzanne. Commentary: needs of the living should come first. *BMJ: British Medical Journal* 2004 April 17; 328(7445): 954. NRCBL: 8.4; 1.3.12; 8.3.3.


Abstract: OBJECTIVES: Recent legislative changes within the United Kingdom have stimulated professional debate about access to patient data within research. However, there is currently little awareness of public views about such research. The authors sought to explore attitudes of the public, and their lay representatives, towards the use of primary care medical record data for research when patient consent was not being sought. METHODS: 49 members of the public and four non-medical members of local community health councils in South Wales, UK gave their views on the value and acceptability of three current research scenarios, each describing access to data without patient consent. RESULTS: Among focus group participants, awareness of research in primary care was low, and the appropriateness of general practitioners as researchers was questioned. There was general support for research but also concerns expressed about data collection without consent. These included lack of respect and patient control over the process. Unauthorised access to data by external agencies was a common fear. Current data collection practices, including population based disease registers elicited much anxiety. The key informants were equally critical of the scenarios and generally less accepting. CONCLUSIONS: This exploratory study has highlighted a number of areas of public concern when medical records are accessed for research without patient consent. Public acceptability regarding the use of medical records in research cannot simply be assumed. Further work is required to determine how widespread such views are and to inform those advising on confidentiality issues.

Room, Stewart. Data protection, informed consent, and research — Data Protection Act does not bar medical research [letter]. *BMJ: British Medical Journal* 2004 June 12; 328(7453): 1437. NRCBL: 8.4; 1.3.12; 18.2; 1.3.9.


SC (Subject Caption): an=analytical cs=case studies em=empirical le=legal po=popular rv=review


Smith, J.E.; Wallis, L.A. Self-assessment exercises — legal and ethical dilemmas in medicine. *Journal of the Royal Army Medical Corps* 2004 June; 150(2): 134-136. NRCBL: 8.4; 7.4; 8.3.1; 8.3.2. SC: cs.


Sullivan, Cris M.; Cain, Debra. Ethical and safety considerations when obtaining information from or about battered women for research purposes. *Journal of Interpersonal Violence* 2004 May; 19(5): 603-618. NRCBL: 8.4; 9.5.5; 9.1.


Abstract: The purpose of this presentation is to analyse the relations between: medical professionals (physicians, nurses, pharmacists) and health institutions (their managers), and, press and other media, from the point of view of Polish law. In this respect the medical professional or institution is situated between health law and press law—sometimes without realising the common problems of both, such as the problem of access to information versus personal privacy or the question related to medicine-press contacts in the advertising of professionals, institutions and pharmaceuticals. In this paper I shall attempt to examine the interdisciplinary areas of current Polish law.


Abstract: The research reported in this article examined the influence of nurses’ attitudes, subjective norms and perceived behavioral control on maintaining patients’ privacy during hospitalization. The data were gathered from 109 nurses in six internal medicine wards at an Israeli hospital. The research was based on the theories of reasoned action and planned behavior. A positive and significant correlation was shown between nurses’ attitude to promoting and maintaining patient privacy and their planned behavior, while perceived behavioral control was the best variable for predicting the nurses’ behavior. Better educated nurses believed that they had fewer resources and anticipated more obstacles in acting to promote and maintain patient privacy. This research adds a new dimension to what is already known about nurses’ attitudes to maintaining patients’ privacy, nurses’ planned behavior and their actual behavior. The practical implications of the findings are the identification of factors that influence the attitudes and behavior of nursing staff, which, in turn, will enable allocation of resources for solving difficulties and removing obstacles. The results will allow the formulation of educational programs to guide staff and also the application of policies based on both patient and nursing staff needs.


Vaszar, Laszlo T.; Cho, Mildred K.; Raffin, Thomas A. Privacy issues in personalized medicine.


Zimmern, Ron L.; Hall, Alison. Commentary: the arguments could be extended. *BMJ: British Medical Journal* 2004 April 17; 328(7445): 954. NRCBL: 8.4; 1.3.12; 8.3.3.


**CONTRACEPTION**

*See also POPULATION CONTROL; STERILIZATION*

Catholic Charities Petitioner v. California Department of Managed Health et al; real parties in interest: petitioners brief on the merits. *National Catholic Bioethics Quarterly* 2004 Spring; 4(1): 133-149. NRCBL: 11.1; 9.3.1; 1.2. SC: le.


Cantalo, Peter J. Compliance with contraceptive insurance mandates: licit or illicit cooperation in evil? *National Catholic Bioethics Quarterly* 2004 Spring; 4(1): 103-130. NRCBL: 11.1; 9.3.1; 1.2; 12.3; 12.4.3; 4.4. SC: le.


SECTION I

CRYOBankING OF SPERM, OVA, OR EMBRYOS


Klaus, Hanna. The case against Plan B. *Ethics and Medics* 2004 March; 29(3): 3-4. NRCBL: 11.1; 12.3; 10; 9.5.5; 21.1; 9.7. Identifiers: emergency contraception; levonorgestrel.


Steinbrook, Robert. Waiting for plan B — the FDA and nonprescription use of emergency contraception. *New England Journal of Medicine* 2004 June 3; 350(23): 2327-2329. NRCBL: 11.2; 11.1; 5.3; 1.3.5.


Tonti-Filippini, Nicholas; Walsh, Mary. Postcoital intervention — from fear of pregnancy to rape crisis. *National Catholic Bioethics Quarterly* 2004 Summer; 4(2): 275-288. NRCBL: 11.1; 9.5.5; 10; 1.2.


Yavarone, Mark. Do anovulants and IUDs kill early human embryos? A question of conscience. *National Catholic Bioethics Quarterly* 2004 Spring; 4(1): 63-70. NRCBL: 11.1; 9.5.8; 9.5.5; 1.2; 8.3.1. Identifiers: intrauterine device.


COST OF HEALTH CARE See HEALTH CARE ECONOMICS

CRYOBankING OF SPERM, OVA, OR EMBRYOS

Baines, Barry. Respective legal responsibilities among clinicians and scientists for frozen embryos [opinion]. *Reproductive BioMedicine Online* [electronic] 2004 Febru-
CRYOBANKING OF SPERM, OVA, OR EMBRYOS

SECTION I


Landau, R. Posthumous sperm retrieval for the purpose of later insemination or IVF in Israel: an ethical and psychological critique [opinion]. Human Reproduction 2004 September; 19(9): 1952-1956. NRCBL: 14.6; 19.5; 4.4; 1; 8.3.3.


Parker, M. Response to Orr and Siegler — collective intentionality and procreative desires: the permissible view on consent to posthumous conception. Journal of Medical Ethics 2004 August; 30(4): 389-392. NRCBL: 14.6; 20.1; 5.3; 8.3.3. SC: an.

SC (Subject Caption): an=analytical cs=case studies em=empirical le=legal po=popular rv=review
phenomenology of procreative desires which supports the permissible view, and which is compatible with requirements concerning the interests of the decedent, concepts of medical infertility, and the welfare of the future child. The account illustrates how our current obsession with individual rights and autonomy can be self-defeating and repressive.


CULTURAL PLURALISM

Ajlouni, Kamel M. Values, qualifications, ethics and legal standards in Arabic (Islamic) medicine. Saudi Medical Journal 2003 August; 24(8): 820-826. NRCBL: 21.7; 2.2; 4.1.2; 8.3.1.


Garvey, G.; Towney, P.; McPhee, J.R.; Little, M.; Kerridge, I.H. Is there an Aboriginal bioethic? Journal of Medical Ethics 2004 December; 30(6): 570-575. NRCBL: 21.7; 9.5.4. Identifiers: Australia; Aboriginals. Abstract: It is well recognised that medicine manifests social and cultural values and that the institution of health care cannot be structurally disengaged from the sociopolitical processes that create such values. As with many other indigenous peoples, Aboriginal Australians have a lower health status than the rest of the community and frequently experience the effects of prejudice and racism in many aspects of their lives. In this paper the authors highlight values and ethical convictions that may be held by Aboriginal peoples in order to explore how health practitioners can engage Aboriginal patients in a manner that is more appropriate. In doing so the authors consider how the ethics, values, and beliefs of the dominant white Australian culture have framed the treatment and delivery of services that Aboriginal people receive, and whether sufficient effort has been made to understand or acknowledge the different ethical predispositions that form the traditions and identity of Aboriginal Australians.

Nie, Jing-Bao. The myth of the Chinese culture, the myth of the Chinese medical ethics. Bioethics Examiner 1999 Summer; 3(2): 1-2, 5. NRCBL: 21.7; 8.2; 12.3.


DEATH AND DYING

See also ADVANCE DIRECTIVES; ASSISTED SUICIDE; EUTHANASIA AND ALLOWING TO DIE

Kurosu, Mitsuyasu; Mukai, Toshiji; Ohno, Youkichi. Regulations and guidelines on handling human materials obtained from medicolegal autopsy for use in research. Legal Medicine (Tokyo, Japan) 2003 March; 5(Supplement 1): 576-579. NRCBL: 20.1; 8.3.3.


DEATH AND DYING/ ATTITUDES TO DEATH


Cameron, Miriam E. Completing life and dying triumphantly. Journal of Nursing Law 1999; 6(1): 27-32. NRCBL: 20.3.1; 20.4.1; 4.1.1; 8.2.

Chochinov, Harvey Max. Dignity and the eye of the beholder. Journal of Clinical Oncology 2004 April 1; 22(7): 1336-1340. NRCBL: 20.3.1; 4.4; 17.1; 20.4.1. SC: cs.


Hinkka, Heikki; Kosunen, Elise; Lammi, Ulla-Kaija; Metsänoja, Riina; Kellokumpu-Lehtinen, Pirkko. Attitudes to terminal patients’ unorthodox therapy: Finnish doctors’ responses to a case scenario. Supportive Care in Cancer 2004 February; 12(2): 132-136. NRCBL: 20.3.2; 4.1.1; 8.1; 20.4.1. SC: cs; em.


Abstract: OBJECTIVE: To describe the frequency of support for terminal sedation among internists, determine whether support for terminal sedation is accompanied by support for physician assisted suicide (PAS), and explore characteristics of internists who support terminal sedation but not assisted suicide. DESIGN: A statewide, anonymous postal survey. SETTING: Connecticut, USA. PARTICIPANTS: 677 Connecticut members of the American College of Physicians. MEASUREMENTS: Attitudes toward terminal sedation and assisted sui-

Abstract: OBJECTIVE: To obtain feedback from patients receiving palliative care and their relatives from various ethnic backgrounds about their experiences of the disclosure process and their satisfaction with information sharing during the illness. DESIGN: A qualitative study with semistructured single interviews. SETTING: Perth, Western Australia, and Winnipeg, Manitoba, Canada. PARTICIPANTS: 72 participants registered with palliative care: 21 patient-family dyads in Perth and 14 dyads and 2 patients in Winnipeg. RESULTS: Participants described their experiences in great detail. The analysis indicates that in information sharing the process is as important as the content. The timing, management, and delivery of information and perceived attitude of practitioners were critical to the process. This applied to information interactions at all stages of the illness. Main content areas mentioned related to prognosis and hope. Hope can be conveyed in different ways. Secondary information from various sources is accessed and synthesised with the primary information. All patients, regardless of origin, wanted information about their illness and wanted it fully shared with relatives. Almost all patients requested prognostic information, and all family members respected their wishes. Information was perceived as important for patient-family communication. Information needs of patient and family changed and diverged as illness progressed, and communication between them became less verbally explicit. CONCLUSIONS: Information delivery for patients needs to be individualised with particular attention to process at all stages of illness. Patients and families use secondary sources of information to complement and verify information given by health carers.


Kreicbergs, Ulrika; Valdimarsdóttir, Unnur; Steineck, Gunnar; Henter, Jan-Inge. A population-based nationwide study of parents’ perceptions of a questionnaire on their child’s death due to cancer. Lancet 2004 August 28-September 3; 364(9436): 787-789. NRCBL: 20.3.3; 20.4.2; 18.2; 18.3. SC: em.

Abstract: A proposed nationwide postal questionnaire to Swedish parents who had lost a child due to cancer between 1982 and 1997 was denied approval by the local ethics committee. However, a pilot study to assess the harm and benefit of the questionnaire was approved. 95% of parents found the pilot study valuable; thus, we were allowed to proceed with the main study, which consisted of 129 questions about the child’s care and death and five about the parents’ perceptions of the study. 423 (99%) parents found the investigation valuable, 285 (68%) were positively affected, and 123 (28%) were negatively affected (10 [2%] of whom, very much). Although the numerical data cannot be directly translated to ethical conclusions, they can provide guidance for future ethical decisions.


Oh, Do-Youn; Kim, Jee-Eun; Lee, Chee-Hun; Lim, Jae-Sung; Jung, Kyung-Hye; Heo, Dae Seog; Bang, Yung-Jue; Kim, Noe Kyeong. Discrepancies among patients, family members, and physicians in Korea in terms of values regarding the withholding of treatment from patients with terminal malignancies. Cancer 2004 May 1; 100(9): 1961-1966. NRCBL: 20.3.2; 20.3.3; 20.5.1. SC: em.
DEATH AND DYING/ ATTITUDES TO DEATH


Phipps, Etienne; True, Gala; Harris, Diana; Chong, Umi; Tester, William; Chavin, Stephen I.; Braitman, Leonard E. Approaching the end of life: attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. Journal of Clinical Oncology 2003 February 1; 21(3): 549-554. NRCBL: 20.3.3; 20.4.1; 20.5.4; 21.7. SC: em.


Teno, Joan M.; Clarridge, Brian R.; Casey, Virginia; Welch, Lisa C.; Wette, Terrie; Shield, Renee; Mor, Vincent. Family perspectives on end-of-life care at the last place of care. JAMA: The Journal of the American Medical Association 2004 January 7; 291(1): 88-93. NRCBL: 20.3.3; 20.4.1. SC: em.

Tong, Elizabeth; McGraw, Sarah A.; Dobihal, Edward; Baggish, Rosemary; Cherlin, Emily; Bradley, Elizabeth H. What is good death? Minority and non-minority perspectives. Journal of Palliative Care 2003 Autumn; 19(3): 168-175. NRCBL: 20.3.1; 9.5.4. SC: em.

Vig, Elizabeth K.; Pearlman, Robert A. Good and bad dying from the perspective of terminally ill men. Archives of Internal Medicine 2004 May 10; 164(9): 977-981. NRCBL: 20.3.1; 20.4.1; 4.4. SC: em.


one quarter reported concerns with physician communication. More than one third of respondents cared for by a home health agency, nursing home, or hospital reported insufficient emotional support for the patient and/or 1 or more concerns with family emotional support, compared with about one fifth of those receiving home hospice services. Nursing home residents were less likely than those cared for in a hospital or by home hospice services to always have been treated with respect at the end of life (68.2% vs 79.6% and 96.2%, respectively). Family members of patients receiving hospice services were more satisfied with overall quality of care: 70.7% rated care as “excellent” compared with less than 50% of those dying in an institutional setting or with home health services (P001). CONCLUSIONS: Many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect. Family members of decedents who received care at home with hospice services were more likely to report a favorable dying experience.

Abstract: BACKGROUND: Understanding the range of patients’ views about good and bad deaths may be useful to clinicians caring for terminally ill patients. Our current understanding of good and bad deaths, however, comes primarily from input from families and clinicians. This study aimed to learn how terminally ill men conceptualize good and bad deaths. METHODS: We conducted semistructured interviews with 26 men identified as having terminal heart disease or cancer. Participants described good and bad deaths in a section of open-ended questions. Participants also answered closed-ended questions about specific end-of-life scenarios. The open-ended questions were tape-recorded, transcribed, and analyzed using grounded theory methods. The closed-ended questions were analyzed using descriptive statistics. RESULTS: We found heterogeneity in responses to questions about good deaths, bad deaths, and preferred dying experiences. Participants voiced multiple reasons for why dying in one’s sleep led to a good death and why prolonged dying or suffering led to a bad death. Participants did not hold uniform views about the presence of others at the very end of life or preferred location of dying. CONCLUSIONS: In discussing the end of life with terminally ill patients, clinicians may want to identify not only their patients’ views of good and bad deaths but also how the identified attributes contribute to a good or bad death. The discussion can then focus on what might interfere with patients’ attainment of their preferred dying experience and what may be available to help them achieve a death that is most consistent with their wishes.

SC (Subject Caption): an=analytical cs=case studies em=empirical le=legal po=popular rv=review

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SECTION I  DEATH AND DYING/DETERMINATION OF DEATH


Doran, Majella. The presence of family during brain stem death testing. *Intensive and Critical Care Nursing* 2004 February; 20(1): 32-37. NRCBL: 20.2.1; 20.3.3.


DEATH AND DYING/ TERMINAL CARE

Section I


Abstract: Decision making and choices are frequent themes in medical ethics. Game theory is based upon modelled decision making. Game theory, and associated logic traps, may have relevance to the clinical practice of medicine and medical ethics. The “prisoner’s dilemma” is one logic trap from game theory in which “rational” decision making on the part of participating individuals can lead to “suboptimal” situations. An example of such a situation involving brain death is presented and discussed from the perspective of the prisoner’s dilemma.


Sheikh, Asim A.; Cusack, Denis A. Maternal brain death, pregnancy and the foetus: the medico-legal impli ca tions for Ireland. *Proceedings of the Eighth Conference of The European Association for Perinatal Medicine* 2004; 23(2): 237-250. NRCBL: 20.2.1; 9.5.5; 20.5.2; 20.5.1; 9.5.8. SC: le.

Abstract: This paper examines some of the medico-legal issues that arose as a result of a situation which occurred in May 2001 in Ireland when a woman who was a British citizen and who was fourteen weeks pregnant collapsed and suffered a brain haemorrhage. She was taken to hospital where she was placed on life support but declared brain-dead. As a result of the uncertainty regarding the hospital’s obligation to the foetus, life-support was maintained until further opinion was sought. After two weeks the foetus died and life support was only then discontinued. In Ireland there currently exists neither medical guidelines nor legislation to regulate such areas of medical practice. Also, the courts have not had the opportunity to comment on this particular matter and thus there exists widespread concern as to how healthcare providers will act if such situation were to occur again in the future. This article examines the following difficult medico-legal implications that arise from the above situation and especially in light of the constitutional protection of the unborn child in Ireland.


Sperling, Daniel. Maternal brain death. *American Journal of Law and Medicine* 2004; 30(4): 453-500. NRCBL: 20.2.1; 20.5.1; 9.5.5; 9.5.8; 12.4.2; 4.4; 19.5; 8.3.3. SC: le.


DEATH AND DYING/ TERMINAL CARE


Avery, Robert; Byock, Ira; Miles, Steven H. Hospice benefits and phase I cancer trials [letter and reply]. *Annals of Internal Medicine* 2004 January 6; 140(1): 70, 71. NRCBL: 20.4.1; 18.5.7; 9.3.1.

Barilan, Y. Michael. Terminal sedation, terminal elation, and medical parsimony. *Ethics and Medicine* 2004 Fall; 20(3): 151-165. NRCBL: 20.4.1; 4.4; 20.5.1; 9.7; 1.1; 20.3.1; 18.5.2.


Basta, Lofty L. Ethical issues in the management of geriatric cardiac patients: an older cordial patient depended on his younger and healthier wife to make all the financial and medical end-of-life decisions until the wife was diagnosed with an aggressive metastasizing breast cancer. *American Journal of Geriatric Cardiology* 2004 January-February; 13(1): 45-46. NRCBL: 20.4.1. SC: cs.

Basta, Lofty L. Ethical issues in the management of geriatric cardiac patients: a 71-year-old woman was taken away from hospice care to undergo an open lung biopsy and rehabilitation care which diminished her quality of life and probably hastened her death. *American Journal of Geriatric Cardiology* 2003 November-December; 12(6): 373-374. NRCBL: 20.4.1; 4.4. SC: cs.

Baumrucker, Steven J.; Carter, Greg; Morris, Gerald M.; Stolick, Matt; Hentz, Patricia. Case study: when should the scope of care extend beyond the patient? *American Journal of Hospice and Palliative Care* 2004 July-August; 21(4): 294-296. NRCBL: 20.4.1; 8.1. SC: cs; le.

Becker, G.; Momm, F.; Baumgartner, J. Palliativmedizin: Bedarfs und Umsetzung [Palliative care:...
the demand and the realization]. Deutsche Medizinische Wochenschrift 2003 October 17; 128(42): 2209-2212. NRCBL: 20.4.1. Identifiers: Germany.


Boyle, Joseph. Medical ethics and double effect: the case of terminal sedation. Theoretical Medicine and Bioethics 2004; 25(1): 51-60. NRCBL: 20.4.1; 20.5.1; 1.1. SC: an. Abstract: The use of terminal sedation to control the intense discomfort of dying patients appears both to be an established practice in palliative care and to run counter to the moral and legal norm that forbids health care professionals from intentionally killing patients. This raises the worry that the requirements of established palliative care are incompatible with moral and legal opposition to euthanasia. This paper explains how the doctrine of double effect can be relied on to distinguish terminal sedation from euthanasia. The doctrine of double effect is rooted in Catholic moral casuistry, but its application in law and morality need not depend on the particular framework in which it was developed. The paper further explains how the moral weight of the distinction between intended harms and merely foreseen harms in the doctrine of double effect can be justified by appeal to a limitation on the human capacity to pursue good.

Byock, Ira. The ethics of loving care: palliative care, like pediatrics, understands that patients should always be seen as capable of growth. Health Progress 2004 July-August; 85(4): 12-19, 57. NRCBL: 20.4.1; 20.5.1; 7.1; 2.1.


Dresser, Rebecca. Death with dignity: contested boundaries. Journal of Palliative Care 2004 Autumn; 20(3): 201-206. NRCBL: 20.4.1; 20.5.1; 4.4; 20.7; 8.1; 9.2; 9.4; 18.5.7; 8.3.3. Conference: Symposium: "Human Dignity, Narrative Integrity, and Ethical Decision Making at the End of Life," St. John’s, Newfoundland and Labrador, June 2004.


Enes, S. Patricia D.; de Vries, Kay. A survey of ethical issues experienced by nurses caring for terminally ill elderly people. Nursing Ethics 2004 March; 11(2): 150-164. NRCBL: 20.4.1; 7.1; 8.2; 9.5.2. SC: em. Identifiers: Great Britain. Abstract: This study examined the ethical issues experienced by nurses working in a small group of elderly persons’ care settings in the UK, using a survey questionnaire previously used in other countries for examining the cultural aspects of ethical issues. However, ‘culture’ relates not only to ethnicity but also the organizational culture in which care is delivered. Nurses working in elderly persons’ care settings described a range of issues faced when caring for elderly terminally ill people, which illustrated the different needs of patients, relatives, professionals and society. These issues related to the unique needs of elderly people (such as dementia sufferers) and could have an impact on patients’ quality of death.


Glick, Shimon M.; Rietjens, Judith A.C.; van der Heide, Agnes; van der Wal, Gerrit. Terminal sedation in the Netherlands [letter and reply]. Annals of Internal Medicine 2004 December 21; 141(12): 966-967. NRCBL: 20.4.1; 9.7; 20.5.1.


Kissane, David W. The challenge of discrepancies in values among physicians, patients, and family members [editorial]. Cancer 2004 May 1; 100(9): 1771-1775. NRCBL: 20.4.1; 1.1; 8.2; 21.7. Identifiers: Korea.
Krouse, Robert S.; Easson, Alexandra M.; Angelos, Peter. Ethical considerations and barriers to research in surgical palliative care. *Journal of the American College of Surgeons* 2003 March; 196(3): 469-474. NRCBL: 20.4.1; 9.5.1; 18.5.7; 8.3.1.

LaDuke, Sharon. Attending death with dignity: a nurse finds herself the center of controversy after effectively managing pain for a dying patient. *Health Affairs* 2004 May-June; 23(3): 222-227. NRCBL: 20.4.1; 4.4; 8.5. SC: cs; le.


McDonald, Michael. Dignity at the end of our days: personal, familial, and cultural location. *Journal of Palliative Care* 2004 Autumn; 20(3): 163-170. NRCBL: 20.4.1; 20.5.1; 8.3.1; 8.3.3; 4.4; 7.1. Conference: Symposium: “Human Dignity, Narrative Integrity, and Ethical Decision Making at the End of Life,” St. John’s, Newfoundland and Labrador, June 2004.

McIntyre, Alison. The double life of double effect. *Theoretical Medicine and Bioethics* 2004; 25(1): 61-74. NRCBL: 20.4.1; 1.1. SC: an. Abstract: The U.S. Supreme Court’s majority opinion in Vacco v. Quill assumes that the principle of double effect explains the permissibility of hastening death in the context of ordinary palliative care and in extraordinary cases in which painkilling drugs have failed to relieve especially intractable suffering and terminal sedation has been adopted as a last resort. The traditional doctrine of double effect, understood as providing a prohibition on instrumental harming as opposed to incidental harming or harming as a side effect, must be distinguished from other ways in which the claim that a result is not intended might be offered as part of a justification for it. Although double effect might appropriately be invoked as a constraint on ordinary palliative care, it is not clear that it can be coherently extended to justify such practices as terminal sedation. A better approach would reconsider double effect’s traditional prohibition on hastening death as a means to relieve suffering in the context of acute palliative care.


Micco, Guy. Should a loved one be allowed in the resuscitation room? The times they are a-changin’. *Journal of Clinical Ethics* 2004 Fall; 15(3): 243-249. NRCBL: 20.4.1; 20.3.3; 20.3.2.


Mitchell, Susan L.; Kiely, Dan K.; Hamel, Mary Beth. Dying with advanced dementia in the nursing home. *Archives of Internal Medicine* 2004 February 9; 164(3): 321-326. NRCBL: 20.4.1; 9.5.2; 17.1; 20.5.4. SC: em.

Mulaski, Richard A.; Osborne, Molly L. End-of-life care in the critically ill geriatric population. *Critical Care Clinics* 2003 October; 19(4): 789-810. NRCBL: 20.4.1; 9.5.2; 8.1; 8.3.1; 20.5.1.


Oltius, Gert; Dekkers, Wim. Professional competence and palliative care: an ethical perspective. *Journal of Palliative Care* 2003 Autumn; 19(3): 192-197. NRCBL: 20.4.1; 1.1; 8.1; 9.8; 4.1.2.

Orr, Robert D. Just put me to sleep . . . please! Ethical issues in palliative and “terminal” sedation. *Update: Loma Linda University Center for Christian Bioethics* 2002 September; 18(2): 1-4, 8. NRCBL: 20.4.1; 20.5.1; 20.7; 1.2.

Orsino, Angela; Cameron, Jill I.; Seidl, Maja; Mendelsohn, David; Stewart, Donna E. Medical decision-making and information needs in end-stage renal disease patients. *General Hospital Psychiatry* 2003 September-October; 25(5): 324-331. NRCBL: 20.4.1; 19.3; 9.4; 8.1; 8.3.1. SC: em.


Petersen, Andrea. Designing a better place to die; long focused on sustaining life at all costs, some ICUs add hospice-like services. *Wall Street Journal* 2004 April 18; p. D1, D4. NRCBL: 20.4.1; 9.3.1. SC: po.


Place, Michael D. Thoughts on the papal allocution. *Health Progress* 2004 July-August; 85(4): 6, 60. NRCBL: 20.4.1; 1.2.


Puchalski, Christina M. Listening to stories of pain and joy: physicians and other caregivers can help patients find comfort and meaning at the end of life. *Health Progress* 2004 July-August; 85(4): 20-22, 57. NRCBL: 20.4.1; 9.5.1; 1.2.


Rabow, Michael W.; Hauser, Joshua M.; Adams, Jocelia. Supporting family caregivers at the end of life: “they don’t know what they don’t know”. *JAMA: The Journal of the American Medical Association* 2004 January 28; 291(4): 483-491. NRCBL: 20.4.1; 8.1. Abstract: Even for patients receiving complex, intensive medical care for serious and life-threatening illness, family caregiving is typically at the core of what sustains patients at the end of life. The amorphous relationship between physicians and the families of patients at the end of life presents both challenges and opportunities for which physicians may be unprepared. Families play important roles in the practical and emotional aspects of patient care and in decision making at the end of life. At the same time, family members may carry significant burdens as a result of their work. Through the perspectives of the wife, daughter, and home care nurse of a patient who died from pancreatic cancer, we illustrate the range of family caregiver experiences and suggest potentially helpful physician interventions. We describe 5 burdens of family caregiving (time and logistics, physical tasks, financial costs, emotional burdens and mental health risks, and physical health risks) and review the responsibilities of physicians to family caregivers. Based on available evidence, we identify 5 areas of opportunity for physicians to be of service to family members caring for patients at the end of life, including promoting excellent communication with family, encouraging appropriate advance care planning and decision making, supporting home care, demonstrating empathy for family emotions and relationships, and attending to family grief and bereavement. In caring well for family caregivers at the end of life, physicians may not only improve the experiences of patients and family but also find greater sustenance and meaning in their own work.


Speck, Peter; Higginson, Irene; Addington-Hall, Julia. Spiritual needs in health care: may be distinct from religious ones and are integral to palliative care [editorial]. BMJ: British Medical Journal 2004 July 17; 329(7458): 123-124. NRCBL: 20.4.1; 1.2.

Steinhauser, Karen E.; Christakis, Nicholas A.; Clipp, Elizabeth C.; McNeilly, Maya; Grambow, Steven; Parker, Joanna; Tulsky, James A. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. Journal of Pain and Symptom Management 2001 September; 22(3): 727-737. NRCBL: 20.4.1; 20.3.2; 20.3.3. SC: em.


Teno, Joan M.; Field, Marilyn J.; Byock, Ira. The road taken and to be traveled in improving end-of-life care. Journal of Pain and Symptom Management 2001 September; 22(3): 713-716. NRCBL: 20.4.1. Note: Preface to Special Section on Measuring Quality of Care at Life’s End II.


Abstract: OBJECTIVES: To analyse the decision making for end of life care for patients with cancer at a teaching hospital in Japan at two periods 10 years apart. DESIGN AND SETTING: Retrospective study conducted in a 550 bed community teaching hospital in Okinawa, Japan. PATIENTS: There were 124 terminally ill cancer patients (45 women; 79 men; median age, 69 years) admitted both in 1989 and 1999 for end of life care with sufficient data to permit analysis. Main measurements: Basic demographic data, notification to the patient that he or she had cancer, patient involvement in do not resuscitate (DNR) orders, and various medical interventions which were performed in the month prior to the patient’s death were evaluated. RESULTS: In 1989 none of the patients were notified of their diagnosis; in 1999 five patients were informed (p = 0.026). Of the 113 (91%) patients with a written DNR order, none were involved in consenting to the DNR order. In the month before death, patients in both groups received non-palliative treatments such as feeding tube placements (five in 1989; five in 1999), total parenteral nutrition (six in 1989; eight in 1999), and intravenous albumin infusion (four in 1989; five in 1999). Morphine use increased (30%) significantly in 1999 compared with the 1989 group. CONCLUSIONS: The majority of patients dying of cancer were still not informed of their diagnosis and were seldom involved in DNR decision making at a teaching hospital in Japan. There was no change in the number of potentially futile interventions that were performed (6-13%) but morphine use increased. Modern ethical education is urgently needed in Japanese medical practice to improve decision making process in the end of life care.

Trump, Donald L.; Byock, Ira; Miles, Steven H. Hospice benefits and phase I cancer trials [letter and reply]. Annals of Internal Medicine 2004 January 6; 140(1): 70-71. NRCBL: 20.4.1; 9.3.1; 18.5.7.


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DEATH AND DYING/ TERMINAL CARE FOR MINORS


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DELIVERY OF HEALTH CARE See CARE FOR SPECIFIC GROUPS; HEALTH CARE

DETERMINATION OF DEATH See DEATH AND DYING/DETERMINATION OF DEATH

DISCLOSURE See CONFIDENTIALITY; INFORMED CONSENT; HUMAN EXPERIMENTATION/INFORMED CONSENT; TRUTH DISCLOSURE

DISTRIBUTIVE JUSTICE See RESOURCE ALLOCATION

DIVERSITY See CULTURAL PLURALISM; GENETICS AND HUMAN ANCESTRY

DNA FINGERPRINTING See GENETICS/LEGAL ASPECTS

DONATION See BLOOD DONATION AND TRANSFUSION; ORGAN AND TISSUE TRANSPLANTATION/ DONATION AND PROCUREMENT

DRUG INDUSTRY


New code of ethics for device industry. OR Manager 2003 November; 19(11): 22. NRCBL: 9.7; 1.3.2; 7.3; 6.

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with sexual partner(s). Physicians must first evaluate the patient comprehensively, addressing not only erectile function and sexual performance, but overall physical and mental health. Since the drug does impact others, an expanded model for informed consent needs to be considered. Three models to consider include the public health one, ethically justified limits on confidentiality, and a biopsychosocial one. The biopsychosocial model may be preferred because it expands the patient-physician dyad to directly include others. Physicians also need to distinguish between professional, role-related obligations and personal conscience when treating patients whose sexual beliefs and practices differ from their own. Other ethical issues include inappropriate prescribing over the Internet, dealing with unrealistic patient expectations, and fairness in paying for treatment for sexual conditions in both men and women. With these proposed guidelines, physicians can continue to provide steady, reliable guidance for patients while working with yet another scientific advance in medicine.

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Abstract: A 69-year-old woman with several medical problems believes that she is allergic to generic medications. She frequently conflicts with her long-time primary care physician, who, as required by the patient’s insurance coverage, refuses to prescribe brand-name drugs when generic alternatives are available. This conflict intensifies when a crisis leaks the patient develops life-threatening problems and still will not take prescribed generic medications. The presentation of this real case is accompanied by a discussion of the ethical dilemmas the patient’s physician, who must weigh the interests of a patient who clings to beliefs that the physician thinks are unfounded against the interests of a just rationing program and the broader population it serves.


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**DURABLE POWER OF ATTORNEY** See ADVANCE DIRECTIVES

**ECONOMICS** See HEALTH CARE ECONOMICS; ORGAN AND TISSUE TRANSPLANTATION/ DONATION AND PROCUREMENT; ECONOMIC ASPECTS

**EDUCATION** See BIOETHICS AND MEDICAL ETHICS/ EDUCATION; MEDICAL EDUCATION

**ELECTROCONVULSIVE THERAPY**

See also BEHAVIOR CONTROL; CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; INVOLUNTARY COMMITMENT; MENTAL HEALTH THERAPIES; PSYCHOPHARMACOLOGY; PSYCHOTHERAPY


**EMBRYOS** See CARE FOR SPECIFIC GROUPS/ FETUSES; HUMAN EXPERIMENTATION/

**SPECIAL POPULATIONS/ EMBRYOS AND FETUSES**

**ENHANCEMENT**

See also EUGENICS


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Abstract: We outline a number of ethical objections to genetic technologies aimed at enhancing human capacities and traits. We then argue that, despite the persuasiveness of some of these objections, they are insufficient to stop the development and use of genetic enhancement technologies. We contend that the inevitability of the technologies results from a particular guiding worldview of humans as masters of the human evolutionary future, and conclude that recognizing this worldview points to new directions for ethical thinking about genetic enhancement technologies.


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**ETHICS COMMITTEES** See ETHICISTS AND ETHICS COMMITTEES; HUMAN EXPERIMENTATION/ETHICS COMMITTEES AND POLICY GUIDELINES

**EUGENICS**

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EUTHANASIA AND ALLOWING TO DIE
See also ADVANCE DIRECTIVES; ASSISTED SUICIDE; DEATH AND DYING; DEATH AND DYING/DETERMINATION OF DEATH


American Thoracic Society; European Respiratory Society; European Society of Intensive Care Medicine; Society of Critical Care Medicine; Societede Reanima-
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de Vos, Rien. To be resuscitated or not: the concepts in decision making. Journal of Cardiovascular Nursing 2001 October; 16(1): 21-27. NRCBL: 20.5.1; 9.4; 8.1.


Diamond, Eugene F. Karl Brandt in the dock. Linacre Quarterly 2004 November; 71(4): 308-315. NRCBL: 20.5.1; 20.5.2; 15.5. Identifiers: Germany.

Ditillo, Betty A. Should there be a choice for cardiopulmonary resuscitation when death is expected? Revisiting an old idea whose time is yet to come. Journal of Palliative Medicine 2002 February; 5(1): 107-116. NRCBL: 20.5.1; 8.3.4.


Druart, Marie-Louise; Michel, Luc; Van Damme, Hendrik. Euthanasia and surgery: concerning the Belgian law on euthanasia [editorial]. Acta Chirurgica Belgica 2002 December; 102(6): 363-364. NRCBL: 20.5.1; 9.5.1; 9.3.1; 9.8.


Abstract: This paper points out that to persons unfamiliar with the context and suffering of dying patients, their loved ones, and last, but by no means least, the health care team can only discuss the very concrete question of euthanasia in an abstract way unaware of the fact that this question must, in the final analysis, be differently addressed in different specific patients and under specific circumstances. This paper poses questions which must be addressed and will rarely find a good answer but at least the best among a series of unpalatable options. It again points out the important and legitimate place that emotions play in decision-making.


Frei, Andreas; Schenker, Tanja; Finzen, Asmus; Dittmann, Volker; Kraeuchi, Kurt; Hoffmann-Richter, Ulrike. The Werther effect and assisted suicide. Suicide and Life-Threatening Behavior 2003 Summer; 33(2): 192-200. NRCBL: 20.5.1; 20.7; 7.1. SC: em.


Abstract: OBJECTIVE: To examine students’ attitudes and potential behaviour to a competent patient’s request for withdrawal of treatment as they pass through a modern medical curriculum. DESIGN: Cohort design. SETTING: University of Glasgow Medical School, United Kingdom. SUBJECTS: A cohort of students entering Glasgow University’s new learner centre, integrated medical curriculum in October 1996. METHODS: Students’ responses before and after year 1, after year 3, and after year 5 to the assisted suicide vignette of the Ethics in Health Care Survey instrument, were examined quantitatively and qualitatively. Analysis of students’ multichoice answers enabled measurement of the movement towards professional consensus opinion. Analysis of written justifications helped determine whether their reasoning was consistent with professional consensus and enabled measurement of change in knowledge content and recognition of the values inherent in the vignette. Themes on students’ reasoning behind their decision to withdraw treatment or not were also identified. RESULTS: Students’ answers were found to be consistent with professional consensus opinion precurriculum and remained so throughout the curriculum. There was an improvement in the knowledge content of the written responses following the first year of the curriculum, which was sustained postcurriculum. However, students were found to analyse the section mainly in terms of autonomy, with few responses considering the other main ethical principles or the wider ethical perspective. Students were unclear on their legal responsibilities. CONCLUSIONS: Students should be encouraged to consider all relevant ethical principles and the wider ethical perspective when deliberating ethical dilemmas. Students should have a clear understanding of their legal responsibilities.


Goldstein, Nathan E.; Lampert, Rachel; Bradley, Elizabeth; Lynn, Joanne; Krumholz, Harlan M. Management of implantable cardioverter defibrillators in end-of-life care. *Annals of Internal Medicine* 2004 December; 7: 141(11): 835-838. NRCBL: 20.5.1; 8.1. SC: em. Abstract: BACKGROUND: Implantable cardioverter defibrillators (ICDs) can prevent premature death from an arrhythmia but may also prolong the dying process and make it more distressing. OBJECTIVE: To describe the frequency, timing, and correlates of discussions about deactivating ICDs. DESIGN: Retrospective cohort study. SETTING: Telephone survey. PARTICIPANTS: Next of kin of patients with ICDs who died of any cause. Of 136 next of kin contacted, 100 (74%) participated. MEASUREMENTS: Incidence of discussions about deactivating ICDs and timing of last shock from ICD. RESULTS: Next of kin reported that clinicians discussed deactivating the ICD in only 27 of the 100 cases. Most discussions occurred in the last few days of life. Family members reported that 8 patients received a shock from their ICD in the minutes before death. LIMITATIONS: This retrospective survey relied on the reports of next of kin. CONCLUSIONS: Next of kin reported that clinicians discussed deactivating ICDs with few patients. Individuals who choose to receive this device should have the opportunity to choose to discontinue it as death approaches.


Hackler, Chris. Extending the life span: mythic desires and modern dangers. *HEC (Healthcare Ethics Committee)* Forum 2004 September; 16(3): 182-196. NRCBL: 20.5.1; 7.1; 15.4; 9.4; 4.4.

Hagelin, J.; Nilstun, T.; Hau, J.; Carlsson, H.-E. Surveys on attitudes towards legislation of euthanasia: importance of question phrasing. *Journal of Medical Ethics* 2004 December; 30(6): 521-523. NRCBL: 20.5.1. SC: em. Abstract: AIM: To explore whether the phrasing of the questions and the response alternatives would influence the answers to questions about legalisation of euthanasia. METHODS: Results were compared from two different surveys in populations with similar characteristics. The alternatives “positive”, “negative”, and “don’t know” (first questionnaire) were replaced with an explanatory text, “no legal sanction”; four types of legal sanctions, and no possibility to answer “don’t know” (second questionnaire). Four undergraduate student groups (engineering, law, medicine, and nursing) answered. RESULTS: In the first questionnaire (n = 684) 43% accepted euthanasia (range 28-50%), 14% (8-33%) did not, and 43% (39-59%) answered “don’t know”. Two per cent of the respondents declined to answer. In comparison with previous surveys on attitudes to euthanasia the proportion of “don’t know” was large. The results of the second questionnaire (n = 639), showed that 38% favoured “no legal prosecution” (26-50%). However, 62% (50-74%) opted for different kinds of legal sanctions, and two of four groups expressed significantly different views in the two surveys. A proportion of 10% declined to answer the second questionnaire. CONCLUSION: An introduction of an explanatory text and a wider range of response alternatives produced differences between the results of the two surveys conducted.


Hickman, Susan E.; Tolle, Susan W.; Brummel-Smith, Kenneth; Carley, Margaret Murphy. Use of the Physician Orders for Life-Sustaining Treatment Program in Oregon nursing facilities: beyond resuscitation status. Journal of the American Geriatrics Society 2004 September; 52(9): 1424-1429. NRCBL: 20.5.1; 9.5.2; 20.5.4. SC: cs.


Abstract: OBJECTIVES: This study investigated Finnish physicians' experiences of decisions concerning living wills and do not resuscitate (DNR) orders and also their views on the role of patients and family members in these decisions. DESIGN: A questionnaire was sent to 800 physicians representing the following specialties: general practice (n = 400); internal medicine (n = 207); neurology (n = 100), and oncology (n = 93). RESULTS: The response rate was 56%. Most of the respondents had a positive attitude toward (92%), and respect for (86%) living wills, and 72% reported situations in which such a will would have been helpful, although experience with their use was limited. The physicians reported both benefits and problems with living wills. Thirteen per cent had completed a living will of their own. Half did not consider living wills to be reliable if they were several years old. Do not resuscitate orders were interpreted in two ways: resuscitation forbidden (70%) or only palliative (symptom oriented) care required (30%). The respondents also documented DNR orders differently. Seventy-two per cent discussed DNR decisions always or often with patients able to communicate, and even 76% discussed DNR orders with the family members of patients unable to communicate. Most respondents were able to approach a dying patient without difficulty. They also felt that education in general was needed.

CONCLUSIONS: In general Finnish physicians accept living wills, but find they are accompanied by several problems. Many problems could be avoided if physicians and patients conducted progressive discussions about living wills. The differing interpretations of DNR orders are a matter of concern in that they may affect patient treatment. The promotion of patient autonomy with respect to treatment seems rather good, but the limitations of the study need to be kept in mind.


Abstract: BACKGROUND: Coronary heart disease is the leading cause of death in Americans. Despite increased interest in end-of-life care, data regarding the use of do-not-resuscitate (DNR) orders in acutely ill cardiac patients remain extremely limited. The objectives of this study were to describe use of DNR orders, treatment approaches, and hospital outcomes in patients with acute myocardial infarction. METHODS: The study sample consisted of 4621 residents hospitalized with acute myocardial infarction at all metropolitan Worcester, Mass, area hospitals in five 1-year periods from 1991 to 1999. RESULTS: Significant increases in the use of DNR orders were observed during the study decade (from 16% in 1991 to 25% in 1999). The elderly, women, and patients with previous diabetes mellitus or stroke were more likely to have DNR orders. Patients with DNR orders were significantly less likely to be treated with effective cardiac medications, even if the DNR order occurred late in the hospital stay. Less than 1% of patients were noted to have DNR orders before hospital admission. Patients with DNR orders were significantly more likely to die during hospitalization than patients without DNR orders (44%
ity of my claim and to demonstrate how the failure to offer or, at least, to discuss renal dialysis in this case (and, by inference, any other form of treatment which has some hope of prolonging a patient’s life) qualifies as paternalism in its most egregious form. I discuss the actions of the health care team and try to find some plausible reasons why they acted as they did. I conclude that there must be greater emphasis placed on teaching clinicians how better to incorporate frank, open and ongoing discussion about the central elements of the therapeutic relationship with patients long before they lose decisional capacity.


McDonald, Deborah Dillon; Deloge, Jo-Ann; Joslin, Nicole; Petow, Wendy A.; Severson, Judith S.; Votino, Roberta; Shea, Michael D.; Drenge, Jessica M.L.; Brennan, Mary T.; Moran, Andrea B.; Del Signore, Enrico; Saunders, Judith M.; Wilson, Donna. Communicating end-of-life preferences [article and commentaries]. *Western Journal of Nursing Research* 2003 October; 25(6): 652-675. NRCBL: 20.5.1; 8.1. SC: em.


Mitchell, Kay. Nurse, patient and Mr D — dancing the decision-making polka [editorial]. *Journal of Advanced Nursing* 2004 May; 46(4): 345. NRCBL: 20.5.1; 20.4.1; 20.7.

Monteleoni, Carol; Clark, Elizabeth. Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: before and after study. *BMJ: British Medical Journal* 2004 August; 329(7646): 491-494. NRCBL: 20.5.1; 9.5.3; 20.4.1. SC: em.

Abstract: PROBLEM: Despite lack of evidence that enteral feeding tubes benefit patients with dementia, and often contrary to the wishes of patient and family, patients with dementia who have difficulty swallowing or reduced food intake often receive feeding tubes when hospitalised for an acute illness. DESIGN: We conducted a retrospective chart review of all patients receiving percutaneous endoscopic gastrostomy or jejunostomy tubes between March and September 2002. QI interventions including a palliative care consulting service and educational programmes were instituted. We conducted a second chart review for all patients receiving feeding tubes between March and September 2003. SETTING: 652 bed urban acute care hospital. KEY MEASURES FOR IMPROVEMENT: We measured the number of feeding tubes placed in patients with dementia, the number of feeding tubes placed in patients with dementia capable of taking food by mouth, and the number of feeding tubes placed in patients with dementia with an advance directive stating the wish to forgo artificial nutrition and hydration. STRATEGIES FOR CHANGE: Medical and allied health staff received educational programmes on end of life care and on feeding management of patients with dementia. A palliative care consulting team was established. EFFECTS OF CHANGE: After the interventions, the number of feeding tubes placed in all patients and in patients with dementia was greatly reduced. LESSONS LEARNED: Multidisciplinary involvement, including participation by the administration, was essential to effect change in practice. The intensive focus on a particular issue and rapid change led to “culture shift” within the hospital community. The need to establish unified goals of care for each patient was highlighted. BACKGROUND: A growing body of research over the past decade has questioned the utility of placing feeding tubes (percutaneous endoscopic gastrostomy (PEG) or jejunostomy) in patients with advanced dementia. Studies have found no evidence that feeding tubes in this population prevent aspiration, prolong life, improve overall function, or reduce pressure sores. Additionally, the quality of life of a patient with advanced dementia can be adversely affected when a feeding tube is inserted. The patient may require wrist restraints to prevent pulling on the tube or may develop cellulitis at the gastrostomy site, develop decubitus ulcers, be deprived of the social interaction and pleasure surrounding meals, and require placement in a nursing home. Unfortunately, many doctors are unfamiliar with this literature or face barriers-attitudinal, institutional, or imposed by the healthcare industry-to applying its findings to their practice. Thus feeding tubes are placed in patients who will not benefit from this intervention and whose quality of life in the terminal stage of their illness will be adversely affected. With the expected increase of elderly people with dementia, a great change in doctors’ knowledge, attitudes, and practice is necessary to prevent even greater numbers of patients receiving this futile treatment.

NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms.


Abstract: The term “quality of life” has a long history in the bioethics literature. It is usually used in one of two contexts: in resource allocation discussions in the hope of arriving at an objective measure of the worth of an intervention; and in end-of-life discussions as a concept that can justify the forgoing of life-sustaining treatment. In both contexts, the term has valid uses as it is meant to measure the efficacy of a treatment. However, the term has the unfortunate rhetorical problem that it often seems to be a judgment on the life of a human being. As such, it is highly inflammatory. We suggest that a return to a rhetoric that suggests a judgment on the treatment rather than the person is needed.


Oehmichen, Manfred; Meissner, Christoph. Active euthanasia and physician-assisted suicide: the German discussion. *Legal Medicine (Tokyo, Japan)* 2003 March; 5(Supplement 1): S20-S28. NRCBL: 20.5.1; 20.7; 15.5.


Outcomerea Study Group; Azoulay, Élie; Pochard, Frédéric; Garroute-Orgeas, Maité; Moreau, Delphine; Montesino, Laurent; Adrie, Christophe; de Lassence, Arnaud; Cohen, Yves; Timsit, Jean-François. Decisions to forgo life-sustaining therapy in ICU patients independently predict hospital death. *Intensive Care Medicine* 2003 November; 29(11): 1895-1901. NRCBL: 20.5.1. SC: em. Identifiers: France.

Özkara, Erdem; Civaner, Murat; Oglak, Sema; Mayda, Atilla Senih. Euthanasia education for health professionals in Turkey: students change their opinions. *Nursing Ethics* 2004 May; 11(3): 290-297. NRCBL: 20.5.1; 7.2. SC: em.

Abstract: The purpose of this study was to investigate the impact of euthanasia education on the opinions of health sciences students. It was performed among 111 final year students at the College of Health Sciences, Dokuz Eyll University, Izmir, Turkey. These students train to become paramedical professionals and health technicians. Fifteen hours of educational training concerning ethical values and euthanasia was planned and the students’ opinions about euthanasia were sought before and after the course. Statistical analyses of the data were performed with the related samples t-test by means of the Epi-Info program. Significant changes were shown in the students’ opinions on people’s right to decide about their own life, euthanasia in unconscious patients, and reasons for their objection to euthanasia after completing the course. The results of this study suggest that education can significantly change a person’s approach to euthanasia.


Paterson, Craig. On clarifying terms in applied ethics discourse: suicide, assisted suicide, and euthanasia. *Internationa-
SECTION I

EUTHANASIA AND ALLOWING TO DIE

Schade, Stanley. "Tell ing and keeping still; re viv ing and transparent. Detailed information leaflets are of value for a minority of hospitalised patients. METHODS: A study was conducted over three months on a general medical ward and an acute elderly care ward in two district general hospitals. METHODS: A detailed information leaflet on CPR was provided to the nursing staff on the wards. An A4 summary document summarising the CPR decision making process and basic information on cardiopulmonary issues was placed in a folder at the foot of each bed on the elderly care ward. On the general medical ward it was displayed prominently over the head of all beds. RESULTS: Out of the 274 patients admitted to the general medical ward only two requests were received for the detailed information leaflet. On the elderly care ward there were 182 admissions but no patients or their relatives requested the leaflet. CONCLUSIONS: Availability of basic information on cardiopulmonary resuscitation to all patients is practical and does not lead to unnecessary distress or offence to patients or their carers. It makes the decision making process more transparent. Detailed information leaflets are of value for a minority of hospitalised patients.


Abstract: This paper looks at the ambiguities which PAS (physician assisted suicide) and voluntary active euthanasia (VAE) present to the patient, his or her loved ones and the health-care team. The author pleads for a greater emphasis on humanizing the experience of the dying so that a team can meet their physical, emotional and spiritual needs.


Schwarz, Judith Kennedy; Del Bene, Maura L. Withdrawing ventilator support for a home-based amyotrophic lateral sclerosis patient: a case study. Journal of Clinical Ethics 2004 Fall; 15(3): 282-290. NRCBL: 20.5.1; 20.4.1; 20.3.2; 9.6. SC: cs.


Abstract: AIM: The primary aim of the study was to evaluate two different methods of communicating information on cardiopulmonary resuscitation (CPR) to patients admitted to general medical and elderly care wards. The information was either in the form of a detailed information leaflet (appendix I) or a summary document (appendix II). The study examined the willingness of patients in seeking detailed information on cardiopulmonary issues. SETTING: The study was conducted over three months on a general medical ward and an acute elderly care ward in two district general hospitals. METHODS: A detailed information leaflet on CPR was provided to the nursing staff on the wards. An A4 summary document summarising the CPR decision making process and basic information on cardiopulmonary issues was placed in a folder at the foot of each bed on the elderly care ward. On the general medical ward it was displayed prominently over the head of all beds.

Proceedings: Out of the 274 patients admitted to the general medical ward only two requests were received for the detailed information leaflet. On the elderly care ward there were 182 admissions but no patients or their relatives requested the leaflet. CONCLUSIONS: Availability of basic information on cardiopulmonary resuscitation to all patients is practical and does not lead to unnecessary distress or offence to patients or their carers. It makes the decision making process more transparent. Detailed information leaflets are of value for a minority of hospitalised patients.


Straton, Joseph B.; Wang, Nae-Yuh; Meoni, Lucy A.; Ford, Daniel E.; Klag, Michael J.; Casarett, David; Gallo, Joseph J. Physical functioning, depression, and preferences for treatment at the end of life: the Johns Hopkins precursors study. *Journal of the American Geriatrics Society* 2004 April; 52(4): 577-582. NRCBL: 20.5.1; 9.5.2; 17.1. SC: em.

Sulmasy, Daniel P.; Sood, Johanna R.; Ury, Wayne A. The quality of care plans for patients with do-not-resuscitate orders. *Archives of Internal Medicine* 2004 July 26; 164(14): 1573-1578. NRCBL: 20.5.1; 20.4.1; 9.8. SC: em. Abstract: BACKGROUND: Care plans for patients with do-not-resuscitate (DNR) orders often fail to define limits other than cardiopulmonary resuscitation and fail to address other patient care needs. We studied the explicitness and comprehensiveness of care plans for patients with DNR orders and what factors were associated with this aspect of the quality of their care. METHODS: A cross-sectional study was conducted at Georgetown University Medical Center (GUMC), Washington, DC, and St Vincent Catholic Medical Centers (SVCMC), St Vincent’s Hospital-Manhattan, New York, NY. Participants included 189 consecutive medical inpatients with DNR orders. RESULTS: A previously validated medical chart review technique termed concurrent care concerns (CCCs) measured whether 11 possible patient care needs had been addressed within 2 days of the DNR order. Reasons for the DNR order were documented in only 55% of cases, and a consent conversation was documented in only 69%. The mean number of total CCCs per DNR order was 1.55 (1.84 at GUMC and 1.29 at SVCMC; *P* = .007). In a multivariate logistic regression analysis of low (≤ 2) vs high (> 2) CCCs, patients with malignancy (*P* = .002), higher APACHE III (Acute Physiology and Chronic Health Evaluation III) scores (*P* = .007), and a documented consent conversation (*P* = .009) and those at Georgetown (*P* = .005) were more likely to have high attention to CCCs. Patients with dementia were the least likely to have high attention to CCCs. CONCLUSIONS: Documented consent conversations and care plans for patients with DNR orders are less than ideal. Care plans differ in quality by diagnosis, institution, and whether or not a consent conversation is documented. These observations might help to guide interventions that aim to improve the care of patients with DNR orders.

Sulmasy, Daniel P.; Sood, Johanna R.; Ury, Wayne A. The quality of care plans for patients with do-not-resuscitate orders. *Archives of Internal Medicine* 2004 July 26; 164(14): 1573-1578. NRCBL: 20.5.1; 20.4.1; 9.8. SC: em. Abstract: BACKGROUND: Care plans for patients with do-not-resuscitate (DNR) orders often fail to define limits other than cardiopulmonary resuscitation and fail to address other patient care needs. We studied the explicitness and comprehensiveness of care plans for patients with DNR orders and what factors were associated with this aspect of the quality of their care. METHODS: A cross-sectional study was conducted at Georgetown University Medical Center (GUMC), Washington, DC, and St Vincent Catholic Medical Centers (SVCMC), St Vincent’s Hospital-Manhattan, New York, NY. Participants included 189 consecutive medical inpatients with DNR orders. RESULTS: A previously validated medical chart review technique termed concurrent care concerns (CCCs) measured whether 11 possible patient care needs had been addressed within 2 days of the DNR order. Reasons for the DNR order were documented in only 55% of cases, and a consent conversation was documented in only 69%. The mean number of total CCCs per DNR order was 1.55 (1.84 at GUMC and 1.29 at SVCMC; *P* = .007). In a multivariate logistic regression analysis of low (≤ 2) vs high (> 2) CCCs, patients with malignancy (*P* = .002), higher APACHE III (Acute Physiology and Chronic Health Evaluation III) scores (*P* = .007), and a documented consent conversation (*P* = .009) and those at Georgetown (*P* = .005) were more likely to have high attention to CCCs. Patients with dementia were the least likely to have high attention to CCCs. CONCLUSIONS: Documented consent conversations and care plans for patients with DNR orders are less than ideal. Care plans differ in quality by diagnosis, institution, and whether or not a consent conversation is documented. These observations might help to guide interventions that aim to improve the care of patients with DNR orders.

Sulmasy, Daniel P.; Sood, Johanna R.; Ury, Wayne A. The quality of care plans for patients with do-not-resuscitate orders. *Archives of Internal Medicine* 2004 July 26; 164(14): 1573-1578. NRCBL: 20.5.1; 20.4.1; 9.8. SC: em. Abstract: BACKGROUND: Care plans for patients with do-not-resuscitate (DNR) orders often fail to define limits other than cardiopulmonary resuscitation and fail to address other patient care needs. We studied the explicitness and comprehensiveness of care plans for patients with DNR orders and what factors were associated with this aspect of the quality of their care. METHODS: A cross-sectional study was conducted at Georgetown University Medical Center (GUMC), Washington, DC, and St Vincent Catholic Medical Centers (SVCMC), St Vincent’s Hospital-Manhattan, New York, NY. Participants included 189 consecutive medical inpatients with DNR orders. RESULTS: A previously validated medical chart review technique termed concurrent care concerns (CCCs) measured whether 11 possible patient care needs had been addressed within 2 days of the DNR order. Reasons for the DNR order were documented in only 55% of cases, and a consent conversation was documented in only 69%. The mean number of total CCCs per DNR order was 1.55 (1.84 at GUMC and 1.29 at SVCMC; *P* = .007). In a multivariate logistic regression analysis of low (≤ 2) vs high (> 2) CCCs, patients with malignancy (*P* = .002), higher APACHE III (Acute Physiology and Chronic Health Evaluation III) scores (*P* = .007), and a documented consent conversation (*P* = .009) and those at Georgetown (*P* = .005) were more likely to have high attention to CCCs. Patients with dementia were the least likely to have high attention to CCCs. CONCLUSIONS: Documented consent conversations and care plans for patients with DNR orders are less than ideal. Care plans differ in quality by diagnosis, institution, and whether or not a consent conversation is documented. These observations might help to guide interventions that aim to improve the care of patients with DNR orders.

Sulmasy, Daniel P.; Sood, Johanna R.; Ury, Wayne A. The quality of care plans for patients with do-not-resuscitate orders. *Archives of Internal Medicine* 2004 July 26; 164(14): 1573-1578. NRCBL: 20.5.1; 20.4.1; 9.8. SC: em. Abstract: BACKGROUND: Care plans for patients with do-not-resuscitate (DNR) orders often fail to define limits other than cardiopulmonary resuscitation and fail to address other patient care needs. We studied the explicitness and comprehensiveness of care plans for patients with DNR orders and what factors were associated with this aspect of the quality of their care. METHODS: A cross-sectional study was conducted at Georgetown University Medical Center (GUMC), Washington, DC, and St Vincent Catholic Medical Centers (SVCMC), St Vincent’s Hospital-Manhattan, New York, NY. Participants included 189 consecutive medical inpatients with DNR orders. RESULTS: A previously validated medical chart review technique termed concurrent care concerns (CCCs) measured whether 11 possible patient care needs had been addressed within 2 days of the DNR order. Reasons for the DNR order were documented in only 55% of cases, and a consent conversation was documented in only 69%. The mean number of total CCCs per DNR order was 1.55 (1.84 at GUMC and 1.29 at SVCMC; *P* = .007). In a multivariate logistic regression analysis of low (≤ 2) vs high (> 2) CCCs, patients with malignancy (*P* = .002), higher APACHE III (Acute Physiology and Chronic Health Evaluation III) scores (*P* = .007), and a documented consent conversation (*P* = .009) and those at Georgetown (*P* = .005) were more likely to have high attention to CCCs. Patients with dementia were the least likely to have high attention to CCCs. CONCLUSIONS: Documented consent conversations and care plans for patients with DNR orders are less than ideal. Care plans differ in quality by diagnosis, institution, and whether or not a consent conversation is documented. These observations might help to guide interventions that aim to improve the care of patients with DNR orders.


SECTION I  EUTHANASIA AND ALLOWING TO DIE

Van Biesen, Wim; Lameire, Norbert; Veys, Nic; Vanderhaegen, Bert. From curing to caring: one character change makes a world of difference. Issues related to withholding/withdrawing renal replacement therapy (RRT) from patients with important co-morbidities. *Nephrology, Dialysis, Transplantation* 2004 March; 19(3): 536-540. NRCBL: 20.5.1; 19.3.


Abstract: As patients approach the end of life, their disease process may create an immediate life-threatening emergency, yet invasive interventions may be less likely to provide benefit while carrying the same or greater risks. Knowing when it is time to shift from life-prolonging to more palliative approaches, focused on quality of life and comfort, is emotionally and clinically challenging for patients, families, and physicians. Key factors in the decision process include prognosis, risk-benefit analysis of the proposed intervention, current symptom burden, temporal pattern of the illness, patient’s age and life stage, and the patient’s goals of care. A structured approach to decision making includes assessing the patient’s physical, psychological, and spiritual needs; assessing the patient’s support system; discussing prognosis; and assessing patient-specific goals. Physicians can best help patients decide which treatments are appropriate by taking the necessary time to explore all curative and palliative care options, providing honest and timely prognostic information, making clear recommendations, facilitating patient-family discussions, and affirming patient choices.


Windsle, William J. The minimally conscious patient: when can life support be terminated? *Journal of Head Trauma Rehabilitation* 2002 February; 17(1): 71-73. NRCBL: 20.5.1; 20.5.4.


World Federation of Catholic Medical Association (FIAMC); Pontifical Academy for Life. Considerations on the scientific and ethical problems related to the vegetative state. *National Catholic Bioethics Quarterly* 2004 Autumn; 4(3): 579-581. NRCBL: 20.5.1; 20.2.1; 20.4.1; 4.4.


Abstract: Some patients have no chance of surviving if not treated, but very little chance if treated. A number of medical ethicists and physicians have argued that treatment in such cases is medically futile and a matter of physician discretion. This paper critically examines that position. According to

NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms.
Howard Brody and others, a judgment of medical futility is a purely technical matter, which physicians are uniquely qualified to make. Although Brody later retracted these claims, he held to the view that physicians need not consult the patient or his family to determine their values before deciding not to treat. This is because professional integrity dictates that treatment should not be undertaken. The argument for this claim is that medicine is a profession and a social practice, and thus capable of breaches of professional integrity. Underlying professional integrity are two moral principles, one concerning harm, the other fraud. According to Brody both point to the fact that when the odds of survival are very low treatment is a violation of professional integrity. The details of this skeletal argument are exposed and explained, and the full argument is criticised. On a number of counts, it is found wanting. If anything, professional integrity points to the opposite conclusion.

Wros, Peggy L.; Doutrich, Dawn; Izumi, Shigeko. Ethical concerns: comparison of values from two cultures. Nursing and Health Sciences 2004 June; 6(2): 131-140. NRCBL: 20.5.1; 8.2; 21.7. SC: em. Identifiers: Japan; United States.

Youngner, Stuart J. Medical futility and the social contract (who are the real doctors on Howard Brody’s island?). Seton Hall Law Review 1995; 25(3): 1015-1026. NRCBL: 20.5.1; 9.4; 8.1. SC: cs.


EUTHANASIA AND ALLOWING TO DIE/ LEGAL ASPECTS

The feeding tube. Health Care Food and Nutrition Focus 2004 July; 21(7): 6-7. NRCBL: 20.5.1; 1.2. SC: le.


Bambose, Oluymenisi. Euthanasia: another face of murder. International Journal of Offender Therapy and Comparative Criminology 2004 February; 48(1): 111-121. NRCBL: 20.5.1; 8.3.1; 21.1. SC: le. Identifiers: Australia; Belgium; Canada; Denmark; Great Britain; Netherlands; Nigeria; Norway; Poland; Portugal; Spain; United States; Wales.

Barilan, Y.M. Is the clock ticking for terminally ill patients in Israel? Preliminary comment on a proposal for a bill of rights for the terminally ill. Journal of Medical Ethics 2004 August; 30(4): 353-357. NRCBL: 20.5.1; 20.4.1. SC: le.

Abstract: This paper presents and discusses a recent Israeli proposal to legislate on the rights of the dying patient. A gap exists between elitist biases of the committee proposing the law, and popular values and sentiments. The proposed law divides the dying patients into two groups: "those who wish to go on living" and "those who wish to die". The former will have a right to life prolonging extraordinary care. It is not clear who would foot the bill for this care. Also it is hard to see how this munificence could fail to discriminate against all other patients. Both the secular ethicists and the rabbis involved in drawing up the proposal accepted the assumption that it is good for some terminal patients to die. The rabbis objected, however, to direct and active interventions that shorten life. The solution arrived at was to install timers in the ventilators so as to allow them to expire automatically unless the patient wishes for their resetting.


Booij, Leo H.D.J. End-of-life decisions in The Netherlands [editorial]. European Journal of Anaesthesiology...
SECTION I
EUTHANASIA AND ALLOWING TO DIE/ LEGAL ASPECTS


Castledine, George. The patient should be a the centre of all decisions. British Journal of Nursing 2004 September 9-22; 13(16): 1003. NRCBL: 20.5.1. SC: le.

Chin, J.J.; Sahadevan, S. Neurofibrillary and ethico-legal tangles: in search of surrogates for dementia patients lacking decision-making capacity and relatives. Annals of the Academy of Medicine, Singapore 2003 November; 32(6): 756-763. NRCBL: 20.5.1; 9.5.2; 17.1; 20.5.4. SC: cs; le.


Dupuis, Helen M. Euthanasia in the Netherlands: 25 years of experience. Legal Medicine (Tokyo, Japan) 2003 March; 5(Supplement 1): S60-S64. NRCBL: 20.5.1; 1.1. SC: le; rv.


Flamm, Anne L. The Texas “futility” procedure: no such thing as a fairy-tale ending. Medical Ethics Newsletter [Lahey Clinic] 2004 Spring; 11(2): 4, 11. NRCBL: 20.5.1; 9.4; 8.1; 20.5.4; 5.3. SC: le.


Abstract: On 23 September 2002, the Belgian law on euthanasia came into force. This makes Belgium the second country in the world (after the Netherlands) to have an Act on euthanasia. Even though there is currently legal regulation of euthanasia in Belgium, very little is known about how this legal regulation could be translated into care for patients who request euthanasia.

EUTHANASIA AND ALLOWING TO DIE/ LEGAL ASPECTS

SECTION I

NRCBL: 20.5.1. SC: le. Identifiers: General Medical Council.


Gordijn, Bert; Janssens, Rien. Euthanasia and palliative care in the Netherlands: an analysis of the latest development. Health Care Analysis: An International Journal of Health Care Philosophy and Policy 2004 September; 12(3): 195-207. NRCBL: 20.5.1; 20.4.1; 20.7. SC: le. Abstract: This article discusses the recent developments regarding euthanasia and palliative care in the Netherlands. On the one hand, a legally codified practice of euthanasia has been established. On the other hand, there has been a strong development of palliative care. The combination of these simultaneous processes seems to be rather unique. This contribution first focuses on these remarkable developments. Subsequently, the analysis concentrates on the question of how these new developments have influenced the ethical debate.


Hartley, Jo. DNR case highlights ethical dilemma. Nursing Times 2004 January 20-26; 100(3): 10-11. NRCBL: 20.5.1; 4.1.3. SC: le.

Hatzinikolaou, Nikolaos. Prolonging life or hindering death? An Orthodox perspective on death, dying and euthanasia. Christian Bioethics 2003 August-December; 9(2-3): 187-201. NRCBL: 20.5.1; 20.1; 1.2. SC: le. Abstract: This article addresses death as a biological event and attempts to approach it as a mystery within the light of the Orthodox Christian theology and tradition. First, the value of the last moments of the life of a human being is analyzed; then the state of living is differentiated from the state of surviving that results, in some extreme cases, from the intrusion of technology in medicine. The article elaborates on the sacred and spiritual character of death which, when viewed within the light of the Christ’s resurrection, is transformed into a great blessing. The last part of the article focuses on the newly emerged issue of euthanasia and the reasons behind it. It poses certain vital questions that ought to be answered before legalization gets on its way. Finally, the conclusion summarizes the position of the Orthodox Church of Greece on death, dying and euthanasia.


Kater, Loes; Houtepen, Rob; De Vries, Raymond G.; Widdershoven, Guy. Health care ethics and health law in the Dutch discussion on end-of-life decisions: a historical analysis of the dynamics and development of both disciplines. Studies in History and Philosophy of Biological and Biomedical Sciences 2003 December; 34(4): 669-684. NRCBL: 20.5.1; 2.2; 8.3.3. SC: le. Identifiers: The Netherlands.


Oldershaw, John B.; Atkinson, Jeff; Boshes, Louis D. Persistent vegetative state: medical, ethical, religious, economic and legal perspectives. DePaul Journal of Health Care Law 1997 Spring; 1(3): 495-536. NRCBL: 20.5.1; 20.2.1; 1.2; 9.3.1. SC: le.

Özkara, Erdem; Hanci, Hamit; Civaner, Murat; Yorulmaz, Coskun; Karagöz, Mustafa; Mayda, Atilla Senih; Gören, Süleyman; Kök, Ahmet Nezih. Turkey’s physicians’ attitudes toward euthanasia: a brief research report. Omega: Journal of Death and Dying 2004; 49(2): 109-115. NRCBL: 20.5.1; 20.7; 21.1; 20.3.2. SC: em; le.
SECTION I  EUTHANASIA AND ALLOWING TO DIE/ MINORS


Ridley, Donald T.; Sade, Robert M.; McKneally, Martin F. Legal consequences of disregarding the wishes of a patient [letter and replies]. Annals of Thoracic Surgery 2003 October; 76(4): 1336-1337. NRCBL: 20.5.1; 8.3.2. SC: le.


Schotsmans, Paul T. Relational responsibility, and not only stewardship. A Roman Catholic view on voluntary euthanasia for dying and non-dying patients. Christian Bioethics 2003 August-December; 9(2-3): 285-298. NRCBL: 20.5.1; 1.2; 1.1; 4.4; 20.4.1. SC: le.

Abstract: The Roman Catholic theological approach to euthanasia is radically prohibitive. The main theological argument for this prohibition is the so-called “stewardship argument”: Christians cannot escape accounting to God for stewardship of the bodies given them on earth. This contribution presents an alternative approach based on European existentialist and philosophical traditions. The suggestion is that exploring the fullness of our relational responsibility is more apt for a pluralist—and even secular—debate on the legitimacy of euthanasia.


Sperling, Daniel. Breaking through the silence: illegality of performing resuscitation procedures on the “newly-dead”. Annals of Health Law 2004 Summer; 13(2): 393-426. NRCBL: 20.5.1; 7.3; 8.3.3; 4.4; 8.5. SC: le.


EUTHANASIA AND ALLOWING TO DIE/ MINORS


Ballard, Dustin W.; Li, Yuelin; Evans, Jacquelyn; Ballard, Roberta A.; Ubel, Peter A. Fear of litigation may increase resuscitation of infants born near the limits of

Bostrom, Barry A. Miller v HCA, Inc. *Issues in Law and Medicine* 2003 Fall; 19(2): 171-173. NRCBL: 20.5.2; 8.3.4; 8.3.2. SC: le.


Boyle, R.J.; Salter, R.; Arnander, M.W. Ethics of refusing parental requests to withhold or withdraw treatment from their premature baby. *Journal of Medical Ethics* 2004 August; 30(4): 402-405. NRCBL: 20.5.2; 8.3.2; 8.3.4; 12.4.2.

Abstract: In the United Kingdom women have access to termination of pregnancy for maternal reasons until 24 weeks’ completed gestation, but it is accepted practice for children born at or beyond 25 weeks’ gestation to be treated according to the child’s perceived best interests even if this is not in accordance with parental wishes. The authors present a case drawn from clinical practice which highlights the discomfort that parents may feel about such an abrupt change in their rights over their child, and argue that parents should have greater autonomy over treatment decisions regarding their prematurely born children.

Brazier, M. Letting Charlotte die — the High Court ruling that a premature baby should not be resuscitated. *Journal of Medical Ethics* 2004 December; 30(6): 519-520. NRCBL: 20.5.2. SC: le. Identifiers: Great Britain.

Conway, Alison; Moloney-Harmon, Patricia A. Ethical issues in the neonatal intensive care unit. *Critical Care Nursing Clinics of North America* 2004 June; 16(2): 271-278. NRCBL: 20.5.2; 1.1; 1.2; 4.4.


da Costa, D.E.; Ghazal, H.; Al Khusaiby, Saleh. Do not resuscitate orders and ethical decisions in a neonatal intensive care unit in a Muslim community. *Archives of Disease in Childhood* 2002 March; 86(2): F115-F119. NRCBL: 20.5.2; 9.4; 1.2; 21.7.


Ford, Paul J. Medical charts and teddy bears. *APA [American Philosophical Association] Newsletters* 2001 Spring; 00(2): 167-169. NRCBL: 20.5.2; 20.3.2; 7.1.


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SC (Subject Caption):  an=analytical  cs=case studies  em=empirical  le=legal  po=popular  rv=review
SECTION I  EUTHANASIA AND ALLOWING TO DIE/ MINORS


Paris, John J.; Schreiber, Michael D.; Reardon, Frank. The “emergent circumstances” exception to the need for consent: the Texas Supreme Court ruling in Miller v. HCA. *Journal of Perinatology* 2004 June; 24(6): 337-342. NRCBL: 20.5.2; 8.3.2; 8.3.4. SC: le.


Rushton, Cynda Hylton. Ethics and palliative care in pediatrics — when should parents agree to withdrawal life-sustaining therapy for children? *AJN: American Journal of Nursing* 2004 April; 104(4): 54-64. NRCBL: 20.5.2; 20.4.2.


Skene, L. An Australian lawyer’s response. *Journal of Medical Ethics* 2004 August; 30(4): 408-409. NRCBL: 20.5.2; 8.3.2; 8.3.4; 12.4.2. Comments: comment on R.J. Boyle, R. Salter, and M.W. Arnamer, “Ethics of refusing parental requests to withhold or withdraw treatment from their premature baby,” *Journal of Medical Ethics* 2004 August; 30(4): 402-405.


Sperlitz, Daniel. From the dead to the unborn: is there an ethical duty to save life? *Medicine and Law: World Association for Medical Law* 2004; 23(3): 567-585. NRCBL: 20.5.2; 9.5.5; 20.2.1; 2.2; 1.1; 2.1.

Abstract: In this paper I examine the question of whether physicians have a legal and ethical duty to sustain pregnancies of women who die during the first or second trimester by the delivery of their fetuses. One ground for such a duty, on which I am focusing, is the duty of “special relationship” between the mother and the fetus. In my paper, I claim that the special relationship the pregnant woman and the fetus have do provide such a moral duty. This moral duty derives from the special and intimate relationship between the mother and the fetus, which has two considerations that support it: the uniqueness of the fetus, and the mother’s understanding and acknowledgement of such uniqueness. However, I argue that when the mother is dead, the nature of the relationship changes, as she is no more aware of her fetus and her relationship with it. Thus, the ethical duty of the mother to save her fetus’ life should be declined upon the end of the relationship between the mother and her fetus with the mother’s death. I support my argument by analyzing the special relationship between the mother and her fetus from four related ethical theories: ethics of relationships, responsibilities to society, ethics of families, and the ethics of care. By discussing these ethical theories, I show how responsibility to society in general, and to social entities, like families, in particular, constitute a moral duty towards the fetus, which, as aforesaid, no longer exists upon the pregnant woman’s death. In addition to being social entities I further show how the intrinsic values of families play an important role in forming such a moral duty. Nevertheless, I argue that such an instrumental duty that enables the establishment of families no more exists as the pregnant woman is no more socially and morally part of the family she belonged to while alive. I strengthen my argument by applying ethics of care, and by analyzing the practical conclusion I arrived at from a religious perspective.


EUTHANASIA AND ALLOWING TO DIE/ PHILOSOPHICAL ASPECTS


Çobanoglu, Nesrin; Algier, Lale. A qualitative analysis of ethical problems experienced by physicians and nurses in intensive care units in Turkey. Nursing Ethics 2004 September; 11(5): 444-458. NRCBL: 20.5.1; 4.1.3; 7.1; 7.3; 8.1. SC: em.

Abstract: In this qualitative study, we aimed to identify and compare the ethical problems perceived by physicians and nurses in intensive care units at Baskent University hospitals in Turkey. A total of 21 physicians and 22 nurses were asked to describe ethical problems that they frequently encounter in their practice. The data were analyzed using an interactive model. The core problem for both physicians and nurses was end-of-life decisions (first level). In this category, physicians were most frequently concerned with euthanasia while nurses were more concerned with do-not-resuscitate orders (second level). At the third level, we saw that almost all of the participants’ responses related to negative perceptions about euthanasia. Communication and hierarchical problems were the second most reported main category. Nurses were more likely to cite problems with hierarchy than physicians. At the third level, a large percentage of nurses described communication problems with authority and hierarchical problems with physicians. In the same category, physicians were most often concerned with communication problems with patients’ relatives. The ethical problems were reported at different frequencies by physicians and nurses. We asked the participants about ethical decision-making styles. The results show that nurses and physicians do not follow a systematic pattern of ethical decision making.


Abstract: Life-extension was the focus for the 10th annual Congress of the International Association of Biomedical Gerontology, held last September at Cambridge University. This scientific convention included a panel of several bioethicists, including Art Caplan, John Harris, and others. The presentations on the ethics of life-extension are reviewed here.


Dupuis, Heleen M. Euthanasia in the Netherlands: 25 years of experience. Legal Medicine (Tokyo, Japan) 2003 March; 5(Supplement 1): S60-S64. NRCBL: 20.5.1; 1.1. SC: le; rv.


Frank, Gelya; Blackhall, Leslie J.; Michel, Vicki; Murphy, Sheila T.; Azen, Stanley P.; Park, Kyeyoung. A discourse of relationships in bioethics: patient autonomy and end-of-life decision making among elderly Korean Americans. Medical Anthropology Quarterly 1998; 12(4): 403-423. NRCBL: 20.5.1; 1.1; 9.5.2; 9.5.4; 21.7.


Halcomb, Elizabeth; Daly, John; Jackson, Debra; Davidson, Patricia. An insight into Australian nurses’ experience of withdrawal/withholding of treatment in the ICU. Intensive and Critical Care Nursing 2004 August; 20(4): 214-222. NRCBL: 20.5.1; 4.1.3; 1.1. SC: em.

Hartley, Jo. DNR case highlights ethical dilemma. Nursing Times 2004 January 20-26; 100(3): 10-11. NRCBL: 20.5.1; 4.1.3. SC: le.


Abstract: In recent years, a number of writers have proposed voluntary stopping of eating and drinking as an alternative to physician-assisted suicide. This paper calls attention to and discusses some of the ethical complications that surround the practice of voluntary stopping of eating and drinking. The paper argues that voluntary stopping of eating and drinking raises very difficult ethical questions. These questions center on the moral responsibility of clinicians who care for the terminally ill as well as the nature and limits of the authority they exercise over them.


Abstract: This paper discusses physician-assisted suicide (PAS) and voluntary active euthanasia (VAE), supplies a short history and argues in favour of permitting both once rigid criteria have been set and the cases retro-reviewed. I suggest that among these criteria should be that VAE should only be permitted with one more necessary criterion: that VAE should only be allowed when physician assisted suicide is not a possible option. If the patient is able to ingest and absorb the medication there is no reason why VAE should be permitted. A brief history of VAE and PAS is given and some of the arguments which have been given are analyzed. The Principle of the Double Effect is briefly discussed and why, in my opinion, it is not a valid principle is briefly discussed.


Abstract: This paper outlines the relationship between euthanasia and its ethical norms and practices in a part of West Africa.

The various sub-types of euthanasia are described in detail, parallel with the role of African ethical theories in determining their relevance. The author discusses the implications of this approach relative to the social and economic state of African communities.

Post, Stephen G. Establishing an appropriate ethical framework: the moral conversation around the goal of prolongevity. *Journals of Gerontology: Series A, Biological Sciences and Medical Sciences* 2004 June; 59(6): B534-B539. NRCBL: 20.5.1; 1.1; 9.5.2; 4.4.

Price, Mark L. Mercy and autonomy — the failure of Battin’s justification for euthanasia. *National Catholic Bioethics Quarterly* 2004 Autumn; 4(3): 483-487. NRCBL: 20.5.1; 20.4.1; 1.1; 4.4.

Schotmans, Paul T. Relational responsibility, and not only stewardship. A Roman Catholic view on voluntary euthanasia for dying and non-dying patients. *Christian Bioethics* 2003 August-December; 9(2-3): 285-298. NRCBL: 20.5.1; 1.2; 1.1; 4.4; 20.4.1. SC: le.

Abstract: The Roman Catholic theological approach to euthanasia is radically prohibitive. The main theological argument for this prohibition is the so-called “stewardship argument”: Christians cannot escape accounting to God for stewardship of the bodies given them on earth. This contribution presents an alternative approach based on European existentialist and philosophical traditions. The suggestion is that exploring the fullness of our relational responsibility is more apt for a pluralist—and even secular—debat e on the legitimacy of euthanasia.

Shalowitz, David; Emanuel, Ezekiel. Euthanasia and physician-assisted suicide: implications for physicians. *Journal of Clinical Ethics* 2004 Fall; 15(3): 232-236. NRCBL: 20.5.1; 20.3.2; 4.1.2. Identifiers: Netherlands; PAS.


Trotter, Griffin. Why bioethics is ill equipped to contribute to the debate about prolonging lifespans. *HEC (Healthcare Ethics Committee) Forum* 2004 September; 16(3): 197-213. NRCBL: 20.5.1; 2.1; 4.1.2; 4.4; 1.1.

Victoroff, Michael S. There’s no such thing as ‘futile care theory’. *Managed Care* 2004 April; 13(4): 14, 16. NRCBL: 20.5.1; 1.1.

Wildes, Kevin Wm. Living out the tradition. *Christian Bioethics* 2003 August-December; 9(2-3): 299-302. NRCBL: 20.5.1; 1.2; 20.4.1; 1.1.

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The feeding tube. *Health Care Food and Nutrition Focus* 2004 July; 21(7): 6-7. NRCBL: 20.5.1; 1.2. SC: le.

Pope says patients must receive nutrition, hydration [news]. *America* 2004 April 5; 190(12): 4-5. NRCBL: 20.5.1; 1.2; 4.4.
Reactions vary to Pope’s comments on feeding [news]. *America* 2004 May 3; 190(15): 4. NRCBL: 20.5.1; 1.2; 20.4.1.

Aliabbai, Shabbir M.H.; Gordon, Michael; Brett, Allan S.; Jersild, Paul. Muslim and Jewish perspectives on inappropriate treatment at the end of life [letter and reply]. *Archives of Internal Medicine* 2004 April 26; 164(8): 916-917. NRCBL: 20.5.1; 1.2.

Ashley, Benedict; O'Rourke, Kevin; Torchia, Joseph. Food, water, and the PVS patient [letter]. *National Catholic Bioethics Quarterly* 2004 Summer; 4(2): 235-236. NRCBL: 20.5.1; 20.4.1; 4.4; 1.2.


Cahana, Michael Z. Choosing life when life is not a choice. *SH’MA* 2003 October; 34(604): 16. NRCBL: 20.5.1; 1.2.

Cataldo, Peter J. Pope John Paul II on nutrition and hydration — a change of Catholic teaching? *National Catholic Bioethics Quarterly* 2004 Autumn; 4(3): 513-536. NRCBL: 20.5.1; 20.4.1; 1.2; 4.4. Identifiers: Aquinas.

Cataldo, Peter J.; O’Brien, Dan; Slosar, John Paul. Queries on nutrition and hydration [letter and reply]. *National Catholic Bioethics Quarterly* 2004 Winter; 4(4): 659-662. NRCBL: 20.5.1; 1.2; 20.4.1; 8.3.4.


Chapman, Audrey R. Ethical implications of prolonged lives. *Theology Today* 2004 January; 60(4): 479-496. NRCBL: 20.5.1; 4.4; 1.2; 15.4; 9.5.2.

Coleman, Gerald D. Take and eat: morality and medically assisted feeding. *America* 2004 April 5; 190(12): 16-20. NRCBL: 20.5.1; 1.2; 4.4.

Colloquium of the Canadian Catholic Bioethics Institute (CCBI). Reflections on artificial nutrition and hydration. *National Catholic Bioethics Quarterly* 2004 Winter; 4(4): 773-782. NRCBL: 20.5.1; 20.4.1; 1.2; 20.5.4.

Diamond, Eugene F. Assisted nutrition and hydration in persistent vegetative state. *Linacre Quarterly* 2004 August; 71(3): 199-205. NRCBL: 20.5.1; 1.2.

Diamond, Eugene F. Nutrition and hydration: patients in a persistent vegetative state. *Origins* 2004 April 8; 33(43): 741-744. NRCBL: 20.5.1; 20.2.1; 4.4; 20.4.1; 1.2.

Dorff, Elliot N. Judaism, money, and health care. *Sh’mu* 2004 February; 34(608): 20. NRCBL: 20.5.1; 20.7; 20.4.1; 1.2.

Driscoll, David F.; Driscoll, Joseph J. At the bedside. *America* 2004 June 7-June 14: 190(19): 29. NRCBL: 20.5.1; 20.4.1; 4.4; 1.2.


Ford, Norman. Determining what is best for patients. *Origins* 2004 April 8; 33(43): 751-752. NRCBL: 20.5.1; 20.4.1; 1.2; 4.4.

Ford, Norman M. A future ethical issue [letter]. *National Catholic Bioethics Quarterly* 2004 Winter; 4(4): 663. NRCBL: 20.5.1; 20.2.1; 4.4; 1.2; 20.4.1.

Hamel, Ronald; Panicola, Michael. Must we preserve life? *America* 2004 April 19-26: 190(14): 6-13. NRCBL: 20.5.1; 20.7; 1.2; 4.4.

Handzo, George; Jacobs, Martha R. The patient’s right to faith [letter]. *Archives of Internal Medicine* 2004 April 26; 164(8): 916. NRCBL: 20.5.1; 1.2.


Harvey, John; Hamel, Ronald. On withdrawing medically administered nutrition and hydration. *Origins* 2004 April 8; 33(43): 748-751. NRCBL: 20.5.1; 20.5.3; 4.4; 1.2.

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EUTHANASIA AND ALLOWING TO DIE/ RELIGIOUS ASPECTS

Abstract: This article addresses death as a biological event and attempts to approach it as a mystery within the light of the Orthodox Christian theology and tradition. First, the value of the last moments of the life of a human being is analyzed; then the state of living is differentiated from the state of surviving that results, in some extreme cases, from the intrusion of technology in medicine. The article elaborates on the sacred and spiritual character of death which, when viewed within the light of the Christ’s resurrection, is transformed into a great blessing. The last part of the article focuses on the newly emerged issue of euthanasia and the reasons behind it. It poses certain vital questions that ought to be answered before legalization gets on its way. Finally, the conclusion summarizes the position of the Orthodox Church of Greece on death, dying and euthanasia.

Heeren, Oscar; Menon, A. Srikumar; Raskin, Allen; Ruskin, Paul. Religion and end of life treatment preferences among geriatric patients. International Journal of Geriatric Psychiatry 2001 February; 16(2): 203-208. NRCBL: 20.5.1; 9.5.2; 1.2.

Iserson, Kenneth V. From creatures to corpiscles: man’s search for immortality. HEC (Healthcare Ethics Committee) Forum 2004 September; 16(3): 160-172. NRCBL: 20.5.1; 7.1; 1.2; 19.1; 14.5.


Jotkowitz, Alan. Feeding patients with advanced dementia: a Jewish ethical perspective. Journal of Clinical Ethics 2004 Winter; 15(4): 346-349. NRCBL: 20.5.1; 9.5.2; 9.5.3; 2.1; 1.2.

Kahn, Marc J.; Lazarus, Cathy J.; Owens, Donald P. Allowing patients to die: practical, ethical, and religious concerns. Journal of Clinical Oncology 2003 August 1; 21(15): 3000-3002. NRCBL: 20.5.1; 1.2; 4.4; 9.7.

Kavanaugh, John F. Artificial feeding — ‘The Pope’s argument rests on human rights. Why can’t we see that?’. America 2004 June 21-28; 190(20): 7. NRCBL: 20.5.1; 1.2.


Marker, Rita L. Terri Schiavo and the Catholic connection. National Catholic Bioethics Quarterly 2004 Autumn; 4(3): 555-569. NRCBL: 20.5.1; 20.5.3; 20.4.1; 20.2.2; 1.2. SC: cs.


McConnaha, Scott A. Artificial nutrition and hydration: recent changes in understanding obligations. Linacre Quarterly 2004 August; 71(3): 214-231. NRCBL: 20.5.1; 1.2.

McMahon, Kevin. Should nutrition and hydration be considered medical therapy? Origins 2004 April 8; 33(43): 744-748. NRCBL: 20.5.1; 20.4.1; 1.2.


Miech, Ralph P. PVS versus the dying process [letter]. National Catholic Bioethics Quarterly 2004 Autumn; 4(3): 447-448. NRCBL: 20.5.1; 20.4.1; 1.2.


Abstract: The debate about voluntary euthanasia arises (essentially) from a fundamental anthropological question: do humans own themselves? An answer to this question is developed which starts out from the foundational ethic of Emmanuel Levinas. The metaphysics of the countenance of the Other in Levinas is then related to Karl Rahner’s description of God as the absolute enigma which is fated towards us. God, understood as that enigma, is experienced for us concretely in our relationship to the countenance of our neighbor, the other human being. Our being thus referred to the absolutely Other in the countenance of the other human grounds not only the non-disposability of that other human being, but also the non-disposability of myself. This is the decisive point for how one should think about euthanasia. In contrast to the (so-called)
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SECTION I

voluntary euthanasia, accompaniment in dying takes account of that dialogical constitution of man.


O’Brien, Dan; Slosar, John Paul; Tersigni, Anthony R. Utilitarian pessimism, human dignity, and the vegetative state — a practical analysis of the papal allocution. National Catholic Bioethics Quarterly 2004 Autumn; 4(3): 497-512. NRCBL: 20.5.1; 20.4.1; 20.7; 1.2; 1.1; 4.4.

Oldershaw, John B.; Atkinson, Jeff; Boshes, Louis D. Persistent vegetative state: medical, ethical, religious, economic and legal perspectives. DePaul Journal of Health Care Law 1997 Spring; 1(3): 495-536. NRCBL: 20.5.1; 20.2.1; 1.2; 9.3.1. SC: le.

Orr, Robert D.; Meilaender, Gilbert. Ethics and life’s ending [article and commentary]. First Things 2004 August-September; (145): 31-38. NRCBL: 20.5.1; 1.2; 4.4. SC: an.


Schirrmacher, Thomas. Medical killing — an Evangelical perspective. Christian Bioethics 2003 August-December; 9(2-3): 227-244. NRCBL: 20.5.1; 1.2; 7.1. Abstract: Evangelicals are unconditionally opposed to active euthanasia. Indirect euthanasia is seen as simply belonging to the risks inherent in any medical intervention. Passive euthanasia is accepted if used in order to save the dignity of the dying and is seen as merely ceasing to interfere with an irreversible dying process. The basis of evangelical ethics is the Bible supplemented by science and experience as a kind of natural law. Even though natural law comes under Biblical revelation, its acceptance is the reason for the similarity of the Evangelical and the Roman-Catholic position of Evangelicals. Evangelicals stress the necessity of a better counseling and investment for the deadly ill patient.


Schotsmans, Paul T. Relational responsibility, and not only stewardship. A Roman Catholic view on voluntary euthanasia for dying and non-dying patients. Christian Bioethics 2003 August-December; 9(2-3): 285-298. NRCBL: 20.5.1; 1.2; 1.1; 4.4; 20.4.1. SC: le.

Abstract: The Roman Catholic theological approach to euthanasia is radically prohibitive. The main theological argument for this prohibition is the so-called “stewardship argument”: Christians cannot escape accounting to God for stewardship of the bodies given them on earth. This contribution presents an alternative approach based on European existentialist and philosophical traditions. The suggestion is that exploring the fullness of our relational responsibility is more apt for a pluralist—and even secular—debate on the legitimacy of euthanasia.


Smolin, David M. Praying for Baby Rena: religious liberty, medical futility, and miracles. Seton Hall Law Review 1995; 25(3): 960-996. NRCBL: 20.5.1; 9.4; 8.1; 20.5.2; 1.2; 8.3.4; 8.3.2. SC: cs.


Verpoort, Charlotte; Gastmans, Chris; De Bal, Nele; Dierckx de Casterlé, Bernadette. Nurses’ attitudes to euthanasia: a review of the literature. Nursing Ethics 2004 July; 11(4): 349-365. NRCBL: 20.5.1; 1.2; 7.1; 20.3.2; 21.1. SC: rv; em.

Abstract: This article provides an overview of the scarce international literature concerning nurses’ attitudes to euthanasia. Studies show large differences with respect to the percentage of nurses who are (not) in favour of euthanasia. Characteristics such as age, religion and nursing specialty have a significant influence on a nurse’s opinion. The arguments for euthanasia have to do with quality of life, respect for autonomy and dissatisfaction with the current situation. Arguments against euthanasia are the right to a good death, belief in the possibilities offered by palliative care, religious objections and the fear of abuse. Nurses mention the need for more palliative care training, their difficulties in taking a specific position, and their de-
sire to express their ideas about euthanasia. There is a need to include nurses' voices in the end-of-life discourse because they offer a contextual understanding of euthanasia and requests to die, which is borne out of real experience with people facing death.

Wildes, Kevin Wm. Living out the tradition. *Christian Bioethics* 2003 August-December; 9(2-3): 299-302. NRCBL: 20.5.1; 1.2; 20.4.1; 1.1.

**FOREGN NATIONALS See HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ FOREIGN NATIONALS**

**GENE THERAPY/ TRANSFER**


DiMichele, Donna; Miller, F.G.; Fins, J.J. Gene therapy and haemophilia: an inevitable therapeutic future? *Haemophilia* 2003 March; 9(2): 145-152. NRCBL: 15.4; 18.2; 18.5.1; 18.5.2.


DiMichele, Donna; Miller, F.G.; Fins, J.J. Gene therapy and haemophilia: an inevitable therapeutic future? *Haemophilia* 2003 March; 9(2): 145-152. NRCBL: 15.4; 18.2; 18.5.1; 18.5.2.


Abstract: In the newly emerging debates about genetics and justice three distinct principles have begun to emerge concerning what the distributive aim of genetic interventions should be. These principles are: genetic equality, a genetic decent minimum, and the genetic difference principle. In this paper, I examine the rationale of each of these principles and argue that genetic equality and a genetic decent minimum are ill-equipped to tackle what I call the currency problem and the problem of weight. The genetic difference principle is the most promising of the three principles and I develop this principle so that it takes seriously the concerns of just health care and distributive justice in general. Given the strains on public funds for other important social programmes, the costs of pursuing genetic interventions and the nature of genetic interventions, I conclude that a more lax interpretation of the genetic difference principle is appropriate. This interpretation stipulates that genetic inequalities should be arranged so that they are to the greatest reasonable benefit of the least advantaged. Such a proposal is consistent with prioritarianism and provides some practical guidance for non-ideal societies that is, societies that do not have the endless amount of resources needed to satisfy every requirement of justice.


Abstract: John Robertson has famously argued that the right to reproductive autonomy is exceedingly broad in scope. That is, as long as a particular reproductive preference such as having a deaf child is "determinative" of the decision to reproduce then such preferences fall under the protective rubric of reproductive autonomy rights. Importantly, the deafness in question does not constitute a harm to the child thereby wrought since unless the child could be born deaf he or she would otherwise never have existed—his or her prospective parents would simply have chosen to abort. As such, for this child, being born deaf counts as a benefit, albeit of the "backhanded" variety, since the only other practical alternative is nonexistence. In what follows, I want to investigate this argument in detail. The target of my investigation will be the possible future use of gene therapy technology.
to “disenhance” one’s offspring. I intend to show that the apparently unlimited right to reproductive autonomy, that is, the right to choose both the quantity and qualities of future offspring, entailed by the argument from backhanded benefit can in fact be “sidestepped” through considering what sorts of reproductive practices we as a society ought to allow.

Iredale, Rachel; Dolan, Gina; McDonald, Kevin; Kirk, Maggie. Public attitudes to human gene therapy: a pilot study in Wales. Community Genetics 2004 June; 6(3): 139-146. NRCBL: 15.4; 5.1. SC: em.


Pace, Andrew. The Catholic theology of genetic manipulation. Linacre Quarterly 2004 August; 71(3): 254-263. NRCBL: 15.4; 14.1; 18.5.4; 1.2.


Scully, Jackie Leach; Rippberger, Christine; Rehmann-Sutter, Christoph. Non-professionals’ evaluations of gene therapy ethics. Social Science and Medicine 2004 April; 58(7): 1415-1425. NRCBL: 15.4. SC: em.


GENETIC COUNSELING
See also ABORTION; GENETIC SCREENING; SEX DETERMINATION


Parents resort to IVF to choose their baby’s sex. New Scientist 2004 June 12-18; 182(2451): 7. NRCBL: 15.2; 14.3; 14.4.

Preimplantation genetic diagnosis — for or against humanity [editorial]. Lancet 2004 November 13-19; 364(9447): 1729-1730. NRCBL: 15.2; 14.4; 15.5.
Alkuraya, Fowzan S.; Kilani, Ramzi A. Attitude of Saudi families affected with hemoglobinopathies towards prenatal screening and abortion and the influence of religious ruling (Fatwa). Prenatal Diagnosis 2001 June; 21(6): 448-451. NRCBL: 15.2; 12.5.2; 1.2; 21.7.


Boyle, Philip J. Genetics and pastoral counseling: a special report. Second Opinion 2004 April; (11): 4-56. NRCBL: 15.2; 1.2; 15.1; 7.3; 8.1. SC: em.

Bradbury, Ian; Wright, Dave; Slattery, Jim; Ritchie, Karen; Kuppermann, Miriam; Nease, Robert F., Jr.; Harris, Ryan; Washington, A.E. Cost utility of prenatal diagnosis [letter and reply]. Lancet 2004 April 3; 363(9415): 1164-1165. NRCBL: 15.2; 9.5.3; 9.3.1.

Broyde, Michael J. Pre-implantation genetic diagnosis, stem cells and Jewish law. Tradition 2004 Spring; 38(1): 54-75. NRCBL: 15.2; 14.4; 15.1; 18.5.4; 14.1; 19.5; 22.1; 1.2.


de Lacey, Sheryl; Norman, R.J. What should we do with donated embryos that may be genetically affected? Human Reproduction 2004 May; 19(5): 1065-1068. NRCBL: 15.2; 14.6; 8.3.1.


Elger, B.; Harding, T. Huntington’s disease: do future physicians and lawyers think eugenically? Clinical Genetics 2003 October; 64(4): 327-338. NRCBL: 15.2; 7.2; 8.4; 11.3; 15.5. SC: em; le.

Evans, Marilyn; Bergum, Vangie; Bamforth, Stephen; MacPhail, Sandra. Relational ethics and genetic counseling. Nursing Ethics 2004 September; 11(5): 459-471. NRCBL: 15.2; 8.1.

Abstract: Genetic counseling is viewed as a therapeutic interrelationship between genetic counselors and their clients. In a previous relational ethics research project, various themes were identified as key components of relational ethics practice grounded in everyday health situations. In this article the relational ethics approach is further explored in the context of genetic counseling to enhance our understanding of how the counselor-client relationship is contextually developed and maintained. Qualitative interviews were conducted with six adult clients undergoing genetic counseling for predictive testing. Engagement, dialogue and presence were revealed as relevant to genetic counselor-client relationships. A relational ethics approach in genetic counseling challenges the concept of nondirectiveness and may enhance the outcome of counseling for both counselor and client.
As so ci a tion and re ply]. 505-509. NRCBL: 15.2; 12.5.2. SC: em.

Ford, Nor man M. An Inter discipl in ary Study. Saint Louis: Saint Louis Uni -
versity Press; 2004: 197-215. NRCBL: 15.2; 14.4; 18.5.

Fasth, An ders; Wahlström, Jan; Kuliev, Anver;


Hall, Sue; Abramsky, Lenore; Marteau, Theresa M. Health professionals’ reports of information given to parents following the prenatal diagnosis of sex chromosome anomalies and outcomes of pregnancies: a pilot study. Prenatal Diagnosis 2003 July; 23(7): 535-538. NRCBL: 15.2; 8.1; 12.1.


Häyry, Matti. There is a difference between selecting a deaf embryo and deafening a hearing child. Journal of Medical Ethics 2004 October; 30(5): 510-512. NRCBL: 15.2; 14.4; 9.5.1. SC: an.

Abstract: If genetic diagnosis and preimplantation selection could be employed to produce deaf children, would it be acceptable for deaf parents to do so? Some say no, because there is no moral difference between selecting a deaf embryo and deafening a hearing child, and because it would be wrong to deafen infants. It is argued in this paper, however, that this view is untenable. There are differences between the two activities, and it is perfectly possible to condone genetic selection for deafness while condemning attempts to deafen infants at birth.

Hopwood, Penelope; Howell, Anthony; Laloo, Fiona; Evans, Gareth. Do women understand the odds? Risk perceptions and recall of risk information in women with a family history of breast cancer. Community Genetics 2004 August; 6(4): 214-223. NRCBL: 15.2; 9.5.1; 9.5.5. SC: em.

SC (Subject Caption): an=analytical cs=case studies em=empirical le=legal po=popular rv=review

Kahn, Jeffrey P.; Mastroianni, Anna C. Creating a stem cell donor: a case study in reproductive genetics. *Kennedy Institute of Ethics Journal* 2004 March; 14(1): 81-96. NRCBL: 15.2; 14.4; 19.5; 5.3. SC: cs. Identifiers: Molly Nash; directed donations; preimplantation genetic diagnosis (PGD).

Abstract: During the nearly 10 years since its introduction, preimplantation genetic diagnosis (PGD) has been used predominantly to avoid giving birth to a child with identified genetic disease. Recently, PGD was used by a couple not only to test IVF-created embryos for genetic disease, but also to test for a nondisease trait related to immune compatibility with a child in the family in need of an hematopoietic stem cell transplant. This article describes the case, raises some ethical and policy issues, highlights gaps in U.S. policy, and finally makes some recommendations for addressing advancing genetic and reproductive technologies.


Khoshnood, Babak; Blondel, Béatrice; De Vigan, Catherine; Bréart, Gérard. Socioeconomic barriers to informed decisionmaking regarding maternal serum screening for Down syndrome: results of the French National Perinatal Survey of 1998. *American Journal of Public Health* 2004 March; 94(3): 484-491. NRCBL: 15.2; 9.5.3; 8.3.4; 8.3.1; 9.2; 9.3.1; 9.4. SC: em. Abstract: OBJECTIVES: We sought to evaluate socioeconomic disparities in serum screening for Down syndrome and assess whether such disparities are more likely to reflect limits in access or information or, rather, informed decisionmaking. METHODS: A nationally representative sample of 12 869 French women completed interviews after giving birth. RESULTS: We found substantial disparities in the likelihood of (1) women not being offered screening, (2) screening not being offered as a result of late prenatal care, and (3) women not knowing whether or not they had undergone screening. Except in the case of nationality, there was essentially no evidence of differences in refusal of testing. CONCLUSIONS: Rather than representing informed decisionmaking, socioeconomic disparities in screening for Down syndrome are mostly due to limits in access or to information.


Krones, Tanja; Richter, Gerd. Preimplantation Genetic Diagnosis (PGD): European perspectives and the German situation. *Journal of Medicine and Philosophy* 2004 October; 29(5): 623-640. NRCBL: 15.2; 2.2; 14.4; 21.1. SC: le; rv. Identifiers: Europe; Germany.

Abstract: This article gives an overview about the ethical dispute on preimplantation genetic diagnosis (PGD), its legal status and its practical usage in Europe. We provide a detailed description of the situation in Germany wherein prenatal diagnosis is routinely applied, but PGD is prohibited on the basis of the internationally unique embryo protection act (EPA) that was put into force in 1991. Both PGD and stem cell research were vigorously debated in Germany during the last four years. As regards the PGD debate specifically, the voices of the ones directly affected were not adequately taken into consideration. We describe the predominant lines of argumentation in this debate and some essential results of our “bioethical field study” of opinions on and usage of PGD in Germany and their implications for the German legislation and ethical theory.


Offit, Kenneth; Groeger, Elizabeth; Turner, Sam; Wadsworth, Eve A.; Weiser, Mary A. The “duty to warn” a patient’s family members about hereditary disease risks. *JAMA: The Journal of the American Medical Association* 2004 September 22-29; 292(12): 1469-1473. NRCBL: 15.2; 8.4.

Abstract: Genetic tests for adult-onset disorders, including common forms of cancer, are now commercially available, and tests for genetic polymorphisms that predict drug effects or toxicity after treatment are under development. For each of these circumstances, testing of 1 individual may imply an increased risk to his/her relative. The obligation, if any, to warn family members of the identification of a genetic mutation has generated concerns regarding the conflict between the physician’s
ethical obligations to respect the privacy of genetic information and the potential liabilities resulting from the physician’s failure to notify at-risk relatives. A duty to warn relatives about risks due to some infectious agents has been assumed by state and local health agencies, and the duty to breach confidentiality to warn of imminent harm has been the subject of case law. In general, the special nature of genetic tests has been viewed as a barrier to physicians’ breaches of the confidentiality of personal genetic information. However, the failure to warn family members about hereditary disease risks has already resulted in 3 lawsuits against physicians in the United States. While the findings of case law and the state and federal statutes that bear on the issue of “duty to warn” of inherited health risk are still being defined, we believe that health care professionals have a responsibility to encourage but not to coerce the sharing of genetic information in families, while respecting the boundaries imposed by the law and by the ethical practice of medicine.


Petrov, Stavros; Mugford, Miranda. Should prenatal diagnostic testing be offered to all pregnant women on economic grounds? [opinion]. *Lancet* 2004 January 24; 363(9405): 258-259. NRCBL: 15.2; 9.3.1; 9.1; 9.4; 9.8.


Raz, Aviad E.; Atar, Marcela; Rodnay, Maya; Shoham-Vardi, Ilana. Between acculturation and ambivalence: knowledge of genetics and attitudes towards genetic testing in a consanguineous Bedouin community. *Community Genetics* 2003 October; 6(2): 88-95. NRCBL: 15.2; 21.7. SC: em.

Rowe, R.E.; Garcia, J.; Davidson, L.L. Social and ethnic inequalities in the offer and uptake of prenatal screening and diagnosis in the UK: a systematic review. *Public Health* 2004 April; 118(3): 177-189. NRCBL: 15.2; 7.1; 9.2. SC: em.

Saukko, Paula. Genomic susceptibility-testing and pregnancy: something old, something new. *New Genetics and Society* 2004 December; 23(3): 313-325. NRCBL: 15.2; 12.5.3; 9.5.5; 4.4; 3.1.

Sermon, Karen; Van Steirteghem, André; Liebaers, Inge. Preimplantation genetic diagnosis. *Lancet* 2004 May 15; 363(9421): 1633-1641. NRCBL: 15.2; 14.4. SC: rv. Abstract: Preimplantation genetic diagnosis (PGD) was introduced at the beginning of the 1990s as an alternative to prenatal diagnosis, to prevent termination of pregnancy in couples with a high risk for offspring affected by a sex-linked genetic disease. At that time, embryos obtained in vitro were tested to ascertain their sex, and only female embryos were transferred. Since then, techniques for genetic analysis at the single-cell level, involving assessment of first and second polar bodies from oocytes or blastomeres from cleavage-stage embryos, have evolved. Fluorescence in-situ hybridisation (FISH) has been introduced for the analysis of chromosomes and PCR for the analysis of genes in cases of monogenic diseases. In-vitro culture of embryos has also improved through the use of sequential media. Here, we provide an overview of indications for, and techniques used in, PGD, and discuss results obtained with the technique and outcomes of pregnancies. A brief review of new technologies is also included.

Sheldon, S.; Wilkinson, S. Should selecting saviour siblings be banned? *Journal of Medical Ethics* 2004 December; 30(6): 533-537. NRCBL: 15.2; 14.4; 19.5. SC: an. Abstract: By using tissue typing in conjunction with preimplantation genetic diagnosis doctors are able to pick a human embryo for implantation which, if all goes well, will become a “saviour sibling”, a brother or sister capable of donating life-saving tissue to an existing child. This paper addresses the question of whether this form of selection should be banned and concludes that it should not. Three main prohibitionist arguments are considered and found wanting: (a) the argument that human embryos are not commodities; (b) a slippery slope argument, which suggests that this practice will lead to the creation of so-called “designer babies”; and (c) a child welfare argument, according to which saviour siblings will be physically and/or psychologically harmed.


Stain ton, T. Identity, difference and the ethical politics of prenatal testing. Journal of Intellectual Disability Research 2003 October; 47(part 7): 533-539. NRCBL: 15.2; 4.4; 9.5.3.


Taub, Sara; Morin, Karine; Spillman, Monique A.; Sade, Robert M.; Riddick, Frank A. Managing familial risk in genetic testing. Genetic Testing 2004 Fall; 8(3): 356-359. NRCBL: 15.2; 8.4; 8.3.1; 15.1.


Verlinsky, Yury; Rechitsky, Svetlana; Sharapova, Tatyana; Morris, Randy; Taranissi, Mohammed; Kuliev, Anver. Preimplantation HLA testing. JAMA: The Journal of the American Medical Association 2004 May 5; 291(17): 2079-2085. NRCBL: 15.2; 14.4; 19.5.

Abstract: CONTEXT: Preimplantation genetic diagnosis (PGD) has become an option for couples for whom termination of an affected pregnancy identified by traditional prenatal diagnosis is unacceptable and is applicable to indications beyond those of prenatal diagnosis, such as HLA matching to affected siblings to provide stem cell transplantation. OBJECTIVE: To describe preimplantation HLA typing, not involving identification of a causative gene, for couples who had children with bone marrow disorders at need for HLA-matched stem cell transplantation. DESIGN, SETTING, AND PARTICIPANTS: HLA matching procedures conducted at a single site during 2002-2003 in an in vitro fertilization program for 9 couples with children affected by acute lymphoid leukemia, acute myeloid leukemia, or Diamond-Blackfan anemia requiring HLA-matched stem cell transplantation. In 13 clinical cycles, DNA in single blastomeres removed from 8-cell embryos following in vitro fertilization was analyzed for HLA genes simultaneously with analysis for short tandem repeats in the HLA region to select and transfer only those embryos that were HLA matched to affected siblings. MAIN OUTCOME MEASURES: Results of HLA matching and pregnancy outcome. RESULTS: As a result of testing a total of 199 embryos, 45 (23%) HLA-matched embryos were selected, of which 28 were transferred in 12 clinical cycles, resulting in 5 singleton pregnancies and birth of 5 HLA-matched healthy children. CONCLUSION: This is the first known experience of preimplantation HLA typing performed without PGD for a causative gene, providing couples with a realistic option of having HLA-matched offspring to serve as potential donors of stem cells for their affected siblings.


Wagner, John E.; Kahn, Jeffrey P.; Wolf, Susan M.; Lipton, Jeffrey M.; Kuliev, Anver; Rechitsky, Svetlana; Verlinsky, Yury. Preimplantation testing to produce an HLA-matched donor infant [letter and reply]. JAMA: The Journal of the American Medical Association 2004 August 18; 292(7): 803-804. NRCBL: 15.2; 14.4; 18.5.


Abstract: Preimplantation genetic diagnosis (PGD) raises serious moral questions concerning the parent-child relationship. Good parents accept their children unconditionally: they do not reject/attack them because they do not have the features they want. There is nothing wrong with treating a child as someone who can help promote some other worthwhile end, providing the child is also respected as an end in him or herself. However, if the child’s presence is not valued in itself, regardless of any further benefits it brings, the child is not being treated as an end in the full sense of the term, in this paper, I argue that these principles apply to human embryos, as well as to born human offspring: the human moral subject is a bodily being, whose interests and rights begin with the onset of his or her bodily life. The rights of the living, bodily human individual include a right not to be attacked/abandoned because of his or her genetic profile. PGD is harmful to the parent-child relationship, and we give mixed messages to parents by expecting them to show unconditional commitment to offspring after birth, while inviting them to take a very different approach at the prenatal stage.


Wüstner, Kerstin. Ethics and practice: two worlds? The example of genetic counselling. New Genetics and Society 2003 April; 22(1): 61-87. NRCBL: 15.2; 8.3.1; 8.4; 2.1.


Abstract: Enhancement of autonomous choice may be considered as an important reason for facilitating the use of genetic tests such as preimplantation genetic diagnosis. The principle of respect for autonomy is a crucial component not only of Western liberal traditions but also of Western bioethics. This is...
especially so in bioethical discussions and analyses of clinical encounters within medicine. On the basis of an analysis of qualitative research interviews performed with British, Italian and Swedish geneticists and gynaecologists on ethical aspects of preimplantation genetic diagnosis, the plausibility of the notion of autonomy within reproductive medicine is discussed. The analysis of interviews indicates not only that there is a gap between theoretical discussions and concrete practice, but also that an increase in choice—paradoxically—can hamper couples’ choice.


**GENETIC RESEARCH**

**GENETIC RESEARCH**

**GENETIC ENHANCEMENT** See ENHANCEMENT

**GENETIC RESEARCH**

See also BEHAVIORAL GENETICS; BIOMEDICAL RESEARCH


Berry, Roberta M. Genetic information and research: emerging legal issues. *HEC (Healthcare Ethics Committee) Forum* 2003 March; 15(1): 70-99. NRCBL: 15.1; 15.3; 15.8; 8.4. SC: le.


Cogle, Christopher R.; Guthrie, Steven M.; Sanders, Ronald C.; Allen, William L.; Scott, Edward W.; Petersen, Bryon E. An overview of stem cell research and regulatory issues. *Mayo Clinic Proceedings* 2003 August; 78(8): 993-1003. NRCBL: 15.1; 18.5.4.

DeCamp, Matthew; Sugarman, Jeremy. Ethics and research assessing the relative roles of genes and the environment. *Accountability in Research* 2004 July-December; 11(3-4): 161-182. NRCBL: 15.1; 16.1; 9.7; 9.5.4.

DeCamp, Matthew; Sugarman, Jeremy. Ethics in population-based genetic research. *Accountability in Research* 2004 January-March; 11(1): 1-26. NRCBL: 15.1; 13.1; 5.1; 15.10; 1.3.12; 18.2; 18.3; 1.3.9; 7.1.

Abstract: Population-based genetic research, including genetic epidemiology, shows tremendous potential to elucidate the role of genes as causal factors in complex and common human diseases. Like all research with human subjects, full realization of these benefits requires careful attention to its ethical conduct, establishing an appropriate balance between individual protections and the advancement of scientific and medical knowledge. This article reviews the growing literature on genetistics research and ethics to describe some of the fundamental ethical issues in population-based genetics research, including research design, recruitment and informed consent, and dealing with research results. Its focus is on areas where consensus is forming and where future work is needed.


Abstract: The global value of the biotechnology industry is now estimated at 17 billion dollars, with over 1300 firms involved as of the year 2000.(2) It has been said that ‘What we are witnessing is nothing less than a new kind of gold rush, and the territory is the body.’ As in previous gold rushes, prospectors are flooding into unexplored and ‘wide open’ territories from all over the world, with possible ramifications for exploitation of Third World populations. These territories are also the Wild West of bioethics insofar as the law has very little hold on them: existing medical and patent law, such as the Moore and Chakrabarty cases, exert little control over powerful economic interests in both the United States and Europe. In the absence of a unified and consistent law on property in the body, the focus is increasingly on refining the consent approach to rights in human tissue and the human genome, with sensitive and promising developments from the Human Genetics Commission and the Department for International Development consultation on intellectual property. These developments incorporate the views of vulnerable genetic communities such as Native Americans or some Third World populations, and should be welcomed because they recognise the power imbalance between such groups and First World researchers or firms. However, they also highlight the continued tension about what is really wrong with commodifying human tissue or the human genome. Where’s the injustice, and can it be solved by a more sophisticated consent procedure?

European Society of Human Genetics’ Public and Professional Policy Committee [PPPC]. Data storage and DNA banking for biomedical research: technical, social and ethical issues. *European Journal of Human Genetics* 2003 December; 11(12): 906-908. NRCBL: 15.1; 1.3.12; 18.1; 18.3.


GENETIC SCREENING


Moutel, Grégoire; de Montgolfier, Sandrine; Duchange, Nathalie; Sharara, Lama; Beaumont, Catherine; Hervé, Christian. Study of the involvement of research ethics committees in the constitution and use of biobanks in France. *Pharmacogenetics* 2004 March; 14(3): 195-198. NRCBL: 15.1; 1.3.12; 18.2; 18.3; 7.1. SC: en.


Serra, Angelo. Ethical problems in biological research in medicine. *Dolentiunum Hominum* 1995; 10(1): 130-137. NRCBL: 15.1; 2.2; 15.10; 15.2; 15.4; 5.1; 1.3.9; 18.3; 13.1. Conference: Proceedings of the Ninth International Conference organized by the Pontifical Council for Pastoral Assistance to Health Care Workers: To Know, Love, and Serve Life; Vatican City, 24-26 November 1994.

Sosnowski, Kristie. Genetic research: are more limitations needed in the field? *Journal of Law and Health* 2000-2001; 15(1): 121-146. NRCBL: 15.1; 15.3; 15.4; 15.10; 18.5.4; 8.4; 9.3.1. SC: le.

Taub, Sara; Morin, Karine; Sade, Robert M.; Spillman, Monique A. Safeguards in the use of DNA databanks in genomic research. *Genetics in Medicine* 2004 November-December; 6(6): 526-529. NRCBL: 15.1; 1.3.12; 18.3. Identifiers: presumed consent; Iceland.


Abstract: The increasing possibilities for using tissue for research and development in genetics and biotechnology have made stored human biological materials more important than ever. Using stored human biological materials raises many legal and ethical questions. On an international level however, the use of these materials has not been regulated in a detailed manner so far. The Council of Europe recently declassified the text of the proposal for an instrument on the use of archived human biological materials in biomedical research for public consultation. The purpose of this paper is to comment on this document regarding its primary goal, which is to protect the rights and fundamental freedoms of the individual whose biological materials could be included in a research project. The guidelines of other good basic protection for sources of identifiable human biological materials but, surprisingly, offer no protection to sources of anonymous or anonymised materials.


Yeh, Max; Morley, Katherine I.; Hall, Wayne D. The policy and ethical implications of genetic research on attention deficit hyperactivity disorder. *Australian and New Zealand Journal of Psychiatry* 2004 January-February; 38(1-2): 10-19. NRCBL: 15.1; 9.5.7; 15.3.

GENETIC SCREENING

See also GENETIC COUNSELING; GENOME MAPPING

Direct-to-consumer marketing for genetic testing [case study]. *Health Progress* 2003 September-October; 84(5): 35-36, 50. NRCBL: 15.3; 9.7; 1.3.2. SC: cs.

Lack of consent is an ethical issue [case study]. *Health Progress* 2003 July-August; 84(4): 43, 53. NRCBL: 15.3; 8.3.1. SC: cs.

No genotype left untreated [editorial]. *Nature Genetics* 2004 May; 36(5): 429-430. NRCBL: 15.3; 8.4; 15.1; 9.3.1. SC: le.


Aldred, Michael J.; Crawford, P.M.; Savarirayan, R.; Savulescu, J. It’s only teeth — are there limits to genetic testing? *Clinical Genetics* 2003 May; 63(5): 333-339. NRCBL: 15.3; 15.7; 15.2.


American College of Medical Genetics [ACMG]. Board of Directors. ACMG statement on direct-to-consumer genetic testing. *Genetics in Medicine* 2004 January-February; 6(1): 60. NRCBL: 15.3; 9.8; 1.3.2.

Andorno, Roberto. The right not to know: an autonomy based approach. *Journal of Medical Ethics* 2004 October; 30(5): 435-440. NRCBL: 15.3; 8.3.1; 8.2; 1.1.

NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
Abstract: The emerging international biomedical law tends to recognise the right not to know one’s genetic status. However, the basis and conditions for the exercise of this right remain unclear in domestic laws. In addition to this, such a right has been criticised at the theoretical level as being in contradiction with patient’s autonomy, with doctors’ duty to inform patients, and with solidarity with family members. This happens especially when non-disclosure poses a risk of serious harm to the patient’s relatives who, without that vital information, could be deprived of preventive or therapeutic measures. This paper argues, firstly, that individuals may have a legitimate interest in not knowing their genetic make up to avoid serious psychological consequences; secondly, that this interest, far from being contrary to autonomy, may constitute an enhancement of autonomy; thirdly, that the right not to know cannot be presumed, but must be “activated” by the individual’s explicit choice, and fourthly, that this is not an absolute right, in the sense that it may be restricted when disclosure to the patient is necessary in order to avoid a risk of serious harm to third persons.


Basset, Ken; Lee, Patricia M.; Green, Carolyn J.; Mitchell, Lisa; Kazanjian, Arminée. Improving population health or the population itself? Health technology assessment and our genetic future. International Journal of Technology Assessment in Health Care 2004 Spring; 20(2): 106-114. NRCBL: 15.3; 9.1; 5.2; 15.5; 8.3.1; 7.1; 9.3.1.


Abstract: Should a growing market for genetic self-tests be welcomed or feared? From the point of view of personal autonomy the increasing availability of predictive health information seems promising. Yet it is frequently pointed out that genetic information about future health may cause anxiety, distress and even loss of “life-hopes.” In this article the argument that genetic self-tests undermine personal autonomy is assessed and criticized. I contend that opportunities for autonomous choice cannot be reduced by genetic information but by misperceptions and misunderstandings of the results of genetic tests. Since the interpretation of genetic information is sometimes distorted by the information provided about the genetic products, more attention should be given to deceitful marketing that overblows the utility of genetic products. Yet personal autonomy is reduced neither by genetic tests nor by genetic information and there is consequently no compelling case for the conclusion that genetic self-tests should be prohibited.


Blandy, Cécile; Chabal, Françoise; Stoppa-Lyonnet, Dominique; Julian-Reynier, Claire. Testing participation in BRCA1/2-positive families: initiator role of index cases. Genetic Testing 2003 Fall; 7(3): 225-233. NRCBL: 15.3; 9.5.5; 9.5.1.


Burgess, Michael M. Beyond consent: ethical and social issues in genetic testing. Nature Reviews: Genetics 2001 February; 2(2): 147-152. NRCBL: 15.3; 8.3.1; 15.2.


Campbell, Elizabeth; Ross, Lainie Friedman. Parental attitudes regarding newborn screening of PKU and DMD. American Journal of Medical Genetics 2003 July 15; 120A(2): 209-214. NRCBL: 15.3; 9.5.7; 8.3.2. SC: em.
Campbell, Elizabeth; Ross, Lainie Friedman. Professional and personal attitudes about access and confidentiality in the genetic testing of children: a pilot study. Genetic Testing 2003 Summer; (7)(2): 123-130. NRCBL: 15.3; 15.1; 8.4; 9.5.7. SC: em.

Campbell, E.; Ross, L.F. Attitudes of healthcare professionals and parents regarding genetic testing for violent traits in childhood. Journal of Medical Ethics 2004 December; 30(6): 580-586. NRCBL: 15.3; 15.6; 9.5.7. SC: em.


Claes, Erna; Evers-Kiebooms, Gerry; Boogaerts, Andrea; Decruyenaere, Marleen; Denayer, Lieve; Legius, Eric. Diagnostic genetic testing for hereditary breast and ovarian cancer in cancer patients: women’s looking back on the pre-test period and a psychological evaluation. Genetic Testing 2004 Spring; 8(1): 13-21. NRCBL: 15.3; 9.5.5.


Cox, Susan M.; Starzomski, Rosalie C. Genes and geneticization? The social construction of autosomal dominant polycystic kidney disease. New Genetics and Society 2004 August; 23(2): 137-166. NRCBL: 15.3; 19.3; 4.2. SC: em.

Cox, Suzanne M.; Faucett, W. Andrew; Chen, Bin; Dequaker, Elisabeth; Boone, D. Joe; McGovern, Margaret M.; Lubin, Ira M. International genetic testing [opinion]. Genetics in Medicine 2003 May-June; 5(3): 176-182. NRCBL: 15.3; 21.1. SC: le.


Dennis, Carina. Deaf by design: employing genetic diagnosis to avoid having a baby with a disability is controversial enough. But a minority of deaf people would consider testing to ensure that they had a deaf child [news]. Nature 2004 October 21; 431(7011): 894-896. NRCBL: 15.3; 15.2; 14.4; 9.5.1.


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SECTION I  GENETIC SCREENING

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Williams-Jones, Bryn; Burgess, Michael M. Social contract theory and just decision making: lessons from genetic testing for the BRCA mutations. Kennedy Institute of Ethics Journal 2004 June; 14(2): 115-142. NRCBL: 15.3; 1.1; 9.3.1; 5.3. SC: po.

Abstract: Decisions about funding health services are crucial to controlling costs in health care insurance plans, yet they encounter serious challenges from intellectual property protection—e.g., patents—of health care services. Using Myriad Genetics’ commercial genetic susceptibility test for hereditary breast cancer (BRCA testing) in the context of the Canadian health insurance system as a case study, this paper applies concepts from social contract theory to help develop more just and rational approaches to health care decision making. Specifically, Daniels’s and Sabin’s “accountability for reasonableness” is compared to broader notions of public consultation, demonstrating that expert assessments in specific decisions must be transparent and accountable and supplemented by public consultation.

**GENETICS**


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Abstract: A major moral problem in relation to the deCODE genetics database project in Iceland is that the heavy emphasis placed on technical security of healthcare information has precluded discussion about the issue of consent for participation in the database. On the other hand, critics who have emphasised the issue of consent have most often demanded that informed consent for participation in research be obtained. While I think that individual consent is of major significance, I argue that this demand for informed consent is neither suitable nor desirable in this case. I distinguish between three aspects of the database and show that different types of consent are appropriate for each. In particular, I describe the idea of a written authorisation based on general information about the database as an alternative to informed consent and presumed consent in database research.

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Abstract: The extent to which society utilises the law to enforce its moral judgments remains a dominant issue in this era of embryonic stem cell research, preimplantation genetic diagnosis, and human reproductive cloning. Balancing the potential health benefits and diverse moral values of society can be a tremendous challenge. In this context, governments often adopt legis-
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Abstract: This essay examines an overlooked element of the precautionary principle: a prudent assessment of the long-range or remote catastrophes possibly associated with technological development must include the catastrophes that may take place because of the absence of such technologies. In short, this brief essay attempts to turn the precautionary principle on its head by arguing that, (1) if the long-term survival of any life form is precarious, especially given contemporary urban population densities, and (2) if technological innovation and progress are necessary in order rapidly to adapt humans to meet environmental threats that would otherwise be catastrophic on a large scale (e.g., pandemics of highly lethal diseases), then (3) the development of biomedical technologies in many forms, but in particular including human germ-line genetic engineering, may be required by the precautionary principle, given the prospect of the obliteration of humans in the absence of such enhanced biotechnology. The precautionary principle thus properly understood requires an ethic that should generally support technological innovation, at least in particular areas of biotechnology.


Abstract: The way people think about equality as a value will influence how they think genetic interventions should be regulated. In this paper the author uses the taxonomy of equality put forth by Derek Parfit and applies this to the issue of genetic interventions. It is argued that telic egalitarianism is untenable and that deontic egalitarianism collapses into prioritarianism. The priority view maintains that it is morally more important to benefit the people who are worse off. Once this precision has been given to the concerns egalitarians have, a number of diverse issues must be considered before determining what the just regulation of genetic interventions would be. Consideration must be given to the current situation of the least advantaged, the fiscal realities behind genetic interventions, the budget constraints on other social programmes egalitarians believe should receive scarce public funds, and the interconnected nature of genetic information. These considerations might lead egalitarians to abandon what they take to be the obvious policy recommendations for them to endorse regarding the regulation of gene therapies and enhancements.


Abstract: BACKGROUND: Over the past few years, research ethics committees have increasingly demanded explicit consent before archival tissue samples can be used in research projects. Current UK guidance in this area requires an assessment of whether it is “practical” to obtain explicit consent. Ethics committees have little experience or evidence to help them to judge what is “practical” in this context. METHODS: We attempted to obtain general consent for research use of surplus tissue from renal transplant biopsies from the entire patient population of the renal transplant unit in Leicester. The nature of this patient population would be expected to facilitate this task. RESULTS:
A total of 495 letters were sent. Attempts were made to contact non-responders when they attended the outpatient clinic. One year after the initiation of the project, the opinions of 26% of the patients had still not been ascertained. CONCLUSIONS: The results confirm that the vast majority of patients are happy for “surplus” biopsy material to be used for research; the situation does not parallel the use of autopsy tissue. A requirement to obtain explicit consent for the study of archival tissue is likely, however, to block or at least seriously delay research, which is contrary to the public interest and specifically may harm the interests of the patients concerned. In the UK, the problem of tissue being used against the wishes of the donor has now been largely replaced by the problem of prohibition of tissue use against the wishes of the donor.


Hamajima, Nobuyuki; Atsuta, Yoshiko; Niwa, Yoshimitsu; Nishio, Kazuko; Tanaka, Daisuke; Yamamoto, Kazuhiro; Tamakoshi, Akiko. Precise definition of anonymization in genetic polymorphism studies [opinion]. *Asian Pacific Journal of Cancer Prevention* 2004 January-March; 5(1): 83-88. NRCBL: 15.1; 8.3.1; 8.4; 18.1.


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Howard, Ken. Lack of data privacy could hamper pharmacogenomics studies. *Nature Reviews Drug Discovery* 2004 September; 3(9): 725. NRCBL: 15.1; 1.3.12; 8.4; 9.7.


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SECTION I GENETICS

22.2; 1.3.11; 15.7; 1.1; 22.3; 4.4. SC: an. Identifiers: Balzer; Rollin; Rolston; holistic ethical position.


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Mordini, Emilio. Ethical considerations on pharmacogenomics. Pharmacological Research 2004 April; 49(4): 375-379. NRCBL: 15.1; 9.7; 18.5.6.

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Polkinghorne, J.C. The person, the soul, and genetic engineering. Journal of Medical Ethics 2004 December; 30(6): 593-597. NRCBL: 15.1; 18.5.4; 19.1; 4.4. SC: an. Abstract: Argument about the ethical possibility of the therapeutic use of embryonic stem cells depends critically on the evaluation of the moral status of the very early embryo. Some assert that at the blastocyst stage it is only potentially human, not yet possessing the full ethical status of personhood, while others assert that from its formation the embryo possesses all the moral rights of a human person. It is shown that a decision on this issue is closely related to how human nature is to be understood. The idea of a person as a dual combination of body and spirit correlates naturally with the assertion of absolute personhood from conception, while an idea of human psychosomatic unity encourages a development picture in which the embryo only grows gradually into personhood. The latter view is seen to be encouraged by new advances in science which emphasise the importance of the concept of information in the discussion of complex systems. Other ethical issues related to human genetics are also briefly reviewed.


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NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.
Reilly, Philip R. Public concern about genetics. Annual Review of Genomics and Human Genetics 2000 August; 1(1): 485-506. NRCBL: 15.1; 1.3.11; 5.1; 14.5; 15.3; 22.3.


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Romeo Casabona, Carlos María. Genetics, tissue, and databases. European Journal of Health Law 2004 March; 11(1): 71-75. NRCBL: 15.1; 1.3.12; 17.1; 18.3; 18.2.


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SC (Subject Caption): an=analytical cs=case studies em=empirical le=legal po=popular rv=review


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**GENETICS AND HUMAN ANCESTRY**


Sze, Julie; Prakash, Swati. Human genetics, environment, and communities of color: ethical and social implications. *Environmental Health Perspectives* 2004 May; 112(6): 740-745. NRCBL: 15.11.


**GENOCIDE** See TORTURE, GENOCIDE, AND WAR CRIMES

**GENOME MAPPING**

*See also GENETIC SCREENING*


Lin, Zhen; Owen, Art B.; Altman, Russ B. Genomic research and human subject privacy. *Science* 2004 July 9; 305(5681): 183. NRCBL: 15.10; 1.3.12; 5.2; 8.4.

Magill, Gerard. Ethical perspectives on mapping the human genome. *Health Care Ethics USA* 2001; 9(1): 4 p. NRCBL: 15.10; 15.4; 15.3.

Malakoff, David. Report upholds public access to genetic codes [news]. *Science* 2004 September 17; 305(5691): 1692. NRCBL: 15.10; 1.3.12; 21.3; 5.3.


Sirugo, Giorgio; Van Der Leoff, Maarten Schim; Sam, Omar; Nyan, Ousman; Pinder, Margaret; Hill, Adrian V.; Kwiatkowski, Dominic; Prentice, Andrew; de Toma, Claudia; Cann, Howard M.; Diatta, Mathurin; Jallow, Muminatou; Morgan, Gareth; Clarke, Malcolm; Corrah, Tumani; Whittle, Hilton; McAdam, Keith. A national DNA bank in The Gambia, West Africa, and genomic research in developing countries [letter]. *Nature Genetics* 2004 August; 36(8): 785-786. NRCBL: 15.10; 1.3.12; 13.1.

Tutton, Richard. “They want to know where they came from”: population genetics, identity, and family genealogy. *New Genetics and Society* 2004 April; 23(1): 105-120. NRCBL: 15.10; 13.1; 21.1; 15.11.

SC (Subject Caption): an=analytical cs=case studies em=empirical le=legal po=popular rv=review 176

**HEALTH CARE**

*See also CARE FOR SPECIFIC DISEASES AND GROUPS; HEALTH CARE ECONOMICS; HEALTH CARE QUALITY; RESOURCE ALLOCATION; RIGHT TO HEALTH CARE*


Barratt, Aleandra; Trevena, Lyndal; Davey, Heather M.; McCaffery, Kirsten. Use of decision aids to support informed choices about screening. *BMJ: British Medical Journal* 2004 August 28; 329(7464): 507-510. NRCBL: 9.1; 8.3.1; 8.1.


Briss, Peter; Rimer, Barbara; Reilley, Barbara; Coates, Ralph C.; Lee, Nancy C.; Mullin, Patricia; Corso, Phaedra; Hutchinson, Angela B.; Hiatt, Robert; Kerner, Jon; George, Prethibha; White, Cornelia; Gandhi, Nisha; Saraiya, Mona; Breslow, Rosalind; Isham, George; Teutsch, Steven M.; Himman, Alan R.; Lawrence, Robert. Promoting informed decisions about cancer screening in communities and healthcare systems. *American Journal of Preventive Medicine* 2004 January; 26(1): 67-80. NRCBL: 9.1; 9.3.1; 9.5.1. SC: em; rv. Identifiers: Task Force on Community Preventive Services.


Bruhn, John G. The ethic of “the organizational good”: is doing the right thing enough? *Health Care Manager* 2004 January-March; 23(1): 4-10. NRCBL: 9.1; 1.3.2.


Cohen, Elena N. Disclosing religious restrictions in health care: balancing individual and institutional preferences.
Gender Medicine 2004 August; 1(1): 8-11. NRCBL: 9.1; 1.2; 18.5.3; 20.5.1; 14.1.


Abstract: The idea of a precautionary principle (or precautionary principles) is beginning to come to the wider attention of the environmental community, governmental agencies, regulatory agencies, and the regulated community. Different precautionary principles have not been specified in detail, and, of course, this is difficult to do. Yet some specification must be done in order to understand it better and, if it is to be used for specific action-guidance, to implement it. Moreover, it is important to understand more about the principle, its background assumptions and its comparison with other principles to which we might subscribe. This paper explores aspects of the PP and its background assumptions and presuppositions, comparing them with those for risk assessment and other statements of the PP. It also briefly indicates how it resembles legal principles in addressing problems of uncertainty. Finally, it recapitulates two possible versions of the PP and suggests an application of it for an emerging threat to the environment and public health. This review suggests the PP has plausible applications and is not the radical principle some have suggested.


Doran, Sandra J. The business imperative behind a sound ethics program. Managed Care Quarterly 2003 Winter; 11(1): 49-51. NRCBL: 9.1; 1.3.2.


Abstract: Health care in France falls almost exclusively under the responsibility of the Social Security department, which covers almost all the expenditures related to health care, whether hospitalization or medication is concerned. For severe diseases or surgery the coverage is likely to reach as much as 100%. The medical expenditures for several severe diseases, such as cancer, myocardial infarction, or neurodegenerative diseases are 100% covered for a period of time as long as three months. For some procedures, full coverage may be achieved by using a subscription to private health care insurance. Access to cover by the state has recently been opened to anyone living in France, after passage of a special law. There is still a lack of intensive care and hospice beds, given the rapidly increasing number of elderly who cannot be maintained at home. There is a tendency to reduce the number of beds in private and public hospitals due to the great number of such institutions and the general concern that a low volume of procedures, associated with inexperienced health care professionals, is likely to increase morbidity and mortality as well as public health care expenditure. Patients are still free to choose doctors and hospitals (whether private or public), provided that beds are available and that specific procedures can be carried out in the vicinity. So far no waiting list is needed, except for specific procedures performed by a few specialists of high repute. Health care expenses are increasing continuously, which results in a very expensive system in France.


Goldwater, Paul N.; BraunackMayer, Annette J.; Power, Richard G.; Henning, Paul H.; Gold, Mike S.;


Abstract: The International Health Regulations (IHR), the only global regulations for infectious disease control, have not been significantly changed since they were first issued in 1951. The World Health Organization (WHO) is currently engaged in a process to modernize the IHR. This article reviews WHO’s draft revised IHR and recommends new reforms to improve global health, which include (1) a robust mission, emphasizing the WHO’s core public health purposes, functions, and essential services; (2) broad scope, flexibly covering diverse health threats; (3) global surveillance, developing informational networks of official and unofficial data sources; (4) national public health systems, setting performance criteria, measuring outcomes, and holding states accountable; (5) human rights protection, setting science-based standards and fair procedures; and (6) good governance, adopting the principles of fairness, objectivity, and transparency. The WHO should ensure state compliance with health norms and generous economic and technical assistance to poorer countries. An important issue for the international community is how sovereign countries can join together to make global health work for everyone, the poor and the wealthy alike.


Halpern, Sydney A. Medical authority and the culture of rights. *Journal of Health Politics, Policy and Law* 2004 August-October; 29(4-5): 835-852. NRCBL: 9.1; 7.1; 9.2; 8.1; 9.3.2.


Abstract: In this article I attempt to transcend the mainstream conception of health care ethics, including nursing ethics, by bringing into the foreground a tension between a sense of life and an industrial-bureaucratic style of health care, with its emphasis on the systematic and procedural work culture necessary for mass production. I use the concept of ‘a sense of life’ to draw attention to the wisdom, sensitivity and responsibility that is necessary for the authentic care of others to be given a chance in the development of modern health care. I emphasize the mindfulness that the professional requires for genuine care, and how the systematic organization of modern health care, on the whole, ignores, obstructs and even suppresses such mindfulness.

Illes, Judy; Kann, Dylan; Karetzky, Kim; Letourneau, Phillip; Raffin, Thomas A.; Schraedley-Desmond, Pamela; Koenig, Barbara A.; Atlas, Scott W. Advertising, patient decision making, and self-referral for computed tomographic and magnetic resonance imaging. *Archives of Internal Medicine* 2004 December 13-27; 164(22): 2415-2419. NRCBL: 9.1; 1.3.2. SC: em.


Jennings, Bruce. Trusteeship as representation. In: Jennings, Bruce, et al. The Ethics of Hospital Trustees.


Little, Paul; Dorward, Martina; Warner, Greg; Moore, Michael; Stephens, Katharine; Senior, Jane; Kendrick, Tony. Randomised controlled trial of effect of leaflets to empower patients in consultations in primary care. BMJ: British Medical Journal 2004 February 21; 328(7437): 441-444. NRCBL: 9.1; 8.1. Abstract: OBJECTIVE: To assess the impact of leaflets encouraging patients to raise concerns and to discuss symptoms or other health related issues in the consultation. DESIGN: Randomised controlled trial. SETTING: Five general practices in three settings in the United Kingdom. PARTICIPANTS: 636 consecutive patients, aged 16-80 years, randomised to receive a general leaflet, a depression leaflet, both, or neither. MAIN OUTCOMES: Mean item score on the medical interview satisfaction scale, consultation time, prescribing, referral, and investigation. RESULTS: The general leaflet increased patient satisfaction and was more effective with shorter consultations (leaflet 0.64, 95% confidence interval 0.19 to 1.08; time 0.31, 0.0 to 0.86; interaction between both -0.045, -0.08 to -0.009), with similar results for subscales related to the different aspects of communication. Thus for a 10 minute consultation the leaflet increased satisfaction by 7% (seven centile points) and for a five minute consultation by 14%. The leaflet overall caused a small non-significant increase in consultation time (0.36 minutes, 0.54 to 1.26). Although there was no change in prescribing or referral, a general leaflet increased the numbers of investigations (odds ratio 1.43, 1.00 to 2.05), which persisted when controlling for the major potential confounders of perceived medical need and patient preference (1.87, 1.10 to 3.19). Most of excess investigations were not thought strongly needed by the doctor or the patient. The depression leaflet had no significant effect on any outcome. CONCLUSIONS: Encouraging patients to raise issues and to discuss symptoms and other health related issues in the consultation improves their satisfaction and perceptions of communication, particularly in short consultations. Doctors do, however, need to elicit expectations to provide needless investigations.

Loewy, Erich H. Health-care systems and ethics: what can we learn? Health Care Analysis: An International Journal of Health Care Philosophy and Policy 1999; 7(4): 309-320. NRCBL: 9.1; 9.3.1; 9.3.2. Abstract: Health care systems in different countries and cultures differ and tend to reflect the particular values and, therefore, the particular social structure of a given society. Each of these has ethical problems unique to itself. Some of these problems are briefly discussed. So as to have an individual ethical problem in the context of medical care, access to medical care needs to be assured. It is argued that individual problems are the primary issue in societies in which there is fair access whereas they are of lesser importance in societies which have thus far failed to provide fair access.


Parascandola, M. Hazardous effects of tobacco industry funding [editorial]. Journal of Epidemiology and Community Health 2003 August; 57(8): 548-549. NRCBL: 9.1; 1.3.2; 9.3.1; 7.3.


Pijnenburg, Martien A.M.; ten Have, Henk A.M.J. Catholic hospitals and modern culture: a challenging relationship. National Catholic Bioethics Quarterly 2004 Spring; 4(1): 73-88. NRCBL: 9.1; 1.2; 4.1.2; 7.1; 1.1; 9.3.1; 9.8.


Place, Michael D. The health care crisis: as the number of uninsured grows, the money disappears. America 2004 December 13; 191(19): 7-9. NRCBL: 9.1; 9.3.1; 9.2; 1.2.


Reynolds, T.M. Down’s syndrome screening is unethical: views of today’s research ethics committees. Journal of Clinical Pathology 2003 April; 56(4): 268-270. NRCBL: 9.1; 9.5.3; 18.2; 18.5.6.


Romano, Michael. Separation of health, state. Recent legislation has providers caught in the debate over government involvement in personal medical decisions. Modern Healthcare 2003 October 27; 33(43): 4-5, 12. NRCBL: 9.1; 20.5.1; 1.3.5; 8.1; 9.4.

Rorty, Mary V.; Werhane, Patricia H.; Mills, Ann E. The Rashomon effect: organization ethics in health care. HEC (Healthcare Ethics Committee) Forum 2004 June; 16(2): 75-94. NRCBL: 9.1; 1.3.2; 9.4; 4.1.2; 1.3.1. SC: cs.


HEALTH CARE ECONOMICS


Smith, David H. Health. 1.3.2; 1.1; 9.6. Identifiers: Canada; Nova Scotia; Capital Forum urban health region.


Abstract: Many 21st-century observers explain international efforts to control infectious diseases as a function of globalization and recent transformations in international commerce, transportation, and human migration. However, these contemporary global health initiatives can be more fully understood by also exploring the origins of international health organizations and regulations, which were initially dedicated exclusively to stemming the tide of infectious epidemics. This article reviews 3 eras of international approaches to controlling infectious diseases (1851-1881, 1881-1945, and 1945 to the present) and concludes by assessing how nations have a strong fiscal and humanitarian incentive to invest in infectious disease control programs and infrastructures in and beyond their own borders.


Abstract: The health care systems in Austria, Germany and Switzerland owe their institutional structure to different historical developments. While Austria and Germany voted for the Bismarck-Model of social health insurance, Switzerland adopted a voluntary system of health insurance. In all three countries, until very recently, the different challenges which the health care sector faced were met by piecemeal approaches and by stop and go policies, which, in the long run were not very successful either in containing costs or in improving efficacy and efficiency. During the 1990 more fundamental reforms in the health care systems of all three countries took place. Germany and Switzerland chose the path of deregulation of the health insurance system, which consequently strengthen the competition between the insurance companies, and, to some extent between the suppliers of medical services. While this can be seen as an essential part of the reform process for these two countries. Austria favors a state-oriented and interventionist approach in order to meet the challenges.


HEALTH CARE ECONOMICS

See also RESOURCE ALLOCATION
Abstrac: E. Haavi Morreim’s book, Holding Health Care Accountable, insightfully describes several features of the current crisis in malpractice in relation to the health care marketplace. In this essay, I delineate the key and eminently practical guide for reform that she lays out. I argue that her insights bring us to more fundamental aspects than immanent medical economy and accountability—aspects that are ignored at present. I describe the features of immanent economy and how they tend to cover over epistemological and existential finitude in medicine, show how economy can in fact create new medical knowledge, and show that necessary error is a real feature of day-to-day medical practice. The current system, even with Morreim’s reforms, remains at the level of immanent economy, but with modifications may point to the features of medicine that transcend medical knowledge and economy. The gifts of medicine cannot be reduced to the immanent medical economy, and any attempt to do so results in crisis. A health care that points to finitude and fallibility is one that points to the mystery of human existence and mortality. Any health care financing system that helps to delineate finitude—both epistemological and existential—is one that will give patients a new lease on living and dying.


Abstract: BACKGROUND: We examined the importance for voters of health care as an issue in the presidential election of 2004, how this ranking compares with the importance of health care in past elections, and which issues voters regard as the most important health care issues in the months before the election.

METHODS: We studied data from 22 national opinion surveys, 9 of them conducted as telephone surveys during the 2004 presidential campaign, 10 conducted as telephone surveys during the previous three presidential elections, and 3 conducted as national exit polls of voters. RESULTS: Voters ranked health care as the fourth most important issue in deciding their vote for president in 2004. The top health care issues for voters were the costs of health care and prescription drugs, prescription-drug benefits for the elderly, the uninsured, and Medicare. Bioterrorism and abortion were also important issues for voters. The voters most concerned about health care were older persons and those who identified themselves as Democrats. Four issues less salient to voters were racial disparities in health care, aid to developing countries to prevent and treat human immunodeficiency virus infection and the acquired immunodeficiency syndrome, medical malpractice, and the quality of care. CONCLUSIONS: Although health care ranks higher in importance among voters than most other domestic issues, it is only fourth in importance in deciding their vote for president. The health care issues of greatest concern are the affordability of health care and health care insurance. Health care issues do not appear likely to play a decisive role in the presidential election in 2004, but they might make a difference in some swing states if the race is close.


Chester, Alexander C. A single-payer national health insurance: we gave twice at the office [letter]. Archives of Internal Medicine 2004 November 8; 164(20): 2281. NRCBL: 9.3.1; 7.1.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme  See inside front cover for terms.

Abstract: Last year (1998) saw the celebration of the 50th Anniversary of the British National Health Service (NHS). One of the few completely nationalized systems of health care in the world, the NHS is seen by many as a moral beacon of what it means to provide equitable medical treatment to all citizens on the basis of need and need alone. However, others argue that it has failed to achieve the overall goals for which it was created. Because of scarce resources, some urgently needed care is not available at all, while that which is received is sometimes second class. For these reasons, it is claimed that the NHS should be scrapped and replaced by other systems of health care delivery. This paper outlines the history of the NHS, indicating some of the problems and innovations which have led to its current organization and structure. The philosophical foundations of the NHS are then articulated and defended on the grounds that it still represents a morally coherent and economically efficient approach to the delivery of health care. Scarce resources are the key problem facing the NHS, making rationing inevitable and it is shown that this is not incompatible with the moral foundations of the service. However, there can be little doubt that the NHS is now becoming dangerously under-funded. The paper concludes with arguments about why this is so and what might be done about it.


Fife, Rose S.; Keener, Patricia; Meslin, Eric M.; Randall, Marcus; Schifflmiller, Rebecca L. Faculty ownership of medical facilities: inappropriate conflict or an opportunity that benefits physicians and patients? Academic Medicine 2004 November; 79(11): 1051-1055. NRCBL: 9.3.1; 7.3; 1.3.2.


Giacomini, Mita; Miller, Fiona; O’Brien, Bernie J. Economic considerations for health insurance coverage of emerging genetic tests. Community Genetics 2003 October; 6(2): 61-73. NRCBL: 9.3.1; 15.3; 9.4; 4.4. SC: rv; em.


Goold, Susan Dorr; Green, Stephen A.; Biddle, Andrea K.; Benavides, Ellen; Danis, Marion. Will insured citizens give up benefit coverage to include the uninsured? JGIM: Journal of General Internal Medicine 2004 August; 19(8): 868-874. NRCBL: 9.3.1; 9.4. SC: em.


Johannes, Laura. At Cigna, some patients found conflict of interest in system. Wall Street Journal 2004 November 12; p. A1, A4. NRCBL: 9.3.1; 9.7; 8.3.1. SC: po.


Kluge, Eike-Henner W. The Canadian health care system. Health Care Analysis: An International Journal of Health Care Philosophy and Policy 1999; 7(4): 377-391. NRCBL: 9.3.1; 8.3.2; 9.2; 9.4; 9.5.4. Abstract: The Canadian health care system is a publicly funded system based on the philosophy that health is a right, not a commodity. The implementation of this perspective is hampered by the fact that the Canadian Constitution makes health care a matter of provincial jurisdiction, while most taxing powers lie in the hands of the federal government. Further problems arise because of Canada’s geographic nature and a move to regionalization of provincial health care administration. The issue is compounded by recent developments in reproductive technologies, aboriginal health, changes in consent law, etc.
SECTION I

HEALTH CARE ECONOMICS


Muggli, Monique E.; Hurt, Richard D. A cigarette manufacturer and a managed care company collaborate to censor health information targeted at employees. *American Journal of Public Health* 2004 August; 94(8): 1307-1311. NRCBL: 9.3.1; 13.2; 9.3.2; 1.3.9.


Abstract: Recent reports showing an increase in the number of uninsured individuals in the United States have given heightened attention to increasing health insurance coverage. The American Medical Association (AMA) has proposed a system of tax credits for the purchase of individually owned health insurance and enhancements to individual and group health insurance markets as a means of expanding coverage. Individually owned insurance would enable people to maintain coverage.
without disruption to existing patient-physician relationships, regardless of changes in employers or in work status. The AMA’s plan would empower individuals to choose their health plan and give patients and their physicians more control over health care choices. Employers could continue to offer employment-based coverage, but employees would not be limited to the health plans offered by their employer. With a tax credit large enough to make coverage affordable and the ability to choose their own coverage, consumers would dramatically transform the individual and group health insurance markets. Health insurers would respond to the demands of individual consumers and be more cautious about increasing premiums. Insurers would also tailor benefit packages and develop new forms of coverage to better match the preferences of individuals and families. The AMA supports the development of new health insurance markets through legislative and regulatory changes to foster a wider array of high-quality, affordable plans.


Abstract: BACKGROUND: Patients who present to medical practices without health insurance or with serious co-morbidities can become fiscal disasters to those who care for them. Their consumption of scarce resources has caused consternation among providers and institutions, especially as it concerns the amount and type of care they should receive. In fact, some providers may try to avoid caring for them altogether, or at least try to limit their institutional or practice exposure to them. DISCUSSION: We present a philosophical discourse, with emphasis on the writings of Immanuel Kant and G.F.W. Hegel, as to why physicians have the moral imperative to give such “outliers” considerate and thoughtful care. Outliers are defined and the ideals of morality, responsibility, good will, duty, and principle are applied to the care of patients whose financial means are meager and to those whose care is physiologically futile. Actions of moral worth, unconditional good will, and doing what is right are examined. SUMMARY: Outliers are a legitimate economic concern to individual practitioners and institutions, however this should not lead to an evasion of care. These patients should be identified early in their course of care, but such identification should be preceded by a well-planned recognition of this burden and appropriate staffing and funding should be secured. A thoughtful team approach by medical practices and their institutions, involving both clinicians and non-clinicians, should be pursued.


**Raine, Rosalind; Hutchings, Andrew; Black, Nick.** Is publicly funded health care really distributed according to need? The example of cardiac rehabilitation in the UK. *Health Policy* 2004 February; 67(2): 227-235. NRCBL: 9.3.1; 9.2; 10. Identifiers: United Kingdom.


**Tunis, Sean R.** Why Medicare has not established criteria for coverage decisions [editorial]. *New England Journal of Medicine* 2004 May 20; 350(21): 2196-2198. NRCBL: 9.3.1; 9.5.2; 5.2.


HEALTH CARE/. . ./MANAGED CARE PROGRAMS


Churchill, Larry R. The United States health care system under managed care. Health Care Analysis: An International Journal of Health Care Philosophy and Policy 1999; 7(4): 393-411. NRCBL: 9.3.2; 2.1; 9.3.1. Abstract: Describing the U.S. health care system means describing managed care under commercial forces. Managed care creates new moral tension for practitioners, but more importantly, in its current form it intensifies the commercialization of health expectations and interactions. The largely unregulated marketing of health services under managed care has been a major factor in the increasing number of uninsured citizens, while claims for cost reduction through managed care are equivocal. Risk-rating practices integral to the current medical marketplace thwart concerns for justice in allocation and create vulnerabilities for almost everyone. The political-moral concern of the early 1990s for a right to health care is nowhere in sight.


Povar, Gail J.; Blumen, Helen; Daniel, John; Daub, Suzanne; Evans, Lois; Holm, Richard P.; Levkovitch, Natalie; McCarter, Alice O.; Sabin, James; Snyder, Lois; Sulmasy, Daniel; Vaughan, Peter; Wellikson, Laurence D.; Campbell, Amy. Ethics in practice: man-

Abstract: Cost pressures and changes in the health care environment pose ethical challenges and hard choices for patients, physicians, policymakers, and society. In 2000 and 2001, the American College of Physicians, with the Harvard Pilgrim Health Care Ethics Program, convened a working group of stakeholders—patients, physicians, and managed care representatives, along with medical ethicists—to develop a statement of ethics for managed care. The group explored the impact of a changing health care environment on patient-physician relationships and how to best apply the principles of professionalism in this environment. The statement that emerged offers guidance on preserving the patient-physician relationship, patient rights and responsibilities, confidentiality and privacy, resource allocation and stewardship, the obligation of health plans to foster an ethical environment for the delivery of care, and the clinician’s responsibility to individual patients, the community, and the public health, among other issues.


Schneider, Eric C.; Zaslavsky, Alan M.; Epstein, Arnold M. Use of high-cost operative procedures by Medicare beneficiaries enrolled in for-profit and not-for-profit health plans. New England Journal of Medicine 2004 January 8; 350(2): 143-150. NRCBL: 9.3.2; 9.3.1; 9.5.2; 9.4. SC: em.

Abstract: BACKGROUND: It is widely believed that for-profit health plans are more likely than not-for-profit health plans to respond to financial incentives by restricting access to care, especially access to high-cost procedures. Until recently, data to address this question have been limited. METHODS: We tested the hypothesis that the rates of use of 12 common high-cost procedures would be lower in for-profit health plans than in not-for-profit plans. Using standardized Medicare HEDIS data on 3,726,065 Medicare beneficiaries 65 years of age or older who were enrolled in 254 health plans during 1997, we compared for-profit and not-for-profit plans with respect to rates of cardiac catheterization, coronary-artery bypass grafting, percutaneous transluminal coronary angioplasty, carotid endarterectomy, reduction of femur fracture, total hip replacement, total knee replacement, partial colectomy, open cholecystectomy, closed cholecystectomy, hysterectomy, and prostatectomy. We adjusted the comparisons for sociodemographic case mix and for characteristics of the health plans other than their tax status, including the plans’ location. RESULTS: The rates of carotid endarterectomy, cardiac catheterization, coronary-artery bypass grafting, and percutaneous transluminal coronary angioplasty were higher in for-profit health plans than they were in not-for-profit health plans; the rates of use of other common costly operative procedures were similar in the two types of plan. After adjustment for enrollee case mix and other characteristics of the plans, the for-profit plans had significantly higher rates than the not-for-profit plans for 2 of the 12 procedures we studied and had lower rates for none. The geographic locations of the health plans did not explain these findings. CONCLUSIONS: Contrary to our expectations about the likely effects of financial incentives, the rates of use of high-cost operative procedures were not lower among beneficiaries enrolled in for-profit health plans than among those enrolled in not-for-profit health plans. Copyright 2004 Massachusetts Medical Society


Weech-Maldonado, Robert; Elliott, Marc N.; Morales, Leo S.; Spitzer, Karen; Marshall, Grant N.; Hays, Ron D. Health plan effects on patient assessments of Medicaid managed care among racial/ethnic minorities. JGIM: Journal of General Internal Medicine 2004 February; 19(2): 136-145. NRCBL: 9.3.2; 7.1; 9.3.1; 9.5.4; 9.5.10. SC: em.


HEALTH CARE/ HEALTH CARE QUALITY


Beach, Mary Catherine; Asch, David A.; Jepson, Christopher; Hershey, John C.; Mohr, Tara; McMorrow, Stacey; Ubel, Peter A. Public response to cost-quality tradeoffs in clinical decisions. Medical Decision Making 2003 September-October; 23(5): 369-378. NRCBL: 9.8; 9.3.1.


Bernstein, Mark; Hebert, Philip C.; Ettchells, Edward. Patient safety in neurosurgery: detection of errors, preven-


Abstract: Matters of hospital management do not figure prominently on the medical ethics agenda. However, management decisions that have to be taken in the area of hospital care are in fact riddled with ethical questions and do have significant impact on patients, staff members, and the community being served. In this decision making process evidence based medicine (EBM) plays an increasingly important role as a tool for rationalising as well as rationing health care resources. In this article, ethical issues of hospital management and the role of EBM will be explored, with particular reference to disease management programs, diagnosis related groups, and clinical pathways as recent developments in the German health care system.


Bosek, Marcia Sue DeWolf. NCLEX results to disclose or not disclose: an ethical analysis. *JONA’s Healthcare Law, Ethics, and Regulation* 2004 April-June; 6(2): 39-41. NRCBL: 9.8; 8.2; 7.4. SC: le; cs.


Crigger, Nancy J. Always having to say you’re sorry: an ethical response to making mistakes in professional practice. *Nursing Ethics* 2004 November; 11(6): 568-576. NRCBL: 9.8; 1.1; 8.2.

Abstract: Efforts to decrease errors in health care are directed at prevention rather than at managing a situation when a mistake has occurred. Consequently, nurses and other health care providers may not know how to respond properly and may lack sufficient support to make a healthy recovery from the mental anguish and emotional suffering that often accompany making mistakes. This article explores the conceptualization of mistakes and the ethical response to making a mistake. There are three parts to an ethical response to error: disclosure, apology and amends. Honesty and humility are discussed as important virtues that facilitate coping and personal growth for the health care provider who is involved in mistakes. In conclusion, a healthy view of nursing practice and mistake making is one that prevents error but, when prevention is not possible, accepts fallibility as part of the human condition and achieves the best possible outcome for all.


Keogh, Bruce; Spiegelhalter, David; Bailey, Alan; Roxburgh, James; Magee, Patrick; Hilton, Colin. The legacy of Bristol: public disclosure of individual surgeons’ results. *BMJ: British Medical Journal* 2004 August 21; 329(7463): 450-454. NRCBL: 9.8; 8.2.

Kouchoukos, Nicholas T.; Cohn, Lawrence H.; Sade, Robert M. Are surgeons ethically obligated to refer patients to other surgeons who achieve better results? [de-


Resnik, David B. The precautionary principle and medical decision making. Journal of Medicine and Philosophy 2004 June; 29(3): 281-299. NRCBL: 9.8; 1.1. SC: an. Abstract: The precautionary principle is a useful strategy for decision-making when physicians and patients lack evidence relating to the potential outcomes associated with various choices. According to a version of the principle defended here, one should take reasonable measures to avoid threats that are serious and plausible. The reasonableness of a response to a threat depends on several factors, including benefit vs. harm, realism, proportionality, and consistency. Since a concept of reasonableness plays an essential role in applying the precautionary principle, this principle gives physicians and patients a decision-making strategy that encourages the careful weighing and balancing of different values that one finds in humanistic approaches to clinical reasoning. Properly understood, the principle presents a worthwhile alternative to approaches to clinical reasoning that apply expected utility theory to decision problems.

Rogers, Wendy. Evidence-based medicine and women: do the principles and practice of EBM further women’s health? Bioethics 2004 February; 18(1): 50-71. NRCBL: 9.8; 9.5.5; 4.2; 18.5.3; 18.2; 9.5.4. SC: an. Abstract: Clinicians and policy makers in the world over are embracing evidence-based medicine (EBM). The promise of EBM is to use summaries of research evidence to determine which healthcare interventions are effective and which are not, so that patients may benefit from effective interventions and be protected from useless or harmful ones. EBM provides an ostensibly rational objective means of deciding whether or not an intervention should be provided on the basis of its effectiveness, in theory leading to fair and effective healthcare for all. In this paper I closely examine these claims from the perspective of healthcare for women, using relevant examples. I argue that the current processes of evidence-based medicine contain a number of biases against women. These biases occur in the production of research that informs evidence-based medicine, in the methods used to analyse and synthesise the evidence, and in the application of EBM through the use of guidelines. Finally, the biomedical model of health that underpins most of the medical research used by EBM ignores the social and political context which contributes so much to the ill-health of women.

Rogers, W.A. Evidence based medicine and justice: a framework for looking at the impact of EBM upon vulnerable or disadvantaged groups. Journal of Medical Ethics 2004 April; 30(2): 141-145. NRCBL: 9.8; 1.1; 9.4; 18.1. SC: an. Abstract: This article examines the implicit promises of fairness in evidence based medicine (EBM), namely to avoid discrimination through objective processes, and to distribute effective treatments fairly. The relationship between EBM and vulnerable groups (such as those disadvantaged by virtue of poverty, ethnicity, age, gender, mental health problems or similar) is examined. Several aspects of EBM are explored: the way evidence is created (commissioning and design of, and participation in research), and the way evidence is applied in clinical care and health policy. This analysis suggests that EBM turns our attention away from social and cultural factors that influence health and focuses on a narrow biomedical and individualistic model of health. Those with the greatest burden of ill health are left disenfranchised, as there is little research that is relevant to them, there is poor access to treatments, and attention is diverted away from activities that might have a much greater impact on their health.

Saarni, S.I.; Gylling, H.A. Evidence based medicine guidelines: a solution to rationing or politics disguised as science? Journal of Medical Ethics 2004 April; 30(2): 171-175. NRCBL: 9.8; 7.1; 9.4. SC: an. Abstract: “Evidence based medicine” (EBM) is often seen as a scientific tool for quality improvement, even though its application requires the combination of scientific facts with value judgments and the costing of different treatments. How this is done depends on whether we approach the problem from the perspective of individual patients, doctors, or public health administrators. Evidence based medicine exerts a fundamental influence on certain key aspects of medical professionalism. Since, when clinical practice guidelines are created, costs affect the content of EBM, EBM inevitably becomes a form of rationing and adopts a public health point of view. This challenges traditional professionalism in much the same way as managed care has done in the US. Here we chart some of these major philosophical issues and show why simple solutions cannot be found. The profession needs to pay more attention to different uses of EBM in order to preserve the good aspects of professionalism.


Abstract: Evidence based medicine has had an increasing impact on primary care over the last few years. In the UK it has influenced the development of guidelines and quality standards for clinical practice and the allocation of resources for drug treatments and other interventions. It has informed the thinking around patient involvement in decision making with the concept of evidence based patient choice. There are, however, concerns among primary care clinicians that evidence based medicine is not always relevant to primary care and that undue emphasis placed on it can lead to conflict with a clinician’s duty of care and respect for patient autonomy. In this paper we consider the impact of evidence based medicine on primary care, and the ethical implications of its increasing prominence for clinicians and managers in primary care.


Spector, Nancy; Sheets, Vickie. NCLEX results to disclose or not disclose. JONA’s Healthcare Law, Ethics, and Regulation 2004 April-June; 6(2): 38-39. NRCBL: 9.8; 8.2; 7.4. SC: le; cs.


Abstract: Traditionally, surgical practice has been experiential and based on the contemporary understanding of basic mechanisms of disease. It was both a science and an art and depended to far too great an extent on the individualism and self belief of its main exponents. “Evidence based medicine” (EBM) emerged in the 1980s and a new gospel of “Rules of Evidence” was introduced. There is no doubt that the net effect of EBM has been beneficial, but over reliance on randomised controlled trials and the lack of generalisability of scientific evidence to individual patients has perhaps led to less enthusiasm for its tenets among surgeons. There are valid and spurious reasons for this that are discussed. The situation is improving but inevitable tensions remain between the surgeon committed to the individual patient here and now, and the clinical researcher whose focus is the benefit of future patients in the larger community.

Vos, R.; Willems, D.; Houtepen, R. Coordinating the norms and values of medical research, medical practice and patient worlds — the ethics of evidence based medicine in orphaned fields of medicine. Journal of Medical Ethics 2004 April; 30(2): 166-170. NRCBL: 9.8; 1.3.9; 5.2. SC: an.

Abstract: Evidence based medicine is rightly at the core of current medicine. If patients and society put trust in medical professional competency, and on the basis of that competency delegate all kinds of responsibilities to the medical profession, medical professionals had better make sure their competency is state of the art medical science. What goes for the ethics of clinical trials goes for the ethics of medicine as a whole: anything that is scientifically doubtful is, other things being equal, ethically unacceptable. This particularly applies to so called orphaned fields of medicine, those areas where medical research is weak and diverse, where financial incentives are lacking, and where the evidence regarding the aetiology and treatment of disease is much less clear than in laboratory and hospital based medicine. Examples of such orphaned fields are physiotherapy, psychotherapy, medical psychology, and occupational health, which investigate complex syndromes such as RSI, whiplash, chronic low back pain, and chronic fatigue syndrome. It appears that the primary ethical problem in this context is the lack of attention to the orphaned fields. Although we agree that this issue deserves more attention as a matter of potential injustice, we want to argue that, in order to do justice to the interplay of heterogeneous factors that is so typical of the orphaned fields, other ethical models than justice are required. We propose the coordination model as a window through which to view the important ethical issues which relate to the communication and interaction of scientists, health care workers, and patients.


HEALTH CARE RATIONING See RESOURCE ALLOCATION

HEALTH CARE RIGHTS See RIGHT TO HEALTH CARE

HEALTH, CONCEPT OF

See also MENTAL HEALTH, CONCEPT OF; MENTAL HEALTH THERAPIES; PUBLIC HEALTH


Campbell, Colleen Carroll. The human face of Alzheimer’s. New Atlantis 2004 Summer; 6: 3-17. NRCBL: 4.2; 17.1; 9.5.3.


**Kirby, Jeffrey C.** Disability and justice: a pluralistic account. *Social Theory and Practice* 2004 April; 30(2): 229-246. NRCBL: 4.2; 1.1; 9.5.1; 9.4. SC: an.


**Lewens, Tim; McMillan, John.** Defining disease. *Lancet* 2004 February 21; 363(9409): 664. NRCBL: 4.2; 14.1; 8.3.2; 9.4.


**Pearce, Neil; Foliaki, Sunia; Sporle, Andrew; Cunningham, Chris.** Genetics, race, ethnicity, and health. *BMJ: British Medical Journal* 2004 May 1; 328(7447): 1070-1072. NRCBL: 15.11; 4.2; 9.5.4; 15.1; 9.2; 9.4; 9.3.1.

**Rosen, Christine.** The democratization of beauty. *New Atlantis* 2004 Spring; 5: 19-35. NRCBL: 4.2; 9.5.1; 7.1.


Abstract: The health theories of Nordenfelt and Boorse are compared. Critical attention is focused on Nordenfelt’s description of his theory as one of holistic welfare, contrasting with Boorse’s analytical and statistical approach. Neither theory is found to give an entirely satisfactory account of ‘health’ in scientific medicine or common usage. Because Nordenfelt attenuates the ontological significance of organs and organ parts and simplifies the role of statistics, his theory is regarded as weakly holistic. Boorse underestimates the importance of non-statistical evaluation. A mediating position, termed ‘strong holism’ is suggested as a way of integrating normative and statistical elements in a more adequate health concept.

**Vehmas, Simo.** Dimensions of disability. *CQ: Cambridge Quarterly of Healthcare Ethics* 2004 Winter; 13(1): 34-40. NRCBL: 4.2; 9.5.3; 1.1; 4.3; 5.1.


**HISTORY OF BIOETHICS** See BIOETHICS AND MEDICAL ETHICS/HISTORY

**HOSPICES** See DEATH AND DYING/TERRIHAL CARE

**HOSPITAL ETHICS COMMITTEES** See ETHICISTS AND ETHICS COMMITTEES

**HUMAN EXPERIMENTATION**

See also AIDS; BEHAVIORAL RESEARCH; BIO-MEDICAL RESEARCH; GENETIC RESEARCH; RECOMBINANT DNA RESEARCH

Should you enroll in a clinical trial? Volunteering for a study is a great public service, but don’t forget that you’re participating in an experiment. Know the risks, and ask plenty of questions. *Harvard Health Letter* 2004 January; 29(3): 1-2. NRCBL: 18.1; 9.3.1; 9.7. SC: po.

**Asai, Atsushi; Ohnishi, Motoki; Nishigaki, Etsuyo; Sekimoto, Miho; Fukuhara, Shunichi; Fukui, Tsuguya.** Focus group interviews examining attitudes towards medical research among the Japanese: a qualitative study. *Bioethics* 2004 September; 18(5): 448-470. NRCBL: 18.1; 8.1. SC: em.

Abstract: Objectives: the purpose of this study is to explore laypersons’ attitudes towards and experiences of medical research, and to compare them with those of physicians in Japan. Designs and Participants: fourteen Japanese adults from the general public and seven physicians participated in one of three focus interviews. Setting: Osaka, Japan. Results: trust and distrust in the physician by whom the participants were invited to participate in research played a considerable role in their decisions about participation. That the participants felt an obligation to participate was also expressed. The lay participants perceived medical research as something entirely outside of their world. A greater willingness to volunteer for research was expressed if there were direct benefits to themselves or their families. Research methods such as use of placebos, double
blinds, and randomisations seemed to cause negative attitudes to medical research. All physicians were convinced of the need for medical research, including double-blinded randomised control trials, and its significant role in medical progress. Most physicians thought that the greater awareness of the need for medical research in the community and a better understanding of the psychology of potential research participants were necessary and urgent. Conclusions: there is a good possibility that the lay public and medical professionals have sharply different beliefs about and attitudes towards every aspect of medical research. Building up a better and equal patient-doctor relationship based on trust is a key issue in medical research, and it is mandatory to fill the gap in perception regarding medical research between them through fully informed debates.


Abstract: The view that once prevailed in the U.S.—that research is no more dangerous than the activities of daily life—no longer holds in light of recent experience. Within the past few years, a number of subjects (including normal volunteers) have been seriously injured or killed in research conducted at prestigious institutions. Plainly, when we are talking about research going wrong, we’re talking about something very important. We have seen that experiments can go wrong in several ways. Subjects can be injured—physically, mentally, or by having other interests violated. Investigators can commit fraud in data collection or can abuse subjects. And review mechanisms—such as IRBs—don’t always work. The two major issues when research goes wrong in any of these ways are: first: What will be done for subjects who have suffered an injury or other wrong? and second: How will future problems be prevented? The present system in the U.S. is better at the second task than the first one. Part of the difficulty in addressing the first lies in knowing what “caused” an apparent injury. Moreover, since until recently the problem of research-related injuries was thought to be a small one, there was considerable resistance to setting up a non-fault compensation system, for fear that it would lead to payment in many cases where such compensation was not deserved. Now, with a further nudge from the NBAC there is renewed interest in developing a formal system to compensate for research injuries. Finally, I have tried to show that our system of local oversight is only partially effective in improving the design of experiments and the consent process in light of “unexpected (adverse) results.” As many observers, including the federal General Accounting Office (GAO), have reported, the requirement for “continuing review” of approved research projects is the weak point in the IRB system. The probable solution would be to more strictly apply the requirement that investigators report back any adverse results, de-emphasizing the “screen” introduced by the present language about “unexpected” findings. Yet, despite its weaknesses, there are good aspects to the local basis of our oversight system, and when problems become severe enough, OHRP is likely to evaluate a system and insist on local improvements. Thus, while the U.S. system is far from perfect in responding when research goes wrong, our experience may be useful to others in crafting a system appropriate to their own circumstances. One of the major tasks will be to adequately define what triggers oversight—that is, who reports what to whom and when? The setting of this trigger needs to balance appropriate incentives and penalties. Any system, including our own, will, in my opinion, work much better once an accreditation process is in place, which will offer much more current and detailed information on how each IRB is functioning and what steps are needed to help avoid “experiments going wrong.”


Daikos, George K. Ethical dilemmas encountered during clinical drug trials. International Journal of Antimicrobial Agents 2004 July; 24(1): 24-31. NRCBL: 18.1; 1.3.7; 1.3.9; 9.7; 18.3.

Davies, H. Can Mary Shelley’s Frankenstein be read as an early research ethics text? Medical Humanities 2004 June; 30(1): 32-35. NRCBL: 18.1; 7.1. Abstract: The current popular view of the novel Frankenstein is that it describes the horrors consequent upon scientific experimentation; the pursuit of science leading inevitably to tragedy. In reality the importance of the book is far from this. Although the evil and tragedy resulting from one medical experiment are its theme, a critical and fair reading finds a more balanced view that includes science’s potential to improve the human condition and reasons why such an experiment went awry. The author argues that Frankenstein is an early and balanced text on the ethics of research upon human subjects and that it provides insights that are as valid today as when the novel was written. As a narrative it provides a gripping story that merits careful analysis by those involved in medical research and its ethical review, and it is more enjoyable than many current textbooks! To sup-
port this thesis, the author will place the book in historical, scientific context, analyse it for lessons relevant to those involved in research ethics today, and then draw conclusions.


**Dute, Jos.** Clinical trial insurance in a comparative law perspective. *Medicine and Law: World Association for Medical Law* 2004; 23(2): 211-218. NRCBL: 18.1; 8.5; 9.3.1; 21.1. SC: le. Abstract: This paper presents the results of a comparative legal study on liability and insurance of clinical trials, including Belgium, France, Germany, the Netherlands, Spain, Switzerland, Sweden and the United Kingdom. In most countries the right to compensation of the trial subject is safeguarded, but the existing regimes show much variety. Seen from the perspective of the trial subject there is no justification for linking the extent of compensation to the object of the trial (involving drugs or not), to the nature of the trial (therapeutic or non-therapeutic) or to the status of the researcher (public entity or not).

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**Murphy, Timothy F.** When good institutions behave badly. *Chronicle of Higher Education* 2003 December 19; 50(17): B15. NRCBL: 18.1; 1.3.5.
**SECTION I  HUMAN EXPERIMENTATION/ETHICS COMMITTEES AND POLICY GUIDELINES**


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Schroter, Sara; Morris, Julie; Chaudhry, Samena; Smith, Richard; Barrat, Helen. Does the type of competing interest statement affect readers’ perceptions of the credibility of research? Randomised trial. *BMJ: British Medical Journal* 2004 March 27; 328(7442): 742-743. NRCBL: 18.1; 1.3.9; 7.3. SC: em.


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**HUMAN EXPERIMENTATION/ETHICS COMMITTEES AND POLICY GUIDELINES**


HUMAN EXPERIMENTATION/ETHICS COMMITTEES AND POLICY GUIDELINES SECTION I


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SECTION I  HUMAN EXPERIMENTATION/ ETHICS COMMITTEES AND POLICY GUIDELINES


Abstract: Many people argue that disagreements and inconsistencies between Research Ethics Committees are morally problematic and there has been much effort to ‘harmonise’ their judgements. Some inconsistencies are bad because they are due to irrationality, or carelessness, or the operation of conflicting interests, an so should be reduced or removed. Other inconsistencies, we argue, are not bad and should be left or even encouraged. In this paper we examine three arguments to reject the view that we should strive for complete consistency between committees. The first argument is that differences in judgement are not necessarily incompatible with ideas of justice for patients who are potential participants of research reviewed by different committees. We call this the ‘justice argument’.

The second argument is that such committees do not have access to a single moral truth, to which their judgement is supposed to correspond. We call this the ‘moral pluralism argument.’ The third argument is that the process of ethics committee review is also morally relevant and not solely the outcome. We call this the ‘due process argument.’ While we fall short of establishing exactly how much variation and on what substantive issues would be ethically permissible, we show that it is largely inevitable and that a certain amount of variation could be seen as a desirable part of the institution of medical research.


Abstract: In this paper the authors argue that research ethics committees (RECs) should not be paternalistic by rejecting research that poses risk to people competent to decide for themselves. However it is important they help to ensure valid consent is sought from potential recruits and protect vulnerable people who cannot look after their own best interests. The authors first describe the tragic deaths of Jesse Gelsinger and Ellen Roche. They then discuss the following claims to support their case: (1) competent individuals are epistemologically and ethically in the best position to say which risks are reasonable for them, so RECs should be no more restrictive than the “normal” constraints on people taking risks with themselves; (2) RECs do not judge individual competence (that is for researchers and psychiatrists); (3) individual liberty is mostly limited by what serves the public interest, and RECs do not determine public interest; (4) RECs may have a paternalistic role in preventing exploitation of competent people vulnerable to the use of incentives, and in protecting the interests of incompetent people; however, (5) the moral and political authority of RECs has not been established in this respect.


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Abstract: BACKGROUND: Increasing collaboration between industrialised and developing countries in human research studies has led to concerns regarding the potential exploitation of resource deprived countries. This study, commissioned by the former National Bioethics Advisory Commission of the United States, surveyed developing country researchers about their concerns and opinions regarding ethical review processes and the performance of developing country and US international review boards (IRBs). METHODS: Contact lists from four international organisations were used to identify and survey 670 health researchers in developing countries. A questionnaire with 169 questions explored issues of IRB review, informed consent, and recommendations. RESULTS: The majority of the developing country researchers were middle aged males who were physicians and were employed by educational institutions, carrying out research on part time basis. Forty percent of the respondents reported that their studies were not reviewed by a developing country IRB or Ministry of Health and one third of these studies were funded by the US. During the review process issues such as the need for local language consent forms and letters for approval, and confidentiality protection of participants were raised by US IRBs in significantly higher proportions than by host country IRBs. CONCLUSION: This survey indicates the need for the ethical review of collaborative research in both US and host countries. It also
reflects a desire for focused capacity development in supporting ethical review of research.


Ingelfinger, Julie R.; Drazen, Jeffrey M. Registry research and medical privacy [editorial]. New England Journal of Medicine 2004 April 1; 350(14): 1452-1453. NRCBL: 18.2; 8.3.


Abstract: The new class of anti-inflammatory drugs, the COX-2 inhibitors, have been commercially successful to the point of market dominance within a short time of their launch. They attract a price premium on the basis that they are associated with fewer adverse gastric events than traditional anti-inflammatory drugs. This marketing continues even though a pivotal safety study with one of the COX-2 inhibitors, rofecoxib, showed a significant increase in myocardial infarction with rofecoxib use compared with a traditional anti-inflammatory drug. This finding has led to a series of publications containing pooled analyses of existing data that both support and refute the possibility of increased cardiovascular risk with COX-2 inhibitors. These medical journal publications have served to obfuscate rather than provide guidance for medical practitioners. Consideration of a research ethics committee approach to this issue suggests that it would deal with the controversy in a straightforward manner—namely, it would simply inform research participants of the trial results with rofecoxib. The certainty of this research ethics committee approach raises the issue of whether it should be applied in normal medical practice outside of the research environment. A consideration of the legal tests for disclosure of information suggests that therapeutic medical practice should mirror that within the research environment, in this case.


Abstract: OBJECTIVE: To assess whether publicly funded adult cancer trials satisfy the uncertainty principle, which states that physicians should enrol a patient in a trial only if they are substantially uncertain which of the treatments in the trial is most appropriate for the patient. This principle is violated if trials systematically favour either the experimental or the standard treatment. DESIGN: Retrospective cohort study of completed cancer trials, with randomisation as the unit of analysis. SETTING: Two cooperative research groups in the United States. STUDIES INCLUDED: 93 phase III randomised trials (103 randomisations) that completed recruitment of patients between 1981 and 1995. MAIN OUTCOME MEASURES: Whether the randomisation favoured the experimental treatment, the standard treatment, or neither treatment; effect size (outcome of the experimental treatment compared with outcome of the standard treatment) for each randomisation. RESULTS: Three randomisations (3%) favoured the standard treatment, 70 (68%) found no significant difference between treatments, and 30 (29%) favoured the experimental treatment. The average effect size was 1.20 (95% confidence interval 1.13 to 1.28), reflecting a slight advantage for the experimental treatment. CONCLUSIONS: In cooperative group trials in adults with cancer, there is a measurable average improvement in disease control associated with assignment to the experimental rather than the standard arm. However, the heterogeneity of outcomes and the small magnitude of the advantage suggest that, as a group, these trials satisfy the uncertainty principle.


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Kopelman, Loretta M. Minimal risk as an international ethical standard in research. Journal of Medicine and Philosophy 2004 June; 29(3): 351-378. NRCBL: 18.2; 5.2; 22.1; 1.1. SC: an.

Abstract: Classifying research proposals by risk of harm is fundamental to the approval process and the most pivotal risk category in most regulations is that of “minimal risk.” If studies have no more than a minimal risk, for example, a nearly worldwide consensus exists that review boards may sometimes: (1) expedite review, (2) waive or modify some or all elements of informed consent, or (3) enroll vulnerable subjects including healthy children, incapacitated persons and prisoners even if studies do not hold out direct benefits to them. The moral and social purposes behind this threshold are discussed along with relevant views from the National Commission, NBAC, NHRPAC, Grimes v. Kennedy Krieger Institute, The Nuremberg Code, and The WMAs Declaration of Helsinki. Representative policies from Australia, Canada, South Africa, the U.S., and CIOMS are reviewed revealing different understandings of this sorting threshold. Six of nine frequently cited interpretations of “minimal risk” are untenable. The “absolute” interpretation of the “routine examination” standard is defended as best.


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Abstract: OBJECTIVES: Clinical trials in humans in Germany—as in many other countries—must be approved by local research ethics committees (RECs). The current study has been designed to document and evaluate decisions of chairpersons of RECs in the problematic field of non-therapeutic research with minors. The authors’ purpose was to examine whether non-therapeutic research was acceptable for chairpersons at all, and whether there was certainty on how to decide in research trials involving more than minimal risk. DESIGN: In a questionnaire, REC chairpersons had to evaluate five different scenarios with (in parts) non-therapeutic research. The scenarios described realistic potential research projects with minors, involving increasing levels of risk for the research participants. The chairpersons had to decide whether the respective projects should be approved. METHODS: A total of 49 German REC chairpersons were sent questionnaires; 29 questionnaires were returned. The main measurements were approval or rejection of research scenarios. RESULTS: Chairpersons of German RECs generally tend to accept non-therapeutic research with minors if the apparent risk for the participating children is low. If the risk is clearly higher than “minimal”, the chairpersons’ decisions differ widely. CONCLUSION: The fact that there seem to be different attitudes of chairpersons to non-therapeutic research with minors is problematic from an ethical point of view. It suggests a general uncertainty about the standards of protection for minor research participants in Germany. Therefore, further ethical and legal regulation of non-therapeutic research with minors in Germany seems necessary.


Abstract: In this paper, the author argues that the requirement to conduct randomised clinical trials to inform policy in cases where one wants to identify a cheaper alternative to known effective but expensive interventions raises an important ethical issue. This situation will eventually arise whenever there are resource constraints, and a policy decision has been made not to fund an intervention on cost effectiveness grounds. It has been thought that this is an issue only in extremely resource poor settings. This paper gives an example from the United Kingdom illustrating that this is also a problem faced by richer countries.


Abstract: The World Medical Association’s revised Declaration of Helsinki endorses the view that all trial participants in every country are entitled to the worldwide best standard of care. In this paper the authors show that this requirement has been rejected by every national and international committee that has examined this issue. They argue that the consensus view now holds that it is ethically permissible, in some circumstances, to provide research participants less than the worldwide best care. Finally, the authors show that there is also consensus regarding the broad conditions under which this is acceptable.

Lockwood, Alan H. Human testing pesticides: ethical and scientific considerations. *American Journal of Public Health* 2004 November; 94(11): 1908-1915. NRCBL: 18.2; 16.1. Abstract: I reviewed ethical and scientific aspects of 6 human pesticide-dosing studies submitted to the Environmental Protection Agency (EPA) for consideration during the pesticide reregistration process. All had serious ethical or scientific deficiencies—both including unacceptable informed consent procedures, unmanaged financial conflicts of interest, inadequate statistical power, inappropriate test methods and endpoints, and distorted results. Given today’s knowledge of the effects of pesticides, there is no assurance that any such study can be completely free of short-term risks, long-term risks, or both. Therefore, there is no basis for allowing pesticide studies to continue or for using them during the pesticide reregistration process. An EPA committee that is free from political and financial conflicts of interest should review this practice.


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Ravelingien, An; Mortier, F.; Mortier, E.; Kerremans, I.; Braeckman, J.; Braeckman, P. An alternative means of overcoming the safety and ethical issues is suggested: willied body donation for scientific research in the case of permanent vegetative status. This paper argues that conducting trials on such bodies with prior consent is preferable to the use of human subjects without lack of brain function.

Reilly, Philip R. Certificates of confidentiality [editorial]. *Genetic Testing* 2004 Summer; 8(2): 77-78. NRCBL: 18.2; 8.4; 15.1.


Roberts, Laura Weiss; Geppert, Cynthia; Connor, Renee; Nguyen, Khanh; Warner, Teddy D. An invitation for medical educators to focus on ethical and policy issues in research and scholarly practice. *Academic Medicine* 2001 September; 76(9): 876-885. NRCBL: 18.2; 7.2; 1.3.3. SC: em.


Rosenbaum, Julie Rothstein; Sepkowitz, Kent A. Infectious disease experimentation involving human volunteers. *Clinical Infectious Diseases* 2002 April 1; 34(7): 963-971. NRCBL: 18.2; 18.5.1; 18.6. Note: Epub 2002 Mar 01.


Rothmier, Justin D.; Lasley, Mary V.; Shapiro, Gail G. Factors influencing parental consent in pediatric clinical research. *Pediatrics* 2003 May; 111(5): 1037-1041. NRCBL: 18.2; 18.5.2; 18.3.

Sansone, R.A.; McDonald, S.; Hanley, P.; Sellbom, M.; Gaither, G.A. The stipulations of one institutional review board: a five year review. *Journal of Medical Ethics* 2004 June; 30(3): 308-310. NRCBL: 18.2. SC: em. Abstract: OBJECTIVES: This study was designed to explore the prevalence and types of stipulations (such as clarifications or changes) required of investigators by the institutional review board (IRB) of one institution over a five year period. DESIGN: Stipulations to research proposals (n = 124) were documented from the minutes of the IRB meetings. SETTING: Community hospital. PARTICIPANTS: IRB submissions. Main measurements: Number and type of IRB stipulations. RESULTS: Nineteen research submissions (15.3%) were approved without any stipulations. For the remainder, the majority of stipulations re-
lated to consent forms (74.2%). CONCLUSIONS: Consent forms appear to be at highest risk for IRB stipulations. Being aware of high risk areas before submission of research proposals may reduce the frequency of stipulations required of investigators.


Abstract: It is argued by Lie et al in the current issue of the Journal of Medical Ethics that an international consensus opinion has formed on the issue of standards of care in clinical trials undertaken in developing countries. This opinion, so they argue, rejects the Declaration of Helsinki’s traditional view on this matter. They propose furthermore that the Declaration of Helsinki has lost its moral authority in the controversy in research ethics. Although the latter conclusion is supported by this author, it will be demonstrated in this paper that there is not such a thing as an international consensus opinion, and that the authorities used by Lie et al as evidence in support of their claim should not be relied upon as authorities or final arbiters in this debate. Furthermore, it will be shown that arguments advanced substantively to show that lower standards of care are ethically acceptable in the developing world, conflate scientific with economic reasons, and ultimately fail to bolster the case they are designed to support.


Abstract: CONTEXT: Federal regulations allow children in the United States to be enrolled in clinical research only when the institutional review board (IRB) determines that the risks are minimal or a minor increase over minimal, or that the research offers a prospect of direct benefit. Despite this reliance on IRBs, no data exist on how IRBs apply the risk and benefit categories for pediatric research. OBJECTIVE: To determine how IRB chairpersons apply the federal risk and benefit categories for pediatric research. DESIGN, SETTING, AND PARTICIPANTS: Telephone survey, conducted between May and August 2002 of 188 randomly selected chairpersons of IRBs in the United States. The survey consisted of 21 questions to assess the application of federal risk standards to research procedures, whether certain interventions offer a prospect of direct benefit to participating children, and the extent to which IRBs use the federal definition of minimal risk when categorizing the risks of research procedures in children. MAIN OUTCOME MEASURES: Responses regarding categorization of the risk level and direct benefits of pediatric research procedures. RESULTS: A single blood draw was the only procedure categorized as minimal risk by a majority (152 or 81%) of the 188 respondents. An electromyogram was categorized as minimal or a minor increase over minimal risk by 100 (53%) and as more than a minor increase over minimal risk by 77 (41%). Allergy skin testing was categorized as minimal risk by 43 IRB chairpersons (23%), a minor increase over minimal risk by 81 (43%), and more than a minor increase over minimal risk by 51 (27%). Regarding benefits, 113 chairpersons (60%) considered added psychological counseling to be a direct benefit, while participant payment was considered a direct benefit by 10% (n = 19). CONCLUSIONS: Application of the federal risk and benefit categories for pediatric research by IRB chairpersons is variable and sometimes contradicted by the available data on risks and the regulations themselves. To protect children from excessive risks while allowing appropriate research, IRB chairpersons need guidance on applying the federal risk and benefit categories and also need data on the risks children face in daily life and during routine physical or psychological tests.


Shipp, Allan C.; Patterson, Amy P. The National Institutes of Health system for enhancing the science, safety, and ethics of recombinant DNA research. Comparative Medicine 2003 April; 53(2): 159-164. NRCBL: 18.2; 22.2; 15.1; 18.1.

Sieber, Joan E. Using our best judgment in conducting human research. Ethics and Behavior 2004; 14(4): 297-304. NRCBL: 18.2; 1.1; 1.3.5.


SECTION I  HUMAN EXPERIMENTATION/ ETHICS COMMITTEES AND POLICY GUIDELINES


Sugarman, Jeremy; McKenna, W. Gillies. Ethical hurdles for translational research. Radiation Research 2003; 160: 1-4. NRCBL: 18.2; 7.3; 1.3.2; 9.3.1; 18.6. SC: rv.

Takala, Tuija; Häyry, Matti. Ethics committees in Finland: their levels, methods, and point. Notizie Di Politia 2002; 18(67): 60-64. NRCBL: 18.2; 2.4.


Tangwa, G.B. Between universalism and relativism: a conceptual exploration of problems in formulating and applying international biomedical ethical guidelines. Journal of Medical Ethics 2004 February; 30(1): 63-67. NRCBL: 18.2; 21.1; 2.1. Abstract: In this paper, the author attempts to explore some of the problems connected with the formulation and application of international biomedical ethical guidelines, with particular reference to Africa. Recent attempts at revising and updating some international medical ethical guidelines have been bedeviled by intractable controversies and wrangling regarding both the content and formulation. From the vantage position of relative familiarity with both African and Western contexts, and the privilege of having been involved in the revision and updating of one of the international ethical guidelines, the author reflects broadly on these issues and attempts prescribing an approach from both the theoretical and practical angles liable to mitigate, if not completely eliminate, some of the problems and difficulties.

Temme, Leonard A. Ethics in human experimentation: the two military physicians who helped develop the Nuremberg Code. Aviation, Space, and Environmental Medicine 2003 December; 74(12): 1297-1300. NRCBL: 18.2; 2.2; 6.


Tinker, Anthea; Coomber, V. University research ethics committees: their role, remit and conduct. Bulletin of Medical Ethics 2004 November; (203): 7-8. NRCBL: 18.2; 7.2. Identifiers: Great Britain.


Tu, Jack V.; Willison, Donald J.; Silver, Frank L.; Fang, Jiming; Richards, Janice A.; Laupacis, Andreas; Kapral, Moira K. Impracticability of informed consent in the Registry of the Canadian Stroke Network. *New England Journal of Medicine* 2004 April 1; 350(14): 1414-1421. NRCBL: 18.2; 18.3.

Abstract: BACKGROUND: Government legislators and research ethics boards in some jurisdictions require all patients to give written informed consent before enrollment in clinical registries. However, the effect of such a requirement on the use of clinical registries and the extent to which registry data can be generalized remain uncertain. METHODS: We examined the effectiveness of a comprehensive attempt to obtain informed consent between June 2001 and December 2002 on the overall participation rate and the characteristics of participating patients in the Registry of the Canadian Stroke Network, a prospective registry based at 20 major stroke centers across Canada. RESULTS: The overall participation rate (i.e., the consent rate among all potential participants) was 39.3 percent of 4285 eligible patients during phase 1 of the project (June 2001 through February 2002) and 50.6 percent of 2823 eligible patients during phase 2 (June 2002 through December 2002), despite the presence of neurologic research nurse coordinators at each site. Many patients died or left the hospital before they could be approached for consent. Major selection biases were found: the in-hospital mortality rate was much lower among patients who were enrolled (6.9 percent) than among those who were not enrolled (21.7 percent) (relative risk of in-hospital death, 3.13; 95 percent confidence interval, 2.65 to 3.70; P .001). We estimate that approximately 500,000 dollars (Canadian dollars) was spent on consent-related issues during the first two years of the registry. CONCLUSIONS: Obtaining written informed consent for participation in a stroke registry led to important selection biases, such that registry patients were not representative of the typical patient with stroke at each center. These findings highlight the need for legislation on privacy and policies permitting waivers of informed consent for minimal-risk observational research. Copyright 2004 Massachusetts Medical Society


Abstract: The clinical decision is supposed to be based on evidence. In fact, what counts as evidence is far from being established. Some definition of “proof” is needed to distinguish
between scientific medicine and charlatanism. My thesis is that unfortunately a clear-cut boundary between evidence and lack of evidence cannot be found, for several reasons that I summarise in the paper. Evidence in medicine very often has fuzzy boundaries, and dichotomising fuzziness and uncertainty can have serious consequences. Physicians and patients should accept the irreducible fuzziness of many of the concepts they use when dealing with health and disease.


Wagner, Todd H.; Cruz, Anne Marie; Chadwick, Gary L. Economies of scale in institutional review boards. *Medical Care* 2004 August; 42(8): 817-823. NRCBL: 18.2.


Abstract: Local review of research by ethics committees in the UK has long been held to be an important right of the local research ethics committee and, even with the introduction of the European Clinical Trials Directive, the governance arrangements for research ethics committees continue to allow for local review of multicentre studies. There is no requirement for local review in either the European Union directive or in the guidelines on good clinical practice, and there is little evidence of it anywhere else in Europe. The idea that there can be “local”, as opposed to “central” ethical issues in research is an interesting one, which raises important issues about the nature of research ethics and ethical review. The aim of this paper is to argue that there are no such things as local issues in research ethics, and suggest that those questions currently addressed as local issues properly belong within the research governance framework.


Weijer, Charles. The quest for legitimacy: comment on Cox Macpherson’s ‘to strengthen consensus, consult the stakeholders’. *Bioethics* 2004 June; 18(3): 293-300. NRCBL: 18.2; 1.3.9; 9.8; 21.7. SC: an.


Wendler, David; Miller, Franklin G. Deception in the pursuit of science [opinion]. *Archives of Internal Medicine* 2004 March 22; 164(6): 597-600. NRCBL: 18.2; 18.3; 18.4.

Wilson, M. Getting a fix on good governance [letter]. *Journal of Medical Ethics* 2004 April; 30(2): 232. NRCBL: 18.2; 9.6; 2.1; 7.3. SC: Canada.

Wood, Anne; Grady, Christine; Emanuel, Ezekiel J. Regional ethics organizations for protection of human research participants [opinion]. Nature Medicine 2004 December; 10(12): 1283-1288. NRCBL: 18.2.


Yan, Eric G; Munir, Kerim M. Regulatory and ethical principles in research involving children and individuals with developmental disabilities. Ethics and Behavior 2004; 14(1): 31-49. NRCBL: 18.2; 18.5.2; 18.5.6; 9.4; 1.1; 6. Identifiers: Vulnerable population.


HUMAN EXPERIMENTATION/ . . . / LEGAL ASPECTS

SECTION I

Wood, Anne; Grady, Christine; Emanuel, Ezekiel J. Regional ethics organizations for protection of human research participants [opinion]. Nature Medicine 2004 December; 10(12): 1283-1288. NRCBL: 18.2.


Yan, Eric G; Munir, Kerim M. Regulatory and ethical principles in research involving children and individuals with developmental disabilities. Ethics and Behavior 2004; 14(1): 31-49. NRCBL: 18.2; 18.5.2; 18.5.6; 9.4; 1.1; 6. Identifiers: Vulnerable population.


HUMAN EXPERIMENTATION/ . . . / LEGAL ASPECTS


Abstract: With the adoption of the Clinical Trials Directive it was Europe’s intention to make the performance of multi-national clinical trials in Europe easier through the harmonization of the regulatory procedures. As the Directive was mainly conceived to facilitate the performance of multi-national clinical trials to develop new drugs, it is to be determined to what extent academic clinical trials will be concerned by the Directive and more importantly what will be its impact on daily academic clinical research. Contrary to several national regulations the scope of the Directive is very large only excluding non-interventional trials. This implies that most of the academic clinical trials will be concerned by the Directive. Besides the handling of the regulatory procedures in the different countries, issues related to insurance, labeling requirements and provision of the investigational medical products will expose the academic sponsor to additional administrative and financial challenges that will have to be handled appropriately, as the academic sponsors will be controlled by Inspectors regarding their compliance with the new regulations to come.


Abstract: On the international as well as on the level of the European Union a legal framework has been developed on the protection of test subjects. In 2000, the Declaration of Helsinki,
issued by the World Medical Association, was revised and the previous distinction between therapeutic and non-therapeutic trial situations has been eliminated. Non-therapeutic trials that only aim at the progress of scientific knowledge and do not benefit the patient are now admissible. This is not to the benefit of the position of the test subject and most certainly not when the test subject should be given special protection. The question arises what this recent revision means for the group of incompetent adult patients in clinical trials on medicinal products (hereinafter called drugs) in the European Union (EU). This group needs special protection. Also relevant are national and international legal frameworks and the protection offered by informed consent procedures and screening by ethics committees and member states’ competent authorities.


Gatter, Robert. Walking the talk of trust in human subjects research: the challenge of regulating financial conflicts of interest. Emory Law Journal 2003 Winter; 52(1): 327-401. NRCBL: 18.2; 18.6; 5.3; 1.3.9; 7.3; 8.2. SC: le.


Koski, Greg. Research, regulations, and responsibility: confronting the compliance myth — a reaction to Professor Gatter. Emory Law Journal 2003 Winter; 52(1): 403-416. NRCBL: 18.2; 18.6; 5.3; 1.3.9; 7.3. SC: le.


Markman, Maurie. The needs of science vs the needs of patients: ethical concerns in cancer clinical trials. Cleveland Clinic Journal of Medicine 2003 December; 70(12): 1008-1009, 1013-1014, 1016. NRCBL: 18.3; 18.2; 18.5.1. SC: le.


Noah, Lars. Deputizing institutional review boards to police (audit?) biomedical research. Journal of Legal Medicine 2004 September; 25(3): 267-293. NRCBL: 18.2; 18.6; 5.2; 8.5. SC: le.


Valdes, Sonia; McGuire, Penny. Contract research organizations (CROs) may be the next trend in clinical trials liability. Journal of Biolaw and Business 2004; 7(3): 11-15. NRCBL: 18.2; 18.6; 8.5. SC: le.

HUMAN EXPERIMENTATION/ INFORMED CONSENT

See also INFORMED CONSENT

Early vaccine trials done without consent [news]. Bulletin of Medical Ethics 2004 September; (201): 3-4. NRCBL: 18.3; 18.5.2; 9.7. Identifiers: United Kingdom; whole cell pertussis vaccine (WCPV); whooping cough.


Abstract: OBJECTIVES: To determine the effects of risk and payment on subjects' willingness to participate, and to examine how payment influences subjects' potential behaviours and risk evaluations. METHODS: A 3 (level of risk) x 3 (level of monetary payment), between subjects, completely randomised factorial design was used. Students enrolled at one of five US pharmacy schools read a recruitment notice and informed consent form for a hypothetical study, and completed a questionnaire. Risk level was manipulated using recruitment notices and informed consent documents from hypothetical biomedical research projects. Payment levels were determined using the payment models evaluated by Dickert and Grady as a guide. Five dependent variables were assessed in the questionnaire: willingness to participate, willingness to participate with no payment, propensity to negotiate to tell about restricted activities, propensity to negotiate to tell about negative effects, and risk-rating. RESULTS: Monetary payment had positive effects on respondents' willingness to participate in research, regardless of the level of risk. However, higher monetary payments did not appear to blind respondents to the risks of a study. Payment had some influence on respondents' potential behaviours regarding concealing information about restricted activities. However, payment did not appear to have a significant effect on respondents' propensity to negotiate to tell researchers about negative effects. CONCLUSIONS: Monetary payments appear to do what they are intended to do: make subjects more willing to participate in research. Concerns about payments blinding subjects to risks could not be substantiated in the present study. However, the findings do raise other concerns—notably the potential for payments to diminish the integrity of a study's findings. Future research is critical to make sound decisions about the payment of research subjects.


Bravo, Gina; Dubois, Marie-France; Pâquet, Mariane. The conduct of Canadian researchers and institutional review boards regarding substituted consent for research. IRB: Ethics and Human Research 2004 January-February; 26(1): 1-8. NRCBL: 18.3; 18.2; 18.5.6. SC: em.

Breese, Peter; Burman, William; Rietmeijer, Cornelis; Lezotte, Dennis. The Health Insurance Portability and Accountability Act and the informed consent process [letter]. Annals of Internal Medicine 2004 December 7; 141(11): 897-898. NRCBL: 18.3; 8.4. SC: em; le. Identifiers: HIPAA.

Chang, Esther. Fitting a square peg into a round hole?: imposing informed consent and post-trial obligations on United States sponsored clinical trials in developing countries. Southern California Interdisciplinary Law Journal 2002 Spring; 11(2): 339-360. NRCBL: 18.3; 18.5.9; 18.6; 2.4. SC: le.

Childress, James F. Protestant perspectives on informed consent (particularly in research involving human participants). Fordham Urban Law Journal 2002 November; 30(1): 187-205. NRCBL: 18.3; 8.3.1; 2.1; 1.2; 18.2.


Abstract: Disease control has increasingly shifted towards large scale, disease specific, public health interventions. The emerging problems of HIV, hepatitis, malaria, typhoid, tuberculosis, childhood pneumonia, and meningitis have made community based trials of interventions a cost effective long term investment for the health of a population. The authors conducted this study to explore the complexities involved in obtaining informed consent to participation in rural north India, and how people there make decisions related to participation in clinical research.

Delatycki, Martin. Should third party consent to research be mandated? Should there be a right for third parties to have data about them withdrawn from a research project? Two perspectives. Monash Bioethics Review 2004 January; 23(1): S75-S86. NRCBL: 18.3; 18.6. SC: an; le; cs.

Diviak, Kathleen R.; Curry, Susan J.; Emery, Sherry L.; Meremelstein, Robin J. Human participants challenges in youth tobacco cessation research: researchers' perspectives. Ethics and Behavior 2004; 14(4): 321-334. NRCBL: 18.3; 8.3.2; 18.5.2; 18.2; 8.4; 9.5.9; 7.1. SC: em.

Dreyfuss, Didier. To consent or not to consent, that is (not) the (sole) question [editorial]. Intensive Care Medicine 2004 February; 30(2): 180-182. NRCBL: 18.3; 18.2.


Dunn, Kate M.; Jordan, Kelvin; Lacey, Rosie J.; Shapley, Mark; Jinks, Clare. Patterns of consent in epidemiologic research: evidence from over 25,000 respondents. American Journal of Epidemiology 2004 June 1; 159(11): 1087-1094. NRCBL: 18.3; 7.1. SC: em.


Abstract: Patients participating in the shared benefits of publicly funded health care enjoy the benefits of treatments tested on previous patients. Future patients similarly depend on treatments tested on present patients. Since properly designed research assumes that the treatments being studied are-so far as is known at the outset-equivalent in therapeutic value, no one is clinically disadvantaged merely by taking part in research, provided the research involves administering active treatments to all participants. This paper argues that, because no other practical or moral considerations count decisively against so doing, we could and should oblige patients to agree to receive indicated treatment within the terms of any concurrent research protocols. This ensures their treatment will benefit not only themselves but also future patients through contributing to new knowledge. By analogy with the paying of income tax, patients
should not be allowed to “veto” their social responsibility to take part in clinical research.

Farber, Neil J.; Aboff, Brian M.; DeJoseph, Maria R.; Castellano, Jerry; Weiner, Joan; Boyer, E. Gil. Physicians’ understanding of consent requirements for phase I clinical trials in cognitively impaired or highly vulnerable patients. Accountability in Research 2004 January-March; 11(1): 63-78. NRCBL: 18.3; 8.1. SC: em.

Abstract: We investigated physicians’ attitudes about entering patients who cannot give informed consent or who are of a vulnerable population into clinical trials. A survey instrument asked a nationwide sample of practicing physicians about whether ten hypothetical patients could be enrolled in a phase I clinical trials. The impact of demographic variables on the number of scenarios viewed as completely or somewhat acceptable was analyzed via student’s T tests or analysis of variance (ANOVA) as applicable. All significant (p<0.01) variables were entered into a multiple logistic regression model. Eighty-four percent of respondents indicated that at least one case scenario was acceptable. A majority of those who conduct clinical trials (62%), who had training in the ethics of clinical research (78%), and who sit on institutional review boards (IRBs) (83%) approved of at least one case scenario. Physicians approved of the entry of some patients who cannot give informed consent or who are of a vulnerable population into clinical trials. More effective education on the guidelines involving clinical research should be available to practicing physicians, residents, and medical students. There should also be assurance that physicians who conduct clinical trials or who sit on IRBs have the requisite knowledge about the ethics of clinical research.


Fernandez, Conrad V.; Kodish, Eric; Weijer, Charles. Importance of informed consent in offering to return research results to research participants [letter]. Medical and Pediatric Oncology 2003 December; 41(6): 592-593. NRCBL: 18.3; 18.2.

Fernandez, Conrad V.; Skedgel, Chris; Weijer, Charles. Considerations and costs of disclosing study findings to research participants. CMAJ/JAMC: Canadian Medical Association Journal 2004 April 27; 170(9): 1417-1419. NRCBL: 18.3; 18.2.


Abstract: CONTEXT: Available data suggest that prospective research participants may frequently not understand information disclosed to them in the informed consent process. Little is known about how understanding can be improved. OBJECTIVE: To review research on interventions to improve research participants’ understanding of information disclosed in the informed consent process. DATA SOURCES AND STUDY SELECTION: A search of MEDLINE was performed using the terms informed consent and clinical research and informed consent and (comprehension or understanding) from 1966 to March 2004, which included randomized controlled trials, longitudinal trials, and controlled trials with nonrandom allocation that compared the understanding of research participants who had undergone only a standard informed consent process to that of participants who had received an intervention to improve their understanding. A comprehensive bibliography of empirical research on informed consent published in January 1999 was also reviewed, as were personal files and all issues of the journals IRB and Controlled Clinical Trials. DATA EXTRACTION: Study design, quality criteria, population characteristics, interventions, and outcomes for each trial were extracted. The statistical significance of the interventions’ effects on understanding were noted, as were mean scores for understanding for each group of each trial. For those trials that measured the secondary outcomes of satisfaction and willingness to enroll, results were also summarized. DATA SYNTHESIS: Thirty studies described 42 trials that met inclusion criteria. Of 12 trials of multimedia interventions, 3 showed significant improvement in understanding. Of 15 trials of enhanced consent forms, 6 showed significant improvement in understanding (all P<0.05), but 5 of 6 trials were of limited quality, casting doubt on their practical relevance. Of 5 trials of extended discussion, 3 showed significant improvement in understanding (all P<0.01) and 2 showed trends toward improvement (P=0.054 and P=0.08). Of 5 trials of test feedback, all showed significant improvement in understanding (all P<0.05) but were flawed in that they may have mistaken rote memorization for improvement in understanding. Another 5 trials were put into a miscellaneous category and had varying impact on understanding. Some demographic factors, particularly lower education, were associated with less understanding. Satisfaction and willingness to enroll were never significantly diminished by an intervention. CONCLUSIONS: Efforts to improve understanding through the use of multimedia and enhanced consent forms have had only limited success. Having a study team member or a neutral educator spend more time talking one-on-one to study participants appears to be the most effective available way of improving research participants’ understanding; however, further research is needed.


Abstract: Acute myocardial infarction (AMI) is a common disease in the Western world and has been the topic of much research. Conducting clinical trials with patients in the acute phase of a myocardial infarction, however, poses an ethical challenge. As patients are often under extreme stress and require urgent medical attention, the process of informed consent
is severely constrained. Furthermore, the very procedure of informed consent, which is supposed to protect eligible patients, may be a cause of harm in itself due to the delay in the provision of therapy which it causes. This paper describes how physicians have dealt with the informed consent process in various AMI trials and summarizes the results from empirical studies of the consent process of such trials. Finally, the ethical issues and their implications for future trials involving this particular group of patients are discussed.

**Gill, Dennis.** Guidelines for informed consent in biomedical research involving paediatric populations as research participants. *European Journal of Pediatrics* 2003 July; 162(7-8): 455-458. NRCBL: 18.3; 18.5.2.


Abstract: There is considerable confusion regarding the ethical appropriateness of using incentives in research with human subjects. Previous work on determining whether incentives are unethical considers them as a form of undue influence or coercive offer. We understand the ethical issue of undue influence as an issue, not of coercion, but of corruption of judgment. By doing so we find that, for the most part, the use of incentives to recruit and retain research subjects is innocuous. But there are some instances where it is not. Specifically, incentives become problematic when conjoined with the following factors, singly or in combination with one another: where the subject is in a dependency relationship with the researcher, where the risks are particularly high, where the research is degrading, where the participant will only consent if the incentive is relatively large because the participant’s aversion to the study is strong, and where the aversion is a principled one. The factors we have identified and the kinds of judgments they require differ substantially from those considered crucial in most previous discussions of the ethics of employing incentives in research with human subjects.


**Headache Masters Programme; Linde, M.; May, A.; Limmroth, V.; Dahlof, C.** Ethical aspects of placebo in migraine research. *Cephalalgia* 2003 September; 23(7): 491-495. NRCBL: 18.3; 6; 18.2; 18.5.2; 4.4.


**Hewlett, Sarah.** Consent to research in arthritis: quantity of information versus quality [editorial]. *Arthritis and Rheumatism* 2003 June 15; 49(3): 281-282. NRCBL: 18.3; 18.2; 18.5.1.


**Jansson, Roger L.** Researcher liability for negligence in human subject research: informed consent and researcher...

Abstract: OBJECTIVE: To examine lay persons’ ability to identify methods of random allocation and their acceptability of using methods of random allocation in a clinical trial context. DESIGN: Leaflets containing hypothetical medical, non-medical, and clinical trial scenarios involving random allocation, using material from guidelines for trial information leaflets. SETTING AND PARTICIPANTS: Adults attending further education colleges (n = 130), covering a wide range of ages, occupations, and levels of education. MAIN MEASURES: Judgements of whether each of five methods of allocation to two groups was random in a medical or non-medical scenario. Judgements of whether these allocation methods were acceptable in a randomised clinical trial scenario, with or without a scientific justification for randomisation. RESULTS: The majority of our group of participants judged correctly that allowing people their preference was not random, and that the following were random: using a computer with no information about the individual (recommended wording for MREC trial leaflets), tossing a coin, drawing a name out of a hat. Judgements were split over allocating people in turn (not a random allocation method but shares features with randomisation). Judgements were no different in medical and non-medical scenarios. Few of the correctly identified random methods were judged to be acceptable in a clinical trial scenario. Inclusion of a scientific justification for randomising significantly increased the acceptability of only one random method: allocation by computer. CONCLUSIONS: Current UK guidelines’ recommended description of random allocation by computer seems warranted. However, while potential trial participants may understand what random allocation means, they may find it unacceptable unless offered an acceptable justification for its use.


Abstract: BACKGROUND: Financial conflict of interest in clinical research is an area of active debate. While data exist on the perspectives and roles of academic institutions, investigators, industry sponsors, and scientific journals, little is known about the perspectives of potential research participants. METHODS: The authors surveyed potential research participants over the Internet, using the Harris Interactive Chronic Illness Database. A potential research participant was defined by: (1) self-report of diagnosis by a health care professional and (2) willingness to participate in clinical trials. Email invitations were sent to 20,205 persons with coronary artery disease, breast cancer, or depression; a total of 6,363 persons were screened; of these, 86% or 5,478 met inclusion criteria and completed the survey. The outcome measures were respondents’ ratings on: importance of knowing conflict of interest information, whether its disclosure ought to be required, and its effect on willingness to participate across seven widely discussed scenarios of financial conflicts of interest (ranging from commercial funding to equity ownership). RESULTS: Majority responded that knowing conflict of interest information was “extremely” or “very” important; a larger majority felt financial conflicts of interest should be disclosed as part of informed consent (64% to 87%). In all seven scenarios, a majority was still willing to participate but in some scenarios a sizable minority would be wary of participation. Respondents were more wary of individual than institutional conflicts of interest. Illness group and sociodemographic factors had modest effects and did not affect the main trends. CONCLUSIONS: The prevailing practice of non-disclosure of financial conflicts of interest in clinical research appears contrary to the values of potential research participants.


Abstract: Autonomy has been hailed as the foremost principle of bioethics, and yet patients’ decisions and research subjects’ voluntary participation are being subjected to frequent restrictions. It has been argued that patient care is best served by a limited form of paternalism because the doctor is better qualified to take critical decisions than the patient, who is distracted by illness. The revival of paternalism is unwarranted on two grounds: firstly, because prejudging that the sick are not fully autonomous is a biased and unsubstantial view; secondly, because the technical knowledge of healthcare professionals does not include the ethical qualifications and prerogative to decide for others. Clinical research settings are even more prone to erode subjects’ autonomy than clinical settings because of the tendency and temptation to resort to such practices as shading the truth when consent to participation is sought, or waiving consent altogether when research is done in emergency settings. Instead of supporting such dubious practices with unconvincing arguments, it would seem to be the task of bioethics to insist on reinforcing autonomy.


Levine, Robert. Placebo controls in clinical trials of new therapies for conditions for which there are known effective treatments. *In*: Guess, Harry A.; Kleinman, Arthur; Kusek, John W.; Engel, Linda W., eds. The Science of the...
SECTION I  HUMAN EXPERIMENTATION/INFORMED CONSENT


Lo, Bernard; Chou, Vicki; Cedars, Marcelle I.; Gates, Elena; Taylor, Robert N.; Wagner, Richard M.; Wolf, Leslie; Yamamoto, Keith R. Informed consent in human oocyte, embryo, and embryonic stem cell research. Fertility and Sterility 2004 September; 82(3): 559-563. NRCBL: 18.3; 14.4; 15.1; 18.5.4.

Magder, Sheldon; Lefebvre, Annette. Obtaining consent for research studies on incompetent subjects: the Quebec experience. Intensive Care Medicine 2003 March; 29(3): 496-498. NRCBL: 18.3; 18.5.6; 18.2.


Markman, Maurie. The needs of science vs the needs of patients: ethical concerns in cancer clinical trials. Cleveland Clinic Journal of Medicine 2003 December; 70(12): 1008-1009, 1013-1014, 1016. NRCBL: 18.3; 18.2; 18.5.1. SC: le.

Markman, Maurie; DeMarco, Joseph. Potential conflict between fundamental ethical principles and requirements of the oncology drug approval process: ethical conflict in drug approval. Cancer 2003 July 15; 98(2): 215-218. NRCBL: 18.3; 18.2; 9.5.1; 18.5.1; 9.7.


Michel, Luc. Ethical and philosophical foundations of the informed consent [editorial]. Acta Chirurgica Belgica 2003; 103: 1-3. NRCBL: 18.3; 1.1; 8.3.1; 2.2.


Abstract: This article draws on ethnographic field data collected during an investigation of the informed consent process and AIDS clinical trials. It describes the involvement of care providers (physicians, nurse practitioners, physician assistants) during the enlistment, or recruitment, phase of the informed consent process. It shows that sometimes care providers are involved in the receipt, evaluation and distribution of information on clinical trials through their interactions with research professionals and patients. It suggests that the involvement of care providers has the potential to influence the informed consent process. Some of the ethical and practice considerations of this are discussed.


Porzsolt, Franz; Schlotz-Gorton, Nicole; Biller-Andorno, Nikola; Thim, Anke; Meissner, Karin; Roesch-Wiedmann, Irmgard; Herzberger, Barbara; Ziegler, Renatus; Gaus, Wilhelm; Poppel, Ernst. Applying evidence to support ethical decisions: is the placebo really powerless? Science and Engineering Ethics 2004 January; 10(1): 119-132. NRCBL: 18.3. SC: em. Conference: Placebo: Its Action and Place in Health Research Today, Warsaw, Poland, 12-13, April, 2003, meeting held under the auspices of the Secretary General, Council of Europe, Minister of Science and the Minister of Health, Poland.


Abstract: This article explores the concept of internationally acceptable codes of ethics within the context of an Egyptian nurse’s PhD studies. Theoretical work, including gaining ethical approval for the project, took place in the UK, while the data collection phase of the study was done in Egypt. This highlighted areas where the Arab Muslim interpretation of some ethical principles, especially around the issue of gaining informed consent, differed from that currently accepted in British research ethics. The authors argue that it may not be possible, or even desirable, to standardize codes of ethics globally in areas such as academic research. Ethical principles develop from a unique mix of culture and religion. It may be more important to develop cultural competence that includes the ability to understand and respect the way in which ethical principles are interpreted by various societies.

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Rosenfeld, Barry. The psychology of competence and informed consent: understanding decision-making with regard to clinical research. Fordham Urban Law Journal 2002 November; 30(1): 173-185. NRCBL: 18.3; 8.3.3; 20.5.4. SC: le.


Shah, Amit Navin; Sugarman, Jeremy. Protecting research subjects under the waiver of informed consent for emergency research: experiences with efforts to inform the community. Annals of Emergency Medicine 2003 January; 41(1): 72-78. NRCBL: 18.3; 18.2; 8.3.3.

Siminoff, Laura A.; Caputo, Marie; Burant, Christopher. The promise of empirical research in the study of informed consent theory and practice. HEC (Healthcare Ethics Committee) Forum 2004 March; 16(1): 53-71. NRCBL: 18.3; 2.2; 8.3.3; 18.5.2; 18.5.7. SC: em.


Steinke, Elaine E. Research ethics, informed consent, and participant recruitment. Clinical Nurse Specialist 2004 March-April; 18(2): 88-95. NRCBL: 18.3; 9.3.1; 18.5.3.

Streiner, David L. Placebo-controlled trials: when are they needed? Schizophrenia Research 1999 February 15; 35(3): 201-210. NRCBL: 18.3; 18.5.6; 18.2; 17.4.


Sytsma, Sharon. Ethical dilemmas in retrospective studies on genital surgery in the treatment of intersexual infants. CQ: Cambridge Quarterly of Healthcare Ethics 2004 Fall; 13(4): 394-403. NRCBL: 18.3; 18.5.1; 10; 17.1. Identifiers: ethical limits in human subjects research.

Tait, Alan R.; Voepel-Lewis, Terri; Robinson, Angela; Malviya, Shobha. Priorities for disclosure of the elements of informed consent for research: a comparison between parents and investigators. Paediatric Anaesthesia 2002; 12: 332-336. NRCBL: 18.3; 18.5.2; 18.2.

Takayanagi, Risa; Nakamura, Yuko; Nakajima, Yuko; Shimizu, Akemi; Nakamura, Hitoshi; Yamada, Yasuhiro; Suzuki, Hiroshi; Arakawa, Yoshihiro; Omata, Masao; Iga, Tatsuj. Analysis of information submitted by clinical trial sponsors regarding the safety of investigational drugs. Yakugaku Zasshi 2004 April;
van Wyk, Christa. Identifiers: The Netherlands. van Dijk, Yteke; van der Voort, Peter H.J.; Kuiper, Michael A.; Kesecioglu, Jozef. Van Wyk, Christa. The participation of minors in preventive HIV research trials in South Africa: legal and human rights considerations. Medicine and Law: World Association for Medical Law 2003; 22(4): 589-598. NRCBL: 18.3; 18.2; 18.5.2; 9.5.6. SC: le. Abstract: The constitutional prohibition of experimentation/research without the individual subject's (own) consent is investigated. A distinction is drawn between therapeutic and non-therapeutic research. A minor of 14 is competent to consent independently to medical treatment (which would include therapeutic research), but not to non-therapeutic research. A minor must be at least 18 years to be able to do so. Proxy consent can be secured for the participation of minors under 18 in non-therapeutic research only if they assent, if their participation in the research is indispensable and the research carries no more than negligible risk. Since the risks inherent in HIV preventive vaccine trials may carry more than negligible risk, these trials may not be carried out on children under 18. The limitation of rights and the consideration of foreign and international law in the interpretation of the South African Bill of Rights are investigated.

Vinson, Norman G.; Singer, Janice A. Consent issues raised by observational research in organisations. NCEHR Communicique CNERH 2004 Spring; 12(2): 35-36. NRCBL: 18.3; 13.2; 18.4; 1.3.12.


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Cannistra, Stephen A. The ethics of early stopping rules: who is protecting whom? Journal of Clinical Oncology 2004 May 1; 22(9): 1542-1545. NRCBL: 18.6; 18.2; 18.3.


Consortium to Examine Clinical Research Ethics; Levine, Carol; Faden, Ruth; Grady, Christine; Hammerschmidt, Dale; Eckenwiler, Lisa; Sugarman, Jeremy. “Special scrutiny”: a targeted form of research protocol review [opinion]. Annals of Internal Medicine 2004 February 3; 140(3): 220-223. NRCBL: 18.6; 18.2. Abstract: Research participants require ongoing protection of the kind already established in law and regulation. However, “special scrutiny” for certain types of research is also needed. Three criteria for special scrutiny are 1) research that involves initial experiences of translating new scientific advances into humans, especially when the intervention is novel, irreversible, or both; 2) research with a known or credible risk for significant harm (death or serious disability are the clearest examples) to research participants as a consequence of the experimental intervention and with no potential for offsetting direct medical benefit; or 3) research with a protocol that raises ethical questions about research design or implementation for which there is no consensus. Special scrutiny recognizes that not all research protocols are equally ethically challenging and aims to provide appropriate protection for all research participants.

De Angelis, Catherine; Drazen, Jeffrey M.; Frizelle, Frank A.; Haug, Charlotte; Hoey, John; Horton, Richard; Kotzin, Sheldon; Laine, Christine; Marusic, Ana; Overbeke, A. John P.M.; Schroeder, Torben V.; Sox, Hal C.; Van Der Weyden, Martin B. Clinical trial registration: a statement from the International Committee of Medical Journal Editors. Lancet 2004 September 11-17; 364(9438): 911-912. NRCBL: 18.6; 1.3.7; 1.3.12; 21.1.

De Angelis, Catherine; Drazen, Jeffrey M.; Frizelle, Frank A.; Haug, Charlotte; Hoey, John; Horton, Richard; Kotzin, Sheldon; Laine, Christine; Marusic, Ana; Overbeke, A. John P.M.; Schroeder, Torben V.; Sox, Hal C.; Van Der Weyden, Martin B. Clinical trial registration: a statement from the International Committee of Medical Journal Editors [editorial]. New England Journal of Medicine 2004 September 16; 351(12): 1250-1251. NRCBL: 18.6; 1.3.7; 1.3.12; 21.1.

DeAngelis, Catherine D.; Drazen, Jeffrey M.; Frizelle, Frank A.; Haug, Charlotte; Hoey, John; Horton, Richard; Kotzin, Sheldon; Laine, Christine; Marusic, Ana; Overbeke, A. John P.M.; Schroeder, Torben V.; Sox, Hal C.; Van Der Weyden, Martin B. Clinical trial registration — a statement from the International Committee on Medical Journal Editors. JAMA: The Journal of the American Medical Association 2004 September 15; 292(11): 1363-1364. NRCBL: 18.6; 1.3.7; 1.3.12; 21.1.

Douglass, Alison; Crampton, Peter. Protection of health research participants in the United States: a review of two cases. New Zealand Bioethics Journal 2004 June; 5(2): 6-12. NRCBL: 18.6; 18.2; 18.3. Identifiers: Ellen Roche; Jesse Gelsinger.

Emanuel, Ezekiel J.; Wood, Anne; Fleischman, Alan; Bowen, Angela; Getz, Kenneth A.; Grady, Christine;

Abstract. The oversight of research involving human participants is widely believed to be inadequate. The U.S. Congress, national commissions, the Department of Health and Human Services, the Institute of Medicine, numerous professional societies, and others are proposing remedies based on the assumption that the main problems are researchers’ conflict of interest, lack of institutional review board (IRB) resources, and the volume and complexity of clinical research. Developing appropriate reform proposals requires carefully delineating the problems of the current system to know what reforms are needed. To stimulate a more informed and meaningful debate, we delineate 15 current problems into 3 broad categories. First, structural problems encompass 8 specific problems related to the way the research oversight system is organized. Second, procedural problems constitute 5 specific problems related to the operations of IRB review. Finally, performance assessment problems include 2 problems related to absence of systematic assessment of the outcomes of the oversight system. We critically assess proposed reforms, such as accreditation and central IRBs, according to how well they address these 15 problems. None of the reforms addresses all 15 problems. Indeed, most focus on the procedural problems, failing to address either the structure or the performance assessment problems. Finally, on the basis of the delineation of problems, we outline components of a more effective reform proposal, including bringing all research under federal oversight, a permanent advisory committee to address recurrent ethical issues in clinical research, mandatory single-time review for multicenter research protocols, additional financial support for IRB functions, and a standardized system for collecting and disseminating data on both adverse events and the performance assessment of IRBs.


Gibbs, Jeffrey N. State regulation of pharmaceutical clinical trials. *Food and Drug Law Journal* 2004; 59(2): 265-285. NRCBL: 18.6; 8.4; 9.3.1; 9.5.6; 9.7; 15.3; 18.5.2; 18.5.6. SC: le; rv.


SECTION I  HUMAN EXPERIMENTATION/ REGULATION

August 1; 33(4): 513-520. NRCBL: 18.6; 9.5.6; 7.1. SC: em.


Oleskey, Christopher; Fleischman, Alan; Goldman, Lynn; Hirschhorn, Kurt; Landrigan, Philip J.; Lappi, Marc; Marshall, Mary Faith; Needleman, Herbert; Rhodes, Rosamond; McCally, Michael. Pesticide testing in humans: ethics and public policy. *Environmental Health Perspectives* 2004 June; 112(8): 914-919. NRCBL: 18.6; 16.1; 18.5.1.

Pediatric Psychopharmacology Initiative; Zito, Julie Magno; Derivan, Albert T.; Greenhill, Laurence L. Making research data available: an ethical imperative demonstrated by the SSRI debacle. *Journal of the American Academy of Child and Adolescent Psychiatry* 2004 May; 43(5): 512-514. NRCBL: 18.6; 1.3.2; 7.1; 8.2; 17.4. Identifiers: selective serotonin reuptake inhibitors.


Sharma, Dinesh C. India pressed to relax rules on clinical trials: drug companies claim changes are essential, but critics fear Indian patients will become guinea pigs [news]. *Lancet* 2004 May 8; 363(9420): 1528-1529. NRCBL: 18.6; 9.7; 21.1; 18.5.9.


Wicclair, Mark R.; DeVita, Michael. Oversight of research involving the dead. *Kennedy Institute of Ethics Journal* 2004 June; 14(2): 143-164. NRCBL: 18.6; 20.1; 8.4; 18.3; 18.2; 18.5.7; 20.3.1. Abstract: Research involving the dead, especially heart-beating cadavers, may facilitate the testing of potentially revolutionary and life-saving medical treatments. However, to ensure that such research is conducted ethically, it is essential to: (1) identify appropriate standards for this research and (2) assign institutional responsibility and a mechanism for oversight. Protocols for research involving the dead should be reviewed by a special committee and assessed according to nine standards intended to ensure scientific merit, to protect deceased patients and their families, and to promote institutional integrity and responsibility. Federal regulation of research involving the dead will foster appropriate standards and, equally importantly, help establish the acceptability of such research.
HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS

Allmark, P. Should research samples reflect the diversity of the population? Journal of Medical Ethics 2004 August; 30(2): 185-189. NRCBL: 18.5.1; 18.2. SC: an.

Abstract: Recent research governance documents say that the body of research evidence must reflect population diversity. The response to this needs to be more sophisticated than simply ensuring minorities are present in samples. For quantitative research looking primarily at treatment effects of drugs and devices four suggestions are made. First, identify where the representation of minorities in samples matters for example, where ethnicity may cause different treatment effects. Second, where the representation of a particular group matters then subgroup analysis of the results will usually be necessary. Third, ensuring representation and subgroup analysis will have costs; deciding on whether such representation is worthwhile will involve cost benefit analysis. Fourth, the representation of minorities should not be seen as mainly a locality issue. For qualitative research it is argued that the representation of diversity is often important. Given the small samples of many qualitative projects, however, the best way to ensure representation occurs is to allow a proliferation of such research, not to stipulate such representation in samples.


Boyce, Nell. Science calls at the deathbed. U.S. News and World Report 2004 January 12; 136(1): 50-51. NRCBL: 18.5.1; 20.1; 18.5.7; 18.3; 19.5; 20.2.1; 5.2. SC: po.


Cooper, Sharon P.; Heitman, Elizabeth; Fox, Erin E.; Quill, Beth; Knudson, Paula; Zahn, Sheila H.; MacNaughton, Nancy; Ryder, Roberta. Ethical issues in conducting migrant farmworker studies. Journal of Immigrant Health 2004 January; 6(1): 29-39. NRCBL: 18.5.1; 9.5.4; 9.5.10; 18.6.

Corbie-Smith, Giselle; Moody-Ayers, Sandra; Thrasher, Angela D. Closing the circle between minority inclusion in research and health disparities. Archives of Internal Medicine 2004 July 12; 164(13): 1362-1364. NRCBL: 18.5.1; 9.5.4.


Elsayed, Dya Eldin M. The current situation of health research and ethics in Sudan. Developing World Bioethics 2004 December; 4(2): 154-159. NRCBL: 18.5.1; 9.1; 21.1. Abstract: At the beginning of the twentieth century, health research in the Sudan developed primarily as a function of the colonial British administration. Ethical issues in the medical profession in the Sudan are governed by the Sudan Medical Council. To address these issues, the Sudan Medical Council issued Medico-legal and Ethical Guidelines in 1967. This important document has focused principally on ethical issues arising in clinical medicine. Throughout the history of health research...
in Sudan it is very difficult to find any reference to research ethics. Nevertheless, there have been a few attempts to articulate ethics in health research. In 1979, Sudan witnessed the establishment of the first ethical review committee, which was established by the initiative of a group of doctors and scientists from the national health research laboratory. This committee got neither political nor institutional recognition. Therefore, it was not developed and came to an end shortly after its inception. Yet, in 2000 the FMOH established an ethical review committee (ERC). The functions of this committee were to review proposals of health research to be carried out in the country for ethical issues irrespective to the funding agents. Unfortunately, the committee devoted all the jobs in reviewing only externally-sponsored health research and research carried out by expatriate researchers or international organizations.


Fry, C.L.; Hall, W. An ethical framework for the drug epidemiology: identifying the issues. Bulletin of Narcotics 2002; 54(1 and 2): 131-142. NRCBL: 18.5.1; 1.1; 7.1; 8.4; 9.5.9; 18.3.


Hall, W.; Carter, L. Ethical issues in using a cocaine vaccine to treat and prevent cocaine abuse and dependence. Journal of Medical Ethics 2004 August; 30(4): 337-340. NRCBL: 18.5.1; 9.5.9.

Abstract: A “cocaine vaccine” is a promising immunotherapeutic approach to treating cocaine dependence which induces the immune system to form antibodies that prevent cocaine from crossing the blood brain barrier to act on receptor sites in the brain. Studies in rats show that cocaine antibodies block cocaine from reaching the brain and prevent the reinstatement of cocaine self administration. A successful phase 1 trial of a human cocaine vaccine has been reported. The most promising application of a cocaine vaccine is to prevent relapse to dependence in abstinent users who voluntarily enter treatment. Any use of a vaccine to treat cocaine addicts under legal coercion raises major ethical issues. If this is done at all, it should be carefully trialled first, and only after considerable clinical experience has been obtained in using the vaccine to treat voluntary patients. There will need to be an informed community debate about what role, if any, a cocaine vaccine may have as a way of preventing cocaine addiction in children and adolescents.


Kutcher, Gerald. Cancer therapy and military cold-war research: crossing epistemological and ethical boundaries. History Workshop Journal 2003 Autumn; (56): 105-130. NRCBL: 18.5.1; 16.2; 2.2. Identifiers: Eugene Saenger; Donnall Thomas; Advisory Committee on Human Radiation Experiments (ACHRE).

Levine, Carol; Faden, Ruth; Grady, Christine; Hammerschmidt, Dale; Eckenwiler, Lisa; Sugarman, Jeremy. The limitations of “vulnerability” as a protection for human research participants. American Journal of Bioethics 2004 Summer; 4(3): 44-49. NRCBL: 18.5.1; 18.2; 18.6; 18.3. Identifiers: Consortium to Examine Clinical Research Ethics.


Markman, Maurie. The needs of science vs the needs of patients: ethical concerns in cancer clinical trials. Cleveland Clinic Journal of Medicine 2003 December; 70(12): 1008-1009, 1013-1014, 1016. NRCBL: 18.3; 18.2; 18.5.1. SC: le.


Murthy, Vivek H.; Krumholz, Harlan M.; Gross, Cary P. Participation in cancer clinical trials: race-, sex-, and age-based disparities. JAMA: The Journal of the American Medical Association 2004 June 9; 291(22): 2720-2726. NRCBL: 18.5.1; 9.5.4; 18.5.3; 18.5.7. SC: em. Abstract: CONTEXT: Despite the importance of diversity of cancer trial participants with regard to race, ethnicity, age, and sex, there is little recent information about the representation of these groups in clinical trials. OBJECTIVE: To characterize the representation of racial and ethnic minorities, the elderly, and women in cancer trials sponsored by the National Cancer Institute. DESIGN, SETTING, AND PATIENTS: Cross-sectional population-based analysis of all participants in therapeutic nonsurgical National Cancer Institute Clinical Trial Cooperative Group breast, colorectal, lung, and prostate cancer clinical trials 2000 through 2002. In a separate analysis, the ethnic distribution of patients enrolled in 2000 through 2002 was compared with those enrolled in 1996 through 1998, using logistic regression models to estimate the relative risk ratio of enrollment for racial and ethnic minorities to that of white patients during these time periods. MAIN OUTCOME MEASURE: Enrollment fraction, defined as the number of trial enrollees divided by the estimated US cancer cases in each race and age subgroup. RESULTS: Cancer research participation varied significantly across racial/ethnic and age groups. Compared with a 1.8% enrollment fraction among white patients, lower enrollment fractions were noted in Hispanic (1.3%; odds ratio [OR] vs whites, 0.72; 95% confidence interval [CI], 0.68-0.77; P001) and black (1.3%; OR, 0.71; 95% CI, 0.66-0.74; P001) patients. There was a strong relationship between age and enrollment fraction, with trial participants 30 to 64 years of age representing 3.0% of incident cancer patients in that age group, in comparison to 1.3% of 65- to 74-year-old patients and 0.5% of patients 75 years of age and older. This inverse relationship between age and trial enrollment fraction was consistent across racial and ethnic groups. Although the total number of trial participants increased during our study period, the representation of racial and ethnic minorities decreased. In comparison to whites, after adjusting for age, cancer type, and sex, patients enrolled in 2000 through 2002 were 24% less likely to be black (adjusted relative risk ratio, 0.76; 95% CI, 0.65-0.89; P001). Men were more likely than women to enroll in colorectal cancer trials (enrollment fractions: 2.1% vs 1.6%, respectively; OR, 1.30; 95% CI, 1.24-1.35; P001) and lung cancer trials (enrollment fractions: 0.9% vs 0.7%, respectively; OR, 1.23; 95% CI, 1.16-1.31; P001). CONCLUSIONS: Enrollment in cancer trials is low for all patient groups. Racial and ethnic minorities, women, and the elderly were less likely to enroll in cooperative group cancer trials than were whites, men, and younger patients, respectively. The proportion of trial participants who are black has declined in recent years.


Quest, Tammie; Marco, Catherine A. Ethics seminars: vulnerable populations in emergency medicine research. Academic Emergency Medicine 2003 November; 10(11): 1294-1298. NRCBL: 18.5.1; 18.3.


Rochon, Paula A.; Mashari, Azad; Cohen, Ariel; Misra, Anjali; Laxer, Tara; Steiner, David L.; Clark, Jocelyn P.; Dergal, Julie M.; Gold, Jennifer. The inclusion of minority groups in clinical trials: problems of under representation and under reporting of data. Accountability in Research 2004 July-December; 11(3-4): 215-223. NRCBL: 18.5.1. SC: em.
**SECTION I**

**HUMAN EXPERIMENTATION/.../AGED AND TERMINALLY ILL**


Abstract: In 1997 a debate broke out about the ethical acceptability of using placebo as a comparative alternative to establish effective treatment in trials conducted in developing countries for the purpose of preventing perinatal HIV-transmission. The debate has now been going on for more than five years. In spite of extensive and numerous attempts at resolving the controversy, the case seems far from being settled. The aim of this paper is to provide an updated account of the debate, by identifying empirical arguments employed in the controversy and by critically assessing their use in the debate. A notion of resolution of moral conflicts will be introduced that makes it possible to give a more positive verdict on the moral results of this controversy. Finally, the procedural problem of safeguarding the selection of empirical arguments against undue forms of normative bias will be addressed.


**HUMAN EXPERIMENTATION/.../AGED AND TERMINALLY ILL**

Arraf, Kelly; Cox, Ginny; Oberle, Kathleen. Using the Canadian Code of Ethics for registered nurses to explore ethics in palliative care research. *Nursing Ethics* 2004 November; 11(6): 600-609. NRCBL: 18.5.7; 4.1.3; 6. Identifiers: Canada. Abstract: Nursing research in palliative care raises specific and challenging ethical issues. Questions have arisen about whether such research is morally justifiable, given the low likelihood of direct benefit to dying patients as research participants. The Canadian Code of Ethics for Registered Nurses outlines eight primary values intended to guide nursing practice. We use these values to explore the moral dimensions of research with the palliative care population. Our conclusion is that palliative care research is needed to foster excellent care for these patients and their families, but that nurses must remain constantly vigilant to ensure that participants are protected from resultant harms. Through this exploration we highlight particular considerations that nurse researchers must contemplate when accessing a vulnerable population.

Bayer, Antony; Fish, Mark. The doctor’s duty to the elderly patient in clinical trials. *Drugs and Aging* 2003; 20(15): 1087-1097. NRCBL: 18.5.7; 18.3.

Berry, Scott R. For purposes of research, palliative care patients should not be considered a vulnerable population [debate]. *Clinical Oncology* 2004 May; 16(3): 223-224. NRCBL: 18.5.7; 18.2.

Crane, Patricia B.; Cody, Marisue; McSweeney, Jean C. Informed consent: a process to facilitate older adults’ participation in research. *Journal of Gerontological Nursing* 2004 April; 30(4): 40-44. NRCBL: 18.5.7; 18.3.


Hawryluck, Laura. People at the end of life are a vulnerable research population [debate]. Clinical Oncology 2004 May; 16(3): 225-226. NRCBL: 18.5.7; 18.3.


HUMAN EXPERIMENTATION/.../ EMBRYOS AND FETUSES

Baby steps: new work shows the promise, and pitfalls, of embryonic-stem-cell research. Economist (The) 2004 January 3; 370(8356): 53-55. NRCBL: 18.5.4; 14.5; 15.1. Identifiers: cloning.

Better to be talked about...the prominence of embryonic stem cells as a key issue in the US presidential election campaign is, at best, a mixed blessing for science [editorial]. Nature 2004 September 16; 431(7006): 229. NRCBL: 18.5.4; 19.1; 15.1. SC: le. Identifiers: United States.

California dreaming: voters in California will decide next month on an initiative that would assign $3 billion to research on human embryonic stem cells [editorial]. Nature 2004 October 14; 431(7010): 723. NRCBL: 18.5.4; 19.1; 15.1; 1.3.9; 18.6. SC: le.

A clone in the hand...[editorial]. Nature Genetics 2004 August; 36(8): 781. NRCBL: 18.5.4; 19.1; 15.1; 14.5. SC: le.

Facts versus ideology in the cloning debate [editorial]. Lancet 2004 February 21; 363(9409): 581. NRCBL: 18.5.4; 14.5; 5.3.

No consensus on stem cells [editorial]. Nature 2004 April 8; 428(6983): 587. NRCBL: 18.5.4; 19.1; 15.1.

The stem cell debate [editorial]. America 2004 December 6; 191(18): 3. NRCBL: 18.5.4; 15.1; 1.2.

The stem-cell state [editorial]. Nature 2004 November 11; 432(7014): 131. NRCBL: 18.5.4; 19.1; 15.1. Identifiers: California; United States.


Abstract: Germany since 1990 has one of the strictest human embryo protection laws, yet according to the Stem Cell Act of 2002 allows, under strict conditions, the import and use of human embryonic stem cells (hESC) for high priority research goals. The author tries to show how this is taken to be coherent by the parliamentary majority (though not necessarily by the general public) in Germany. In doing so, he firstly looks into the chronicle of the debate in Germany showing its different stages since 1999, then dwells upon the relation between the law and the role of ethics in this issue, and thirdly presents the two fundamentally different positions of the German debate, that is, that the human embryo created for IVF purposes is a human being and stands from its very beginnings under the constitutional principles of respect for, and protection of, human life versus the position that before being implanted the human embryo may become a human being and therefore belongs to the human species only potentially, so that its right to life protection may be assessable over against other high priority goals, such as research aiming at possible help for patients with life-endangering diseases. In spite of the Stem Cell Act of 2002, the debate of the German general public goes on, especially due to the recent EU 6th Research Framework Program which plans to also fund hESC research.


Boyce, Nell. An end run for stem cells. U.S. News and World Report 2004 March 15; 136(9): 70. NRCBL: 18.5.4; 15.1; 5.3; 9.3.1. SC: po.

Boyce, Nell. The clone is out of the bottle: now we know the recipe. Can a cloned baby be far behind? U.S. News and World Report 2004 March 1; 136(7): 40-43. NRCBL: 18.5.4; 15.1; 14.5; 5.3; 7.1. SC: po.

Brainard, Jeffrey. Senators grill NIH director over restrictions on stem-cell research. Chronicle of Higher Edu-
Burke, Conn. Hollywood science: should a ballot initiative determine the fate of stem-cell research? New Yorker 2004 October 18: 62, 64, 67-68, 70, 77-78, 80, 82. NRCBL: 18.5.4; 18.5.1; 15.1.


Burne, Jerome. Investing in frozen assets — the world’s first stem cell bank opened in the UK this week and its closely-guarded contents could change our lives. But is the vision flawed? Times (London) 2004 May 22; p. D4-D5. NRCBL: 18.5.4; 15.2; 4.4; 1.2.

Burne, Jerome. The responsibility for holding the media to a higher standard of journalism 2003 June 6; 49(39): A25. NRCBL: 18.5.4; 15.1. Identifiers: National Institutes of Health.


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Abstract: The nineteenth century science of teratology concerned itself with the study of malformations or “monstrosities”, as they were then called. The first major contribution to the field was the work of Isidore Geoffroy Saint-Hilaire, Historie Generale et Particuliere des Anomalies de l’Organisation chez l’Homme et les Animaux, published in 1832, whose classifications formed the basis for the later experimental science of teratology, the art of reproducing monstrosities in animal embryos. In this article, I will argue that recent developments in the field of regenerative medicine can be situated in the tradition of teratological and teratogenic studies dating back to the nineteenth century. In particular, I will be interested in the historical link between studies in teratogenesis (the artificial production of teratomas) and stem cell research. Recent advances in stem cell research, I will suggest, return us to the questions that animated nineteenth century investigations into the nature of the monstrous or the anomalous. In the process, our most intuitive conceptions of “life itself” are undergoing a profound transformation.

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Abstract: In this article I rebut conservative objections to five phases of embryonic stem cell research. I argue that researchers using existing embryonic stem cell lines are not complicit in the past destruction of embryos because beneficiaries of immoral acts are not necessarily morally tainted. Second, such researchers do not encourage the destruction of additional embryos because fertility clinics presently destroy more spare embryos than researchers need. Third, actually harvesting stem cells from slated-to-be-discarded embryos is not wrong. The embryos are not sacrificed for the good of others because they would have been destroyed anyway. Fourth, harvesting stem cells from embryos that are not doomed is morally acceptable, because preserving frozen embryos is futile therapy. Finally, creating embryos solely for the sake of harvesting stem cells from them is morally acceptable because the assumption that embryos have the right to life has very counterintuitive implications.


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Dresser, Rebecca. Genetic modification of preimplantation embryos: toward adequate human research policies. *Milbank Quarterly* 2004; 82(1): 195-214. NRCBL: 18.5.4; 15.1; 18.6. Identifiers: United States. Abstract: Citing advances in transgenic animal research and setbacks in human trials of somatic cell genetic interventions, some scientists and others want to begin planning for research involving the genetic modification of human embryos. Because this form of genetic modification could affect later-born children and their offspring, the protection of human subjects should be a priority in decisions about whether to proceed with such research. Yet because of gaps in existing federal policies, embryo modification proposals might not receive adequate scientific and ethical scrutiny. This article describes current policy shortcomings and recommends policy actions designed to ensure that the investigational genetic modification of embryos meets accepted standards for research on human subjects.


Gómez-Lobo, Alfonso. On the ethical evaluation of stem cell research: remarks on a paper by N. Knoepffler. *Kennedy Institute of Ethics Journal* 2004 March; 14(1): 75-80. NRCBL: 18.5.4; 18.6; 15.1; 14.4; 5.3; 4.4. SC: le. Abstract: This response to Nikolaus Knoepffler’s paper in the same issue of the Journal agrees that if the arguments supporting the first two of the eight human embryonic stem cell research policy options discussed are unsound, as Knoepffler argues, then it seems natural to move to the increasingly permissive options. If the arguments are sound, however, then the more permissive options should be rejected. It is argued that three of the rejected arguments, taken together, constitute very good reasons to hold that a human embryo is endowed with dignity from fertilization onward. Thus, countries that want their public policies to match the moral imperative of respect for human beings should refrain from allowing destructive human embryo research and should devote considerable energy and public funds to research and clinical trials using non-embryonic (“adult”) stem cells.


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NRCBL: National Reference Center for Bioethics Literature Classification Scheme
Abstract: In February 2004, South Korean researchers became the first in the world to successfully harvest stem cells and establish a stem cell line from a cloned human embryo. This is just one of eight possible policy options concerning human embryonic stem cell research. In practice, every kind of stem cell research can be done in one country or another. This paper evaluates the eight policy options concerning human embryonic stem cell research in light of the arguments and decisions behind them.


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Abstract: Debate on the potential and uses of human stem cells tends to be conducted by two constituencies-ethicists and scientists. On many occasions there is little communication between the two, with the result that ethical debate is not informed as well as it might be by scientific insights. The aim of this paper is to highlight the scientific insights that may be of relevance for ethical debate. Environmental factors play a significant role in identifying stem cells and their various subtypes. Research related to the role of the microenvironment has led to emphasis upon “plasticity”, which denotes the ability of one type of stem cell to undergo a transition to cells from other lineages. This could increase the value given to adult stem cells, in comparison with embryonic stem cell research. Any such conclusion should be treated with caution, however, since optimism of this order is not borne out by current research. The role of the environment is also important in distinguishing between the terms totipotency and pluripotency. We argue that blastocysts (early embryos) and embryonic stem cells are only totipotent if they can develop within an appropriate environment. In the absence of this, they are merely pluripotent. Hence, blastocysts in the laboratory are potentially totipotent, in contrast to their counterparts within the human body which are actually totipotent. This may have implications for ethical debate, suggesting as it does that arguments based on potential for life may be of limited relevance.


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Abstract: In 1998, researchers discovered that embryonic stem cells could be derived from early human embryos. This discovery has raised a series of ethical and public-policy questions that are now being confronted by multiple international organizations, nations, cultures, and religious traditions. This essay surveys policies for human embryonic stem cell research in four regions of the world, reports on the recent debate at the United Nations about one type of such research, and reviews the positions that various religious traditions have adopted regarding this novel type of research. In several instances the religious traditions seem to have influenced the public-policy debates.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
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Abstract: To avoid exploitation of host communities, many commentators argue that subjects must receive the best methods available worldwide. Others worry that this requirement may block important research intended to improve health care, especially in developing countries. To resolve this dilemma, we propose a framework for the conditions under which it is acceptable to provide subjects with less than the best methods. Specifically, institutional review boards should assume a default requiring the “worldwide best” methods, meaning the best methods available anywhere in the world, in all cases. However, institutional review boards should be willing to grant exceptions to this default for research studies that satisfy the following four conditions: (1) scientific necessity, (2) relevance for the host community, (3) sufficient host community benefit, and (4) subject and host community non-maleficence.

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Abstract: In a Norwegian study on how children aged 7-12 years cope during a period of serious illness within the family and on their quality of life at this time, several ethical questions became apparent. These were mainly concerned with the vulnerability of children during research, with their ability to make autonomous decisions, and with considerations regarding how to respect their right to confidentiality during the research process. In this article we approach these questions using our experience from this previous study, discussing them within the framework of theories of ethics and relevant research ethical guidelines. Finally, we discuss our experience in the light of the overall purpose of this article: how to deal with the ethical dilemmas that may appear during research involving young children.


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Abstract: CONTEXT: Most children diagnosed as having leukemia become research subjects in randomized clinical trials (RCTs), but little is known about how randomization is explained to or understood by parents. OBJECTIVE: To investigate physicians’ explanation and parental understanding of randomization in childhood leukemia RCTs. DESIGN AND SETTING: A multisite study of the informed consent communication process for RCTs of childhood leukemia. Consecutive cases were recruited from pediatric oncology inpatient wards at 6 US children’s hospitals associated with major academic medical centers from July 1, 1999, until December 31, 2001. The informed consent conferences were observed and audiotaped, and the information obtained was coded and analyzed. Parents were interviewed shortly after the conference to ascertain their understanding. PARTICIPANTS: Parents and members of the health care team who participated in 137 informed consent conferences for children with newly diagnosed acute leukemia. MAIN OUTCOME MEASURES: Observed explanations of randomization and parental understanding of randomization after the consent conference. RESULTS: Randomization was explained by physicians in 83% of cases and a consent document was presented during the conference in 95% of cases. Interviews after the conference demonstrated that 68 (50%) of 137 parents did not understand randomization. Parents of racial minority and lower socioeconomic status were less likely to understand randomization (P001 for each). Discussion of specific clinical trial details and the presence of a nurse during the conference were associated with understanding. Eighty-four percent of children were enrolled in a leukemia trial. CONCLUSIONS: Despite oral and written explanation, half of the parents in this study did not understand randomization for childhood leukemia trials. To make informed consent more effective, future research must seek to improve communication during this critical interchange.

Koren, Gideon; Kearns, Gregory L.; Reed, Michael; Pons, Gerrard. Use of healthy children as volunteers in drug studies: the ethical debate. Clinical Pharmacology and Therapeutics 2003 March; 73(3): 147-152. NRCBL: 18.5.2; 9.7; 18.2.


Lantos, John D. Pediatric research: what is broken and what needs to be fixed? Journal of Pediatrics 2004 February; 144(2): 147-149. NRCBL: 18.5.2; 18.2. SC: le.


McNutt, Briar. The under-enrollment of HIV-infected foster children in clinical trials and protocols and the need for corrective state action. American Journal of Law and Medicine 1994; 20(3): 231-249. NRCBL: 18.5.2; 9.5.6; 18.3; 8.3.2.

Medawar, Charles; Hardon, Anita; Herxheimer, Andrew. Depressing research [letter]. Lancet 2004 June 19; 363(9426): 2087. NRCBL: 18.5.2; 17.4; 1.3.9; 1.3.7; 9.8.

Menikoff, Jerry. The involuntary research subject. CQ: Cambridge Quarterly of Healthcare Ethics 2004 Fall; 13(4): 338-345. NRCBL: 18.5.2; 18.3; 18.2; 9.5.1; 9.1; 9.8; 15.2; 8.3.2. Identifiers: Wisconsin; Linda and Charles Ande; cystic fibrosis; ethical limits in human subjects research.


Quigley, Rosemary B. Uncertain benefit: the public policy of approving smallpox vaccine research. American Journal of Public Health 2004 June; 94(6): 943-947. NRCBL: 18.5.2; 9.5.1; 9.7. Abstract: Without an accurate assessment of the prospect of bioterrorist attack, it is especially challenging to evaluate the protocols for testing smallpox vaccines in the pediatric population. Usual regulatory mechanisms cannot shepherd research protocols with benefits that can only be characterized as “uncertain” in the face of more than minimal risk. When a protocol is placed in a government forum for analysis, the public has a unique opportunity to debate the balancing of research risks and benefits on behalf of children who are unable to assent to research themselves, as well as to express views about vaccination policy broadly. This model for review of pediatric research that may be without benefit will be especially important as challenging studies of various vaccines against a range of infectious properties, such as anthrax and severe acute respiratory syndrome (SARS), emerge.


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Ross, Lainie Friedman. Children in medical research: balancing protection and access: has the pendulum swung too far? Perspectives in Biology and Medicine 2004 Autumn; 47(4): 519-536. NRCBL: 18.5.2.

Ross, Lainie Friedman. Convening a 407 panel for research not otherwise approvable: “precursors to diabetes in Japanese American youth” as a case study. Kennedy In-
Abstract: Subpart D of 45 CFR 46 focuses on research involving children. Section 46.407 addresses research that is not otherwise approvable. The research is not otherwise approvable because either (1) it seeks to enroll healthy children, but offers no prospect of direct benefit and entails more than minimal risk; or (2) it seeks to enroll children with a disorder or condition, but offers no prospect of direct benefit and entails more than a minor increase over minimal risk. According to 46.407, such research can be permissible if it is approved by a panel of experts. Prior to 2000, only two 407 panels had been convened, but in 2001, the Office for Human Research Protections received more than 20 protocols for 407 review. The first, entitled “Precursors to Diabetes in Japanese American Youth,” serves here as a case study in human subject protections.


Roth, Daniel; Boyle, Erin; Beer, Darcy; Malik, Anita; deBruyn, Jen. Depressing research [letter]. Lancet 2004 June 19; 363(9426): 2087. NRCBL: 18.5.2; 17.4; 1.3.9; 13.7; 9.8.


Shamoo, Adil E.; Moreno, Jonathan D. Ethics of research involving mandatory drug testing of high school athletes in Oregon. American Journal of Bioethics 2004 Winter; 4(1): 25-31. NRCBL: 18.5.2; 18.4; 9.5.9; 9.5.7; 18.3; 18.2. Identifiers: Office of Human Research Protection (OHRP); Student Athlete Testing Using Random Notification (SATURN). Abstract: There is consensus that children have questionable decisional capacity and, therefore, in general a parent or a guardian must give permission to enroll a child in a research study. Moreover, freedom from duress and coercion, the cardinal rule in research involving adults, is even more important for children. This principle is embodied prominently in the Nuremberg Code (1947) and is embodied in various federal human research protection regulations. In a program named “SATURN” (Student Athletic Testing Using Random Notification), each school in the Oregon public-school system may implement a mandatory drug-testing program for high school student athletes. A prospective study to identify drug use among student-athletes, SATURN is designed both to evaluate the influence of random drug testing and to validate the survey data through identification of individuals who do not report drug use. The enrollment of students in the drug-testing study is a requirement for playing a school sport. In addition to the coercive nature of this study design, there were ethically questionable practices in recruitment, informed consent, and confidentiality. This article concerns the question of whether research can be conducted with high school students in conjunction with a mandatory drug-testing program, while adhering to prevailing ethical standards regarding human-subjects research and specifically the participation of children in research.


Sina, B.J.; Molyneux, E. Overcoming ethical barriers to childhood tuberculosis research in developing countries. International Journal of Tuberculosis and Lung Disease 2004 May; 8(5): 683-686. NRCBL: 18.5.2; 9.3.1; 18.2; 18.5.9.


Spriggs, M. Canaries in the mines: children, risk, non-therapeutic research, and justice. Journal of Medical Ethics 2004 April; 30(2): 176-187. NRCBL: 18.5.2; 18.3; 18.2. SC: an. Abstract: The Kennedy Krieger lead paint study received a lot of attention after a US Court of Appeals ruled that a parent cannot consent to the participation of a child in non-therapeutic research. The ruling has raised fears that, if it goes unchallenged, valuable research might not proceed and ultimately all children would be harmed. The author discusses significant aspects of the study that have been neglected, and argues that the study was unethical because it involved injustice and its design meant that the study lacked importance and value. Issues of benefit, risk, and consent are vital, but it is sometimes a mistake to consider these issues before settling questions about justice and the importance and value of a research project. The author concludes by offering a strategy for researchers and reviewers of research to appreciate, in a vivid way, the implications of research participation.

Stalker, K.; Carpenter, J.; Connors, C.; Phillips, R. Ethical issues in social research: difficulties encountered gaining access to children in hospital for research. Child: Care,
**SECTION I**

**HUMAN EXPERIMENTATION/ . . . / PRISONERS**

NRCBL: 18.5.2; 18.3; 18.4. SC: em. Identifiers: Great Britain.


Sugarman, Jeremy. Determining the appropriateness of including children in clinical research: how thick is the ice? [editorial]. *JAMA: The Journal of the American Medical Association* 2004 January 28; 291(4): 494-496. NRCBL: 18.5.2; 18.2; 18.3.


Tait, Alan R.; Voepel-Lewis, Terri; Malviya, Shobha. Factors that influence parents' assessments of the risks and benefits of research involving their children. *Pediatrics* 2004 April; 113(4): 727-732. NRCBL: 18.5.2; 18.3; 18.2.

Unger, Jennifer B.; Gallaher, Peggy; Palmer, Paula H.; Baezconde-Garbanati, Lourdes; Lourdus; Trinidad, Dennis R.; Cen, Steven; Johnson, C. Anderson. No news is bad news: characteristics of adolescents who provide neither parental consent nor refusal for participation in school-based survey research. *Evaluation Review* 2004 February; 28(1): 52-63. NRCBL: 18.5.2; 9.5.9; 18.3; 18.4. SC: em.

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Weise, Kathryn L.; Smith, Martin L.; Maschke, Karen J.; Copeland, H. Liesel. National practices regarding payment to research subjects for participating in pediatric research. *Pediatrics* 2002 September; 110(3): 577-582. NRCBL: 18.5.2; 18.2; 9.3.1; 18.3.


Whittington, Craig J.; Kendall, Tim; Fonagy, Peter; Cottrell, David; Cogtegrove, Andrew; Boddington, Ellen. Selective serotonin reuptake inhibitors in childhood depression: systematic review of published versus unpublished data. *Lancet* 2004 April 24; 363(9418): 1341-1345. NRCBL: 18.5.2; 17.4; 9.7; 1.3.9; 1.3.7; 9.8.

Whittle, Amy; Shah, Seema; Wilfond, Benjamin; Gensler, Gary; Wendler, David. Institutional review board practices regarding assent in pediatric research. *Pediatrics* 2004 June; 113(6): 1747-1752. NRCBL: 18.5.2; 18.3. SC: em.

**HUMAN EXPERIMENTATION/ . . . / PRISONERS**

Allotey, Pascale; Lazroo, Catherine. The moral high ground: reflections on ethical dilemmas in unethical circumstances. *Monash Bioethics Review* 2004 October; 23(4): 78-84. NRCBL: 18.5.5; 18.5.9; 21.1.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.


MacQueen, Kathleen M.; Buchler, James W. Ethics, practice, and research in public health. American Journal of Public Health 2004 June; 94(6): 928-931. NRCBL: 18.5.5; 9.5.6; 18.5.1; 9.1.

Abstract: Ethical issues that can arise in distinguishing public health research from practice are highlighted in 2 case studies—an investigation of a tuberculosis outbreak in a prison and an evaluation of a program for improving HIV prevention services. Regardless of whether such public health investigations represent research or practice, we see a need for ethics oversight procedures that reflect actual risks and enable timely responses to crises. Such oversight should accommodate the perspectives of persons and communities affected by public health threats and by governmental responses to those threats; it should further recognize that public health ethics is a distinct field combining bioethics, political philosophy, human rights, and law.


Roelcke, Volker. Nazi medicine and research on human beings. Lancet 2004 December; 364(Special Issue): 6-7. NRCBL: 18.5.5; 21.4; 15.5; 15.1; 7.1.

Steel, Zachary; Silove, Derrick. Science and the common good: indefinite, non-reviewable mandatory detention of asylum seekers and the research imperative. Monash Bioethics Review 2004 October; 23(4): 93-103. NRCBL: 18.5.5; 18.5.9; 21.1.


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HUMAN EXPERIMENTATION/ . . . / WOMEN


Chervenak, Frank A.; McCullough, Laurence B. Ethics of research and the pregnant patient. Current Women’s Health Reports 2003 December; 3(6): 505-509. NRCBL: 18.5.3; 15.2; 15.4; 18.3; 18.5.4.


Fontes, Lisa Aronson. Ethics in violence against women research: the sensitive, the dangerous, and the overlooked. Ethics and Behavior 2004; 14(2): 141-174. NRCBL: 18.5.3; 18.4; 18.5.2; 1.1; 8.4; 21.7; 18.3; 18.2.

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HUMAN RIGHTS See INTERNATIONAL HUMAN RIGHTS

IMMUNIZATION See CARE FOR SPECIFIC GROUPS; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MILITARY PERSONNEL; PUBLIC HEALTH

IN VITRO FERTILIZATION

See also HUMAN EXPERIMENTATION/ EMBRYOS AND FETUSES; REPRODUCTIVE TECHNOLOGIES

Good eggs: there is no place for ageism in reproductive medicine [editorial]. Nature 2004 November 4; 432(7013): 1. NRCBL: 14.4; 14.6; 9.5.5.

SECTION I

IN VITRO FERTILIZATION


Arie, Sophie. Woman forced to have three embryos implanted is allowed fetal reduction to save her life [news]. *BMJ: British Medical Journal* 2004 July 10; 329(7457): 71. NRCBL: 14.4; 12.1. SC: le.


Buckett, William; Tan, Seang Lin. What is the most relevant standard of success in assisted reproduction? The importance of informed choice. *Human Reproduction* 2004 May; 19(5): 1043-1045. NRCBL: 14.4; 9.8; 5.2; 8.3.1.


Collopy, Kate Sullivan. “I couldn’t think that far”: infertile women’s decision making about multifetal reduction. *Research in Nursing and Health* 2004 April; 27(2): 75-86. NRCBL: 14.4; 12.5.2. SC: cm.


Abstract: Most studies on the ethics and provision of assisted reproductive technologies (ART) have taken place in the context of the Judeo-Christian culture of western developed countries. This study looks at ART, its provision and control, in an eastern developed country with a completely different cultural background; Japan. A necessarily brief description of the cultural context of religious belief, the family and reproduction in Japan is followed by a description of the development of ART in Japan together with an analysis of its provision and control.


Hubbard, Ruth. More than making babies: in vitro fertilization is only a beginning. GeneWatch 2004 March-April; 17(2): 10-11, 14. NRCBL: 14.4; 18.5.4; 9.8; 5.3.


Abstract: During the past decade in the United States, increasing attention has been paid to lowering the incidence of multiple gestations resulting from the use of assisted reproductive technology. To determine whether such efforts have been successful, we assessed national trends in embryo-transfer practice patterns and in outcomes after the use of assisted reproductive technology. METHODS: We analyzed data on outcomes of assisted reproductive technology procedures as reported to the Centers for Disease Control and Prevention from 1995 to 2001 by fertility clinics in the United States. We also analyzed data from the National Center for Health Statistics on the rates of twin births and triplet or higher-order multiple births. RESULTS: From 1995 to 2001 in the United States, the number of infertility clinics, the number of fresh-embryo cycles initiated, and the number of fresh-embryo transfers increased steadily. The average number of embryos transferred per cycle began decreasing in 1997, with the steepest decline (an 11.1 percent decrease) between 1998 and 1999. In contrast, the number of pregnancies and live births per cycle during the period from 1995 to 2001 steadily increased. Even though the percentage of pregnancies with twins did not change significantly between 1997 and 2001, the percentage of pregnancies with three or more fetuses significantly decreased every year, with the steepest decline (a 20.8 percent decrease) between 1998 and 1999, after the publication in 1998 of the American Society for Reproductive Medicine guidelines for embryo transfer. CONCLUSIONS: Since 1997 in the United States, there have been consistent decreases in both the number of embryos transferred per cycle and the percentage of pregnancies with three or more fetuses, as well as a consistent increase in the percentage of live births per cycle. Copyright 2004 Massachusetts Medical Society


Abstract: OBJECTIVE: To compare neurological sequelae in twins born after assisted conception with singletons after assisted 1998 conception and naturally conceived twins and to assess neurological sequelae in children conceived after in vitro fertilisation (IVF) compared with intracytoplasmic sperm injection (ICSI). DESIGN: Controlled, national register based, cohort study. PARTICIPANTS: Twins (n = 3393) and singletons (n =
5130) conceived by using assisted reproductive technologies and naturally conceived twins (n = 10 239) born in Denmark between 1995 and 2000. The children’s age at time of follow up was 2-7 years. DATA SOURCES: Children were identified by cross linkage of the national medical birth registry and the national registry for in vitro fertilisation. Neurological and psychiatric diagnoses were retrieved from the national patients’ registry and the Danish psychiatric central registry. MAIN OUTCOME MEASURES: Neurological sequelae, defined as cerebral palsy, mental retardation, severe mental developmental disturbances, and retarded psychomotor development. Further we made separate analyses on the specific cerebral palsy diagnosis. RESULTS: The crude prevalence rates per 1000 of neurological sequelae in twins and singletons after assisted conception and in naturally conceived twins were 8.8, 8.2, and 9.6, and of cerebral palsy 3.2, 2.5, and 4.0, respectively. In twins after assisted conception compared with control twins, the odds ratios of neurological sequelae and specifically of cerebral palsy, adjusted for child sex and year of birth, were 0.9 (95% confidence interval 0.6 to 1.4) and 0.8 (0.4 to 1.6), respectively. The corresponding odds ratios for twins after assisted conception compared with singletons after assisted conception were 1.1 (0.7 to 1.7) for neurological sequelae and 1.3 (0.6 to 2.9) for cerebral palsy. The odds ratio of neurological sequelae in children conceived by ICSI was 0.9 (0.5 to 1.7) in children conceived by IVF. CONCLUSIONS: Twins from assisted conception have a similar risk of neurological sequelae as their naturally conceived peers and singletons from assisted conception. Children born after ICSI have the same risk of neurological sequelae as children born after IVF.

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Trebilcock, Michael; Martin, Melody; Lawson, Anne; Lewis, Penny. Testing the limits of freedom of contract: the commercialization of reproductive materials and services. Osgoode Hall Law Journal 1994 Winter; 32(4): 613-702. NRCBL: 14.4; 9.3.1; 1.3.2. SC: le.


INFORMED CONSENT

SECTION I


INCOMPETENTS See INFORMED CONSENT/INCOMPETENTS

INFANTICIDE See EUTHANASIA AND ALLOWING TO DIE/INFANTS AND MINORS

INFANTS See EUTHANASIA AND ALLOWING TO DIE/INFANTS AND MINORS

INFORMATICS See TELEMEDICINE AND INFORMATICS

INFORMED CONSENT

See also HUMAN EXPERIMENTATION/INFORMED CONSENT; TREATMENT REFUSAL


Guidelines for ethical decisions. SAMJ: South African Medical Journal 2003 September; 93(9): 656. NRCBL: 8.3.1; 7.1; 8.1; 9.4.

Informed consent for cancer registry data collection. Lancet Oncology 2000 December; 1: 197. NRCBL: 8.3.1; 8.4; 9.5.1.


Abstract: Informed consent is one of the most important ethical and legal principles in the United States, including Texas, and reflects a profound respect for individuals and their ability to make decisions in their own best interest. It is also a critical underpinning of medical practice, although how it is actually carried out has not been well studied. A survey was conducted in the private practices and a hospital in the Texas Medical Center in Houston, Texas to ascertain how physicians, patients and patient’s family members perceive and demonstrate the elements of informed consent. In-depth interviews of twelve physicians, three patients and three family members were carried out. For physicians, consent was an explicit and implicit aspect of virtually all medical practice. Physicians would seek patient input concerning medical decisions whenever possible and might also discuss care choices with families. However, they often made decisions based upon what they perceived as the patient’s best interests. Patients expected the physician to involve them in the decision process, but whether they turned to family members, or even others to assist them, varied considerably. Although Texas physicians respect the competent patient as the primary decision maker, they may bypass a formal surrogate decision maker to gain input from others, including their own view of what is in the patient’s best interest.


Abstract: AIM: To assess, against a checklist of specific areas of required information and using standard published criteria, to what extent leaflets given before cataract surgery provided patients with enough information to give adequately informed consent. METHOD: Twelve ophthalmology departments in the West Midlands region were asked to submit the cataract information leaflets given to their patients at the preoperative assessment for analysis. Using criteria published by the General Medical Council, British Medical Association, and Medical Defence Union the leaflets were assessed for their contribution to informed consent for patients considering cataract surgery. Leaflets were scored according to the information they provided on: diagnosis, prognosis, treatment options, costs to the patient, details about the procedure, its purpose, likely benefits, how to prepare for it, what to expect during and after the operation, and the common as well as serious complications that may occur. The readability of the information was also assessed. RESULTS: All the units’ leaflets provided information on diagnosis, the lifestyle changes required postoperatively, and cost involved to the patient. Only five units had leaflets that mentioned the risks involved in cataract surgery. The other areas of information were covered by 50-75% of the leaflets. Fifty per cent of the leaflets included a diagram. The average SMOG readability score was high. CONCLUSION: Although present cataract information leaflets make some contribution to the process of informed consent, most do not address important areas outlined by the General Medical Council. Many of the areas of information that are required for informed consent could easily be covered, and should be borne in mind when designing patient information leaflets. Resources are available on the Internet including toolkits, guides, and means of assessment for the production of patient information leaflets.


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Cazzaniga, Luigi Franco; Maroni, Daniela; Bianchi, Ernestina; Bossi, Alberto; Cagna, Emanuela; Cosentino, Dorian; Palmieri, Luigi; Scandolaro, Luciano; Valli, Maria Carla. Anxiety, depression and informed consent in patients referred to a radiotherapy department. Tumori 2003 March-April; 89(2): 176-182. NRCBL: 8.3.1; 17.1. SC: em.

Chan, Ho Mun. Informed consent Hong Kong style: an instance of moderate familialism. Journal of Medicine and Philosophy 2004 April; 29(2): 195-206. NRCBL: 8.3.1; 8.1; 8.3.3; 8.2; 21.7.

Abstract: This paper examines the practice of informed consent in Hong Kong by drawing on structured interviews conducted with eleven physicians, three patients, and four family members primarily at a well-established public hospital in Hong Kong. The findings of this study show that the Hong Kong approach to medical decision-making lies somewhere between that of America on the one hand, and mainland China on the other. It is argued that the practice of medical decision-making in Hong Kong can be modeled by a moderate familialism that is directed towards achieving the best interests of the patient (1) as understood by the physician, (2) in consultation with the family, (3) under the prima facie presumption that consent is not required for disclosure of information to the family, (4) while aiming at an eventual albeit frequently partial and vague disclosure to the patient.

Abstract: The legal basis of informed consent in Texas may on first examination suggest an unqualified affirmation of persons as the source of authority over themselves. This view of individuals in the practice of informed consent tends to present persons outside of any social context in general and outside of their families in particular. The actual functioning of law and medical practice in Texas, however, is far more complex. This study begins with a brief overview of the roots of Texas law and public policy regarding informed consent. This surface account is then contrasted with examples drawn from the actual functioning of Texas law: Texas legislation regarding out-of-hospital do-not-resuscitate (DNR) orders. As a default approach to medical decision-making when patients lose decisional capacity and have failed to appoint a formal proxy or establish their wishes, this law establishes a defeasible presumption in favor of what the law characterizes as “qualified relatives” who can function as decision-makers for those terminal family members who lose decisional capacity. The study shows how, in the face of a general affirmation of the autonomy of individuals as if they were morally and socially isolated agents, space is nevertheless made for families to choose on behalf of their own members. The result is a multi-tier public morality, one affirming individuals as morally authoritative and the other recognizing the decisional standing of families.


Abstract: This paper argues that the provision of effective informed consent by surgical patients requires the disclosure of material information about the comparative clinical performance of available surgeons. We develop a new ethical argument for the conclusion that comparative information about surgeons’ performance—surgeons’ report cards—should be provided to patients, a conclusion that has already been supported by legal and economic arguments. We consider some recent institutional and legal developments in this area, and we respond to some common objections to the use of report cards on the clinical performance of surgeons.

Coiera, Enrico; Clarke, Roger. e-Consent: the design and implementation of consumer consent mechanisms in an electronic environment [opinion]. Journal of the American Medical Informatics Association 2004 March-April; 11(2): 129-140. NRCBL: 8.3.1; 1.3.12.


Abstract: Bioethics is a subject far removed from the Chinese, even from many Chinese medical students and medical professionals. In-depth interviews with eighteen physicians, patients, and family members provided a deeper understanding of bioethical practices in contemporary China, especially with regard to the doctor-patient relationship (DPR) and informed consent relationship (DFPR) and in comparison to the doctor-family-patient relationship (DFPR), instead of DPR, is taken to reflect Chinese Confucian cultural commitments. An examination of the history of Chinese culture and the profession of medicine in China is used to disclose the deep roots of these commitments. The author predicts that the DFPR model will further develop in China but that it will maintain its Chinese character.


Abstract: Developments in genetics with diagnostic, pre-symptomatic and predictive testing involve significant changes in the decision-making process, because of the complexity of genetic information and the difficulty related to understanding the causes and mechanism of genetic diseases, ethical, psychological and social implications (psychological stress, anxiety, discrimination in employment and assurance, difficulties in interpersonal relationship), and indirect involvement of third parties. When taking genetic decisions, the patient should receive all the information about the objective and the type of the test, the hypothetical risk, the possibility of obtaining unexpected results, possible psycho-physical repercussion, and means of support for the long time that might pass between the diagnostic predictions and the possible onset of the disease: genetic counseling is a complex but essential operation for acquiring the informed consent of the patient. The outlined peculiarities of the process for informed consent in genetics requires the adequate training of medical personnel to manage the relationship with the patient in these complex cases.

Cox, Linda; Lockey, Richard F. Instructions and consent forms for allergen immunotherapy. Clinical Allergy and Immunology 2004; 18: 755-784. NRCBL: 8.3.1.


DeGirolamo, Angela; Mallarreddy, Madhavi; Veerabjadraiah, Deepak; Smina, Mihai; Amoateng-Adjepong, Yaw; Manthous, Constantine A. Informed consent for invasive procedures in a community hospital medical intensive care unit. Connecticut Medicine 2004 April; 68(4): 223-229. NRCBL: 8.3.1. SC: em.


SECTION I  INFORMED CONSENT


Finucane, Thomas E. Decision-making during grave illness: how to show respect for the person [editorial]. Journal of the American Medical Directors Association 2004; 9(9): 977-980. NRCBL: 8.3.1; 8.1; 8.3.3; 8.2; 21.7.


Fleischman, Mark; Garcia, Carlos; Goldberg, David J. Informed consent in dermatologic surgery. Dermatologic Surgery 2003 September; 29(9): 952-955. NRCBL: 8.3.1; 9.5.1; 7.1. SC: em.


Furness, Peter N. Obtaining and using human tissues for research: ethical and practical dilemmas [editorial]. Hospital Medicine 2003 April; 64(4): 198-199. NRCBL: 8.3.1; 8.1; 18.3; 18.6.


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Grady, Denise. Trying to avoid 2nd caesarean, many find choice isn’t theirs. New York Times 2004 November 29; p. A1, A18. NRCBL: 8.3.1; 9.5.5; 9.5.7. SC: po.


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INFORMED CONSENT


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Neves, M. Patrão. Cultural context and consent: an anthropological view. *Medicine, Health Care and Philosophy: A European Journal* 2004; 7(1): 93-98. NRCBL: 8.3.1; 18.3; 2.1. SC: an; em. Abstract: The theme of “consent” is, without question, associated with the origins of bioethics and is one of its most significant paradigms that has remained controversial to the present, as is confirmed by the proposal for its debate during the last World Congress of Bioethics. Seen broadly as a compulsory minimum procedure in the field of biomedical ethics, even today it keeps open the issues that it has raised from the start: whether it is really necessary and whether it can be proven to be effective. My goal will be to attempt to determine the most genuine and relevant meaning of “consent,” going back from its present dominant normative meaning and, from there, identifying or simply sketching other possible forms of its expression in the world we live in, so as to justify its pertinence and validity. This objective will involve three stages: (1) “Consent” as a privileged paradigm of bioethics (the ethical-legal sense),” (2) “The symbolic value of ‘consent’ (the social-cultural sense),” and (3) “‘Consent’ as promotion of the human (the humanistic-personal sense).” It is concluded that the common notion of normative “consent” is not the only one, nor does it hold universal validity; that, from a historical-cultural perspective, new expressions of “consent” appear, adapted to different social contexts and to possibly be implemented in developing countries; and, finally, that “consent” is strictly indispensable in situations of extreme dependence, in its symbolic relational character, in as much as it promotes ethical relationships among strangers and ensures that they remain so.

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Thorevska, Natalya; Tilluckdharry, Lisa; Ticko, Sumit; Havasi, Andrea; Amoateng-Adjepong, Yaw; Manthous, Constantine A. Informed consent for invasive medical procedures from the patient’s perspective. *Connecticut Medicine* 2004 February; 68(2): 101-105. NRCBL: 8.3.1. SC: em; le.

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INFORMED CONSENT/INCOMPETENTS

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Abstract: “Informed consent” is a legal instrument that allows individuals to define their own interests and to protect their bodily privacy. In current medical practice, patients who have consented to surgery are considered to have implied consent to anaesthesia, even though anaesthesia is associated with its own particular set of risks and consequences that are quite separate from those associated with surgery. In addition, anaesthetists often perform interventions that are the only medical treatment received by a patient. Anaesthetists, therefore, should always obtain separate consent for anaesthesia, and should regard the process of consent as a stimulus for active, fluid reciprocal discussion with patients about treatment options.


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Abstract: In this paper we develop a hermeneutic approach to the concept of competence. Patient competence, according to a hermeneutic approach, is not primarily a matter of being able to reason, but of being able to interpret the world and respond to it. Capacity should then not be seen as theoretical, but as practical. From the perspective of practical rationality, competence and capacity are two sides of the same coin. If a person has the capacity to understand the world and give meaning to the situation, he or she is able to make decisions, and is thus competent. People can fail in the area of practical rationality. They can feel ill at ease, uncomfortable or not at home in the situation. Under such conditions, they appear as incompetent, and urge caregivers to respond in such a way that their competence can be raised. The issue is not how to measure their incompetence, but how to help them to become more competent, that is to get a practical grip on their situation and to be able to live out their lives in such a way that they develop their identity in relations with others. From a hermeneutic point of view, assessing a patient’s capacity implies focusing on the patient’s way of making meaning and regarding her behavior from the perspective of practical rationality. The focus should not be on the assessment as a matter of fact, but on improving capacity. This requires allowing the patient to experience the world meaningfully and affording her, in the context of a supportive and trustful institutional environment, the possibility of developing a personal narrative where her choices are expressed verbally or non-verbally.


Abstract: BACKGROUND/AIM: The law on consent has changed in Scotland with the introduction of the Adults with Incapacity (Scotland) Act 2000. This Act introduces the concept of proxy consent in Scotland. Many patients in intensive care are unable to participate in the decision making process because of their illness and its treatment. It is normal practice to provide relatives with information on the patient’s condition, treatment, and prognosis as a substitute for discussion directly with the patient. The relatives of intensive care patients appeared to believe that they already had the right to consent on behalf of an incapacitated adult. The authors’ aim was to assess the level of knowledge among relatives of intensive care patients of both the old and new law using a structured questionnaire. METHODS: The next of kin of 100 consecutive patients completed a structured questionnaire. Each participant had the questions read to them and their answers recorded. Patients were not involved in the study. RESULTS: Few (10%) were aware of the changes. Most (88%) thought that they previously could give consent on behalf of an incapacitated adult. Only 13% have
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ever discussed the preferences for life sustaining treatment with the patient but 84% felt that they could accurately represent the patient’s wishes. CONCLUSIONS: There appeared to be a lack of public awareness of the impending changes. The effectiveness of the Act at improving the care of the mentally incapacitated adult will depend largely on how successful it is at encouraging communication and decision making in advance of incapacity occurring.


Abstract: This article gives a brief introduction to the MacArthur Competence Assessment Tool-Treatment (MacCAT-T) and critically examines its theoretical presuppositions. On the basis of empirical, methodological and ethical critique it is emphasised that the cognitive bias that underlies the MacCAT-T assessment needs to be modified. On the one hand it has to be admitted that the operationalisation of competence in terms of value-free categories, e.g. rational decision abilities, guarantees objectivity to a great extent, but on the other hand it bears severe problems. Firstly, the cognitive focus is in itself a normative convention in the process of anthropological value-attrtribution. Secondly, it misses the complexity of the decision process in real life. It is therefore suggested that values, emotions and other biographic and context specific aspects should be considered when interpreting the cognitive standards according to the MacArthur model. To fill the gap between cognitive and non-cognitive approaches the phenomenological theory of personal constructs is briefly introduced. In conclusion some main demands for further research to develop a multi-step model of competence assessment are outlined.


Brody, Robert V. Possible limits to the surrogate’s role: when a patient lacks decisionmaking capacity, is the surrogate’s role absolute? Commentary [opinion]. CQ: Cambridge Quarterly of Healthcare Ethics 2004 Winter; 13(1): 100. NRCBL: 8.3.3; 4.4; 8.3.4; 20.5.4.


Cea, Christine D.; Fisher, Celia B. Health care decision-making by adults with mental retardation. Mental Retardation 2003 April; 41(2): 78-87. NRCBL: 8.3.3; 18.3; 18.5.6. SC: em.

Chun-yan, Tse; Tao, Julia. Strategic ambiguities in the process of consent: role of the family in decisions to forgo life-sustaining treatment for incompetent elderly patients. Journal of Medicine and Philosophy 2004 April; 29(2): 207-223. NRCBL: 8.3.3; 8.3.4; 20.5.1; 20.7; 9.5.2.

Abstract: This paper evaluates the Hong Kong approach to consent regarding the forgoing of life-sustaining treatment for incompetent elderly patients. It analyzes the contextualized approach in the Hong Kong process-based, consensus-building model, in contrast to other role-based models which emphasize the establishment of a system of formal laws and a clear locus of decisional authority. Without embracing relativism, the paper argues that the Hong Kong model offers an instructive example of how strategic ambiguities can both make good sense within particular cultural context and serve important moral goals.


Abstract: The authors, on the basis of Italian legislative and deontological regulation, discuss the problems which are faced in reconciling rights and ethical considerations involving patients and their families. In Italy, with the exception of parents and guardians (for minors and those incapable of consent), there is no family member that Italian law recognises for the purposes of giving consent in the name of another. In all cases, contact with the family must be authorised by the patient in accordance with Law 675/1996 regarding privacy. However, in some situations having the advice of a member of the family can be useful, as it can be of benefit to know the will, tacitly or expressly demonstrated, of the patient. Nonetheless, their opinion cannot be binding on the doctor and he or she is not obliged to request it. Ethically, this usually demands evaluation of almost every case.


Abstract: It has been argued elsewhere that “consent is the hallmark of our health care system”. If this is correct, then what is the position of those who are not capable of deciding whether (or not) to give consent to health care? This paper briefly examines the law and ethics of substitute decision-making. Its principal arguments are three. Firstly, that because exercising a choice (or exercising one’s autonomy) presupposes the capacity to do so, there are an increasing number of people who are not capable of exercising their autonomy in health care settings. Second, that as they are not capable of making an autonomous choice, the law permits another fundamental bioethical principle, that of beneficence, to operate so as to ensure that such people are not denied treatment which they may need. This principle is reflected in the use of Guardianship tribunals. Finally, very brief comment is made on the leading difficulty in this field, which is ascribing a clear meaning to the term competency—the standard which separates the people who are permitted to exercise an autonomous choice, and those not permitted to do so.

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McMillan, John; Hope, Tony. The morning after the morning-after pill. *Lancet* 2004 April 17; 363(9417): 1330. NRCBL: 8.3.3; 8.3.4; 17.1; 11.1; 12.4.2.

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Nys, Herman; Welie, Sander; Garanis-Papadatos, Tina; Ploumpidis, Dimitris. Patient capacity in mental health care: legal overview. *Health Care Analysis: An International Journal of Health Care Philosophy and Policy* 2004 December; 12(4): 329-337. NRCBL: 8.3.3; 20.5.4; 21.1. SC: le. Identifiers: Netherlands; Great Britain; Germany; Sweden; Italy; Greece.

Abstract: The discriminatory effects of categorizing psychiatric patients into competent and incompetent, have urged lawyers, philosophers and health care professionals to seek a functional approach to capacity assessment. Dutch and English law have produced some guidelines concerning this issue. So far, most legal systems under investigation have concentrated on alternatives for informed consent by the patient in case of mental incapacity, notably substitute decision-making, intervention of a judge and advance directives. It is hard to judge the way in which the law may further adapt to a more functional assessment of capacity, because the nature of law shows that legal re-
forms usually take place only when new methods have been accepted by the field. This is not yet the case today.

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Reynolds, Don F. Project BRIDGE — people with disabilities participate in their health care decisions. *Bioethics Forum* 1999 Summer; 15(2): 36-45. NRCBL: 8.3.3; 20.5.1; 9.5.10; 17.1; 4.4. SC: le.


Abstract: Standard views on surrogate decision making present alternative ideal models of what ideal surrogates should consider in rendering a decision. They do not, however, explain the physician’s responsibility to a patient who lacks decisional capacity or how a physician should regard surrogates and surrogate decisions. The authors argue that it is critical to recognize the moral difference between a patient’s decisions and a surrogate’s and the professional responsibilities implied by that distinction. In every case involving a patient who lacks decisional capacity, physicians and the treatment team have to make judgments about the appropriateness of both the surrogate and the surrogate’s decision. They have to assess the surrogate’s decisional capacity and attitude toward the patient as well as the reasons that support the surrogate’s decision. This paper provides a model for acceptable surrogate decisions and a standard for blocking inappropriate surrogates. Only decisions based on widely shared reasons are allowable for surrogate refusal of highly beneficial treatment.

Rubin, Susan B. Possible limits to the surrogate’s role: when a patient lacks decisionmaking capacity, is the surrogate’s role absolute? *Commentary. CQ: Cambridge Quarterly of Healthcare Ethics* 2004 Winter; 13(1): 98-100. NRCBL: 8.3.3; 9.6; 20.4.1; 4.4; 8.3.4; 1.2.

Rudnik, Abraham; Roe, David. Normal variants of competence to consent to treatment. *HEC (Healthcare Ethics Committee) Forum* 2004 June; 16(2): 129-137. NRCBL: 8.3.3.


Abstract: German legislation demands that decisions about the treatment of mentally incompetent patients require an ‘informed consent’. If this was not given by the patient him-/herself before he/she became incompetent, it has to be sought by the physician from a guardian, who has to be formally legitimized before. Additionally this surrogate has to seek the permission of a Court of Guardianship (Vormundschaftsgericht), if he/she intends to consent to interventions, which pose significant risks to the health or the life of the person under his/her care. This includes ‘end-of-life decisions’. Deviations from this procedure are only allowed in acute emergencies or cases of ‘medical futility’. On the basis of epidemiological and demographical data it can be shown that the vast majority of surrogate decisions on incompetent patients in Germany is not covered by legally valid consent. Moreover, the data suggests that if consent were to be requested according to the legal regulations, both the legal and medical system could realistically never cope with the practical consequences of this. Additionally, empiric research has revealed serious deficits concerning medical ‘end of life-decisions’ and practical performance in palliative care. As a consequence a multidisciplinary discussion has developed in Germany about the reform of present legislation with respect to key-issues like the assessment of mental competence, the options for exercising patient self-determination via advance directives and durable powers of attorney, the improvement of palliative care facilities, the clarification of formal procedures for surrogate decision-making in health care and towards the end of life and the possibilities and their limitations of controlling these decision-making processes ‘externally’ (e.g., by Guardianship Courts or committees). The authors discuss those proposals, which clearly dominate the present debate: They all aim to comply with the scientific basis of German law, jurisdiction and the European traditions of philosophy of health care and bioethics.

Sugarman, Jeremy; Cain, Carole; Wallace, Roberta; Welsh-Bohmer, Kathleen A. How proxies make decisions about research for patients with Alzheimer’s disease. *JAGS: Journal of the American Geriatric Society* 2001; 49: 1110-1119. NRCBL: 8.3.3; 9.5.3; 9.5.2.

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INFORMED CONSENT/ MINORS


André, Nicolas. Involving children in paediatric oncology decision-making. Lancet Oncology 2004 August; 5(8): 467. NRCBL: 8.3.2; 18.3.

Bruzzese, Jean-Marie; Fisher, Celia B. Assessing and enhancing the research consent capacity of children and youth. Applied Developmental Science 2003; 7(1): 13-26. NRCBL: 8.3.2; 9.5.7; 8.3.1.


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Ellerton, Mary-Lou. When parents and children disagree about care. Canadian Nurse 2000 August; 96(7): 35-36. NRCBL: 8.3.2; 9.5.7.


Haddad, Amy. Adolescent has “had enough” with cancer therapy. RN 2002 January; 65(1): 25-26, 28. NRCBL: 8.3.2; 8.2; 9.5.7; 9.4. SC: cs.


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Sheldon, Mark. Medical decision-making for children and the question of legitimate authority. *Theoretical Medicine and Bioethics* 2004; 25(4): 225-228. NRCBL: 8.3.2; 9.5.7; 18.5.2; 8.3.3.

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Stenger, Robert L. Exclusive or concurrent competence to make medical decisions for adolescents in the United States and United Kingdom. *Journal of Law and Health* 1999-2000; 14(2): 209-241. NRCBL: 8.3.2; 8.3.4; 12.4.2; 21.1. SC: le.


Abstract: Capacity and competence in the field of child and adolescent psychiatry are complex issues, because of the many different influences that are involved in how children and adolescents make treatment decisions within the setting of mental health. This article will examine some of the influences which must be considered, namely: developmental aspects, the paradoxical relationship between the need for autonomy and participation and the capacity of children, family psychiatry, and the duty of care towards children and adolescents. The legal frameworks relevant to consideration of consent and competence will be briefly considered, as well as some studies of children’s consent, participation and competence. A case vignette will be used as a focus to consider the complexity of the issue of competence in child and adolescent psychiatry, in the particular mental disorder of anorexia nervosa.

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INSTITUTIONAL REVIEW BOARDS See HUMAN EXPERIMENTATION/ETHICS COMMITTEES

INTERNATIONAL HUMAN RIGHTS

See also TORTURE, GENOCIDE AND WAR CRIMES; WAR AND TERRORISM


Esmail, Aneez. The prejudices of good people — leadership is needed to combat continued institutional racism [editorial]. *BMJ: British Medical Journal* 2004 June 19; 328(7454): 1448-1449. NRCBL: 21.1; 9.5.4; 9.2.


Involuntary Commitment


Abstract: Forging global partnerships between governments, international organizations, NGOs, civil society and business constitutes a key component of the UN and WHO action agenda. Several of these innovative alliances have galvanized important health campaigns and sealed up the response to global health problems. Guiding principles for partnerships design and implementation have been elaborated in particular to ensure quality, accountability and transparency. Partnerships are not intended to substitute commitments made by governments but to complement them, increasing the quality of implementation of international agreements, mobilizing the capacity for action on the ground and forging capacity building efforts to support weaker partners. Partnerships have the potential for weaving together economic law and human rights law, democracies and pluralism. Building into partnerships democratic commitments and safeguards for public interests is essential in creating a true sense of shared global responsibility.


Abstract: Physicians are known to have participated in human rights abuses in Iraq during Saddam Hussein’s Baathist regime, but the nature and extent of that participation are not well documented. OBJECTIVES: To characterize the nature of physician participation in human rights abuses, identify structural factors that facilitated physician participation, and assess approaches for accountability and for prevention of future physician participation in abuses. DESIGN, SETTING, AND PARTICIPANTS: A self-administered survey in June and July, 2003, of a convenience sample of 98 physicians and semistructured interviews of hospital directors and physicians in 3 major hospitals with general surgical units in 2 cities in southern Iraq. MAIN OUTCOME MEASURE: Respondent reports of peer and self-participation in human rights abuses in Iraq since 1988. RESULTS: The majority of participants were male (88% [86/98]) and Shi’i Muslims (97% [95/98]). Respondents reported a mean of 6.8 years in practice. For a total of 71% of respondents (65/91) reported that torture was a problem to an extreme extent in Iraq since 1988. The proportion of respondents indicating that, since 1988, their physician peers as a group were extremely or quite a bit involved in human rights abuses included 50% (42/83) for nontherapeutic amputation of ears as a form of punishment, 49% (39/79) for falsification of medical-legal reports of torture, and 32% (25/78) for falsification of death certificates. Fewer numbers of respondents (range, n = 2 to 6) reported participation in abuses themselves. More than half (52% [48/92]) indicated that physicians did not willingly participate in these abuses; 93% (52/71) reported that the Iraqi paramilitary force Fedayeen Saddam was responsible for initiating physician complicity. Fear of harm to oneself or family members was a common explanation for complicity. Respondents reported that physicians who refused to participate in abuses faced consequences including loss of job, imprisonment, torture, and disappearance. Respondents reported on preventive measures that should be undertaken to prevent physician involvement in future abuses, including increasing human rights and ethics education of physicians (99% [79/80]), legal provisions to ensure effective monitoring (97% [73/75]), punitive sanctions for physicians who commit abuses (96% [77/80]), and ensuring the independence of physicians from state authorities (95% [76/80]). CONCLUSIONS: Although not generalizable beyond the study participants, the findings of this study suggest that among those surveyed, physician participation in human rights abuses included falsification of medical-legal reports of alleged torture, physical mutilation as a form of punishment, and falsification of death certificates. As Iraq rebuilds, it is essential that the country address these violations and enact measures to prevent physicians from future complicity in human rights abuses.

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Involuntary Commitment


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JOURNALISM AND PUBLISHING


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In no one’s best interest [editorial]. Nature 2004 March 4; 428(6978): 1. NRCBL: 1.3.7; 1.3.9. Identifiers: Andrew Wakefield.

Publishing commentary by authors with potential conflicts of interest: when, why, and how [editorial]. Annals of Internal Medicine 2004 July 6; 141(1): 73-74. NRCBL: 1.3.7; 1.3.9.


Abstract: CONTEXT: A number of general medical journals and the International Committee of Medical Journal Editors (ICMJE) request authors to disclose their contributions. Little is known about the effect of journal policies on authors’ disclosure of their contributions. OBJECTIVE: To determine the number of named authors who do not meet ICMJE criteria for authorship, according to their published contributions, in 3 medical journals with different contribution disclosure practices. DESIGN: Observational study of authors’ contributions in research articles published in 2002 in Annals of Internal Medicine (n = 72), BMJ (n = 107), and JAMA (n = 81). BMJ asks authors to describe research contributions in their own words; Annals asks authors to choose from a list of coded contributions; and JAMA uses a structured checklist with instructions on contributions that qualify for ICMJE authorship criteria. Honorary authorship was defined as the lack of contribution from the first ICMJE criterion (study conception and design, or acquisition of data, or analysis and interpretation of data) and/or second (drafting the article or critical revision for important intellectual content) ICMJE criterion. RESULTS: According to authors’ published contributions, the number of honorary authors was

NRCBL: National Reference Center for Bioethics Literature Classification Scheme
highest in Annals (121/562 authors, 21.5%), followed by BMJ (46/482, 9.5%), and JAMA (3/641, 0.5%) (chisq(2) = 146.67, P001). The number of articles with honorary authors was 60% in Annals, 21% in BMJ, and 4% in JAMA. Honorary authors had fewer published contributions than authors who met ICMJE criteria and were positioned more toward the end of the byline. Honorary authors either lacked contributions for both ICMJE criteria (10% in Annals and 22% in BMJ) or contributions to the second ICMJE criterion (75% in Annals, 67% in BMJ, and 2 out of 3 in JAMA). CONCLUSIONS: General medical journals differed in prevalence of honorary authors according to published research contributions of named authors. Different authorship/contribution policies and procedures should be explored as a possible explanation for the differences in contributions disclosed by authors among these journals.


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Abstract: Many journalism organizations have published codes of ethics in recent years. The Association of Newspaper Editors, for example, lists 47 different codes on its website. But an organization of health care journalists felt that none of those codes addressed the unique challenges of covering complex health care topics. The Association of Health Care Journalists (AHCJ) is an independent, non-profit organization dedicated to advancing public understanding of health care issues. Its mission is to improve the quality, accuracy and visibility of health care reporting, writing and editing. AHCJ has written a statement of principles for its 750 members. In it, AHCJ states some of the unique challenges faced by journalists covering health care, and offers suggestions on how to face those challenges. Bioethicists are invited to comment on the statement, and to help generate continued discussion of the issues addressed therein.

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**JUSTICE** See **RIGHT TO HEALTH CARE; RESOURCE ALLOCATION**

**LEGAL ASPECTS** See **ABORTION/LEGAL ASPECTS; AIDS/LEGAL ASPECTS; BIOETHICS AND MEDICAL ETHICS/LEGAL ASPECTS; CLONING/LEGAL ASPECTS; EUTHANASIA AND ALLOWING TO DIE/LEGAL ASPECTS; GENETICS/LEGAL ASPECTS; HUMAN EXPERIMENTATION/ETHICS COMMITTEES AND POLICY GUIDELINES/LEGAL ASPECTS; ORGAN AND TISSUE TRANSPLANTATION/DONATION AND PROCUREMENT/LEGAL ASPECTS**

**LIVING WILLS** See **ADVANCE DIRECTIVES**

**MALPRACTICE** See also **MISCONDUCT**
MASS SCREENING See PUBLIC HEALTH

MEDICAL EDUCATION
See also BIOETHICS AND MEDICAL ETHICS/EDUCATION


What’s wrong with CME [editorial]. CMA/JAMC: Canadian Medical Association Journal 2004 March 16; 170(6): 917. NRCBL: 7.2; 9.7; 9.3.1. Identifiers: continuing medical education; Canadian Medical Association (CMA); Canada.


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Abstract: The field of spirituality and medicine has seen explosive growth in recent years, due in part to significant private support for the development of curricula in more than half of all U.S. medical schools, and for related residency training programs and research centers. While there is no single definition of “spirituality” in use across these initiatives, this article examines the definitions and learning objectives relevant to spirituality that are addressed in a 1999 report of the Medical School Objectives Project (MSOP), with special attention to their ethical implications. It concludes with several “diagnostic” case studies of religious consciousness from the medical literature and in literary texts, again with attention to ethical concerns.

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Abstract: As medical education increasingly acknowledges the importance of the ethical and professional conduct of practitioners, and moves towards more formal assessment of these issues, it is important to consider the evidence base which exists in this area. This article discusses literature about the health needs and problems experienced by medical practitioners as a background to a review of the current efforts in medical education to promote ethical conduct and develop mechanisms for the detection and remediation of problems.


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NRCBL: National Reference Center for Bioethics Literature Classification Scheme

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ulum on students’ proposed behaviour on meeting ethical dilemmas. *Medical Education* 2004 September; 38(9): 942-949. NRCBL: 7.2; 2.3. SC: em. Identifiers: University of Glasgow Medical School, Scotland.

**Goldie, J.; Schwartz, L.; Morrison, J.** Sex and the surgery: students’ attitudes and potential behaviour as they pass through a modern medical curriculum. *Journal of Medical Ethics* 2004 October; 30(5): 480-486. NRCBL: 7.2; 7.3; 7.4; 10. SC: em.

Abstract: OBJECTIVE: To examine students’ attitudes and potential behaviour to a possible intimate relationship with a patient as they pass through a modern medical curriculum.

DESIGN: A cohort study of students entering Glasgow University’s new learner centred, integrated medical curriculum in October 1996.

METHODS: Students’ pre year 1 and post year 1, post year 3, and post year 5 responses to the “attractive patient” vignette of the Ethics in Health Care Survey instrument were examined quantitatively and qualitatively. Analysis of students’ multi-choice answers enabled measurement of the movement towards professional consensus opinion. Analysis of written justifications helped determine whether their reasoning was consistent with professional consensus and enabled measurement of change in knowledge content and recognition of the values inherent in the vignette. Themes on students’ reasoning behind their decision to enter a relationship or not were also identified.

RESULTS: No significant movement towards consensus was found at any point in the curriculum. There was little improvement in students’ performance in terms of knowledge content and their abilities to recognise the values inherent in the vignette. In deciding to enter a relationship with the patient the most frequently used reasoning was that it could be justified if the patient changed their doctor.

CONCLUSIONS: Teaching on the subject of sexual or improper relationships between doctors and patients, including relationships with former patients requires to be made explicit. Case based teaching would fit in with the ethos of the problem based, integrated medical curriculum.


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**Isaacson, Robert J.** Ethics and economics [editorial]. *Angle Orthodontist* 2002 June; 72(3): iv. NRCBL: 7.2; 2.3.

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**Kim; Yong-Soon; Park, Jee-Won; Son, Yoon-Jung; Han, Sung-Suk.** A longitudinal study on the development of moral judgement in Korean nursing students. *Nursing Ethics* 2004 May; 11(3): 254-265. NRCBL: 7.2; 1.3.1; 4.1.3. SC: em.

Abstract: This longitudinal study examined the development of moral judgement in 37 nursing students attending a university in Suwon, Korea. The participants completed the Korean version of the Defining Issues Test to allow analysis of their level of moral judgement. The development of moral judgement was quantified using ‘the moral development score’ at each stage (i.e. the six stages detailed by Kohlberg) and the ‘P(%) score’ (a measure of the overall moral judgement level). The results were as follows: (1) the moral development score for stage 5A was consistently the highest across the four years of the students’ course, showing significant differences in some sociodemographic factors including home, birth order and monthly income; and (2) the P(%) score was higher in fourth-year (47.47 +/- 11.21) than in first-year (46.13 +/- 9.73) students. There was no significant difference in the P(%) score according to sociodemographic factors. Further studies will examine in detail the correlation between curriculum and moral judgement development. We suggest that courses in ethics education should be made more relevant.


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Rognstad, May-Karin; Nortvedt, Per; Aasland, Olaf. Helping motives in late modern society: values and attitudes among nursing students. _Nursing Ethics_ 2004 May;
SECTION I MEDICAL EDUCATION


Abstract: This article reports a follow-up study of Norwegian nursing students entitled ‘The helping motive an important goal for choosing nursing education’. It presents and discusses a significant ambiguity within the altruistic helping motive of 301 nursing students in the light of classical and modern virtue ethics. A quantitative longitudinal survey design was used to study socialization and building professional identity. The follow-up study began after respondents had completed more than two-and-a-half years of the three-year educational programme.

Data were collected using a questionnaire with closed questions, supplemented by 18 semi-structured, in-depth, audiotaped interviews. A motive such as ‘desire for human contact/help others’ appeared to be highly significant. The research questions employed were: What motivates nursing students at the end of their studies to help other people? What does helping others mean for nursing students? Factor analysis revealed two factors. Factor 1 can be expressed as an altruism factor and factor 2 can be interpreted as an ‘acknowledgement-from-the-patient factor’ that in fact indicates an ambiguity within the helping motive itself. Findings from the interviews also reveal ambiguous helping motives. On one hand the students want to be altruistic and on the other they wish to receive positive feedback from patients when giving help. The findings indicate that this positive feedback is essential to the students in order for them to provide altruistic care.


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tion events. Teaching and Learning in Medicine 2003 Fall; 15(4): 267-269. NRCBL: 7.2; 7.3; 9.3.1.


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Wander, Nathaniel; Malone, Ruth E. Selling off or selling out? Medical schools and ethical leadership in tobacco stock divestment. Academic Medicine 2004 November; 79(11): 1017-1026. NRCBL: 7.2; 9.3.1; 1.3.2; 9.5.9.


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White, Gillian E. Medical students' learning needs about setting and maintaining social and sexual boundaries: a report. Medical Education 2003 November; 37(11): 1017-1019. NRCBL: 7.2; 8.1; 10.


Abstract: The purpose of this research was to describe attitudes of nursing students (and paramedic officers) towards marginalized clients. Convenience quota sampling in a major health faculty was employed. Students participated on a voluntary basis. A 58-item Likert scale, developed by the authors, assessed the student nurses’ attitudes. In general, attitudes towards homeless clients were neutral; detailed analyses, however, revealed that student nurses would decline to care for homeless clients in various situations. Personal experience with homeless patients and positive attitudes of nurses significantly contributed to increased quality of care and equality of treatment for homeless clients. Certain student nurse behaviors warrant immediate attention to prevent marginalized patients from being exposed to unfair, inaccessible and biased nursing care. Based on our results, we recommend that further research attention be paid to the role of ethics education and faculty behaviors, as faculty members serve as role models for professionalization.

MEDICAL ERRORS See HEALTH CARE QUALITY

MEDICAL ETHICS See BIOETHICS AND MEDICAL ETHICS

MENTAL HEALTH, CONCEPT OF
See also HEALTH, CONCEPT OF; MENTAL HEALTH THERAPIES


Grover, Sonja. Did I make the grade? Ethical issues in psychological screening of children for adoptive placement. Ethical Human Psychology and Psychiatry 2004 Summer; (6(2): 125-133. NRCBL: 4.3; 9.5.7; 8.4; 21.1; 1.3.10.


Abstract: This article reports on a qualitative study of defense attorneys’ perceptions of the mental competence or rationality of death row inmates’ decisions to waive habeas appeals and proceed directly to execution. Interviews were conducted with twenty attorneys who have either directly represented or been closely involved with would-be volunteers. Through analytic comparison with another end-of-life decision, euthanasia, this article reports on four themes from the interviews: (a) attorneys’ perceptions of the legal standard of competence, (b) their perceptions of the competency evaluation process, (c) implications of competing interpretive frames (i.e., volunteering vs. suicide), and (d) the rationality of decisions to waive appeals. Implications of research findings, particularly in terms of recent restructured models of competence, are also discussed.


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and Psychiatry 2002 July/August; 25(4): 405-426. NRCBL: 4.3; 17.1; 2.2.


MENTAL HEALTH THERAPIES
See also BEHAVIOR CONTROL; ELECTROCONVULSIVE THERAPY; CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; IN VOLUNTARY COMMITMENT; MENTAL HEALTH, CONCEPT OF; OCCUPATIONAL HEALTH; PSYCHOPHARMACOLOGY; PSYCHOTHERAPY


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Austin, Wendy; Bergum, Vangie; Nuttgens, Simon. Addressing oppression in psychiatric care: a relational ethics perspective. Ethical Human Psychology and Psychiatry 2004 Spring; 6(1): 69-78. NRCBL: 17.1; 8.1; 17.3; 1.1; 7.4.

Bartlett, Thomas. Did a university let a sex researcher go too far? A psychology professor returned to his lab, only to draw complaints for a second time. Chronicle of Higher Education 2003 October 24; 50(9): A10-A12. NRCBL: 17.1; 10; 18.4.


Berghmans, R.; Berg, M.; van den Burg, M.; ter Meulen, R. Ethical issues of cost effectiveness analysis and guideline setting in mental health care. Journal of Medical Ethics 2004 April; 30(2): 146-150. NRCBL: 17.1; 9.3.1. SC: an. Abstract: This article discusses ethical issues which are raised as a result of the introduction of economic evidence in mental health care in order to rationalise clinical practice. Cost effectiveness studies and guidelines based on such studies are often seen as impartial, neutral instruments which try to reduce the influence of non-scientific factors. However, such rationalising instruments often hide normative assumptions about the goals of treatment, the selection of treatments, the role of the patient, and the just distribution of scarce resources. These issues are dealt with in the context of increased control over clinical practice by third parties. In particular, health insurers have a great interest in economic evidence in clinical care settings in order to control access to and quality of (mental) health care. The authors conclude that guideline setting and cost effectiveness analysis may be seen as important instruments for making choices in health care, including mental health care, but that such an approach should always go hand in hand with a social and political debate about the goals of medicine and (mental) health care. This article is partly based on the results of a research project on the normative aspects of guideline setting in psychiatry and cardiology which was conducted under the guidance of the Royal Dutch Medical Association.

Bernat, James L. Ethical issues in the perioperative management of neurologic patients. Neurologic Clinics North America 2004 May; 22(2): 457-471. NRCBL: 17.1; 8.3.3; 8.3.4; 20.2.1; 20.5.4.

Bindman, Jonathan; Maingay, Samantha; Szmukler, George. The Human Rights Act and mental health legisla-


Abstract: As people living with Alzheimer’s disease experience their lifetime of memories slowly slipping away, they become dependent on society’s independent practical reasoners, family, health care professionals and society. Many people grow accustomed to the cognitive decline and begin to view the person with dementia as less than a person. In Dependent rational animals, Alasdair MacIntyre emphasized a moral framework that encompasses two sets of virtues needed for human beings to flourish in society and to achieve genuine common goods—the virtues of independent practical reasoners and the virtues of acknowledged dependence. Virtues of acknowledged dependence are discussed ethically in terms of benevolence towards those who are disabled or dependent upon people who are strong and independent. The authors propose that using MacIntyre’s perspective of the two sets of virtues is valuable in the care of persons with Alzheimer’s disease. According to MacIntyre, independent reasoners who understand and practice these two sets of virtues will help those people in communities who are dependent and vulnerable, and, subsequently, human flourishing can occur.


Covinsky, Kenneth E.; Yaffe, Kristine. Dementia, prognosis, and the needs of patients and caregivers [editorial]. Annals of Internal Medicine 2004 April 6; 140(7): 573-574. NRCBL: 17.1; 9.5.2; 20.5.4.


Else, Liz; Boire, Richard Glen. We hold these freedoms to be self-evident . . . [interview]. New Scientist 2004 April 24-30; 182(2444): 46-49. NRCBL: 17.1; 17.3; 17.4. SC: le. Identifiers: Center for Cognitive Liberty and Ethics.


Karlawish, Jason H.; Bonnie, Richard J.; Appelbaum, Paul S.; Lyketsos, Constantine; James, Bryan; Knopman, David; Patusky, Christopher; Kane, Rosalie A.; Karlan, Pamela S. Addressing the ethical, legal, and social issues raised by voting with persons with dementia. JAMA: The Journal of the American Medical Association 2004 September 15; 292(11): 1345-1350. NRCBL: 17.1; 9.5.2; 1.3.5. Abstract: This article addresses an emerging policy problem in the United States participation in the electoral process by citizens with dementia. At present, health care professionals, family caregivers, and long-term care staff lack adequate guidance to decide whether individuals with dementia should be precluded from or assisted in casting a ballot. Voting by persons...
with dementia raises a series of important questions about the autonomy of individuals with dementia, the integrity of the electoral process, and the prevention of fraud. Three subsidiary issues warrant special attention: development of a method to assess capacity to vote; identification of appropriate kinds of assistance to enable persons with cognitive impairment to vote; and formulation of uniform and workable policies for voting in long-term care settings. In some instances, extrapolation from existing policies and research permits reasonable recommendations to guide policy and practice. However, in other instances, additional research is necessary.


McCubbin, Michael; Cohen, David. A systemic and value-based approach to strategic reform of the mental health system. Health Care Analysis: An International Journal of Health Care Philosophy and Policy 1999; 7(1): 57-77. NRCBL: 17.1; 9.1. Abstract: Most writers now recognize that mental health policy and the mental health system are extremely resistant to real changes that reflect genuine biopsychosocial paradigms of mental disorder. Writers bemoaning the intransigence of the mental health system tend to focus on a small analytical level, only to find themselves mired in the rationalities of the existing system. Problems are acknowledged to be system-wide, yet few writers have used a method of analysis appropriate for systemic problems. Drawing upon the General System Theory (GST) analytical perspective, this article advances a systematic approach to understand the mental health system and to facilitate the development of reform strategies that recognize the system’s complexity and changing nature. The article first discusses the failure of major reform efforts in the mental health system and the limitations of mainstream analysis of mental health politics and policies with respect to the objectives of analysis and reform. This article describes how systems thinking has thus far influenced the study of the mental health policy and politics system, and argues that a systemic perspective is profitable for reconceiving the mental health system, enabling a fresh basis for the development of reform strategies. The mental health system should be seen as a social system influenced by larger political and economic dimensions, not just as a ‘delivery system’ scientifically constructed by neutral experts. Furthermore, the policy planning process should be viewed as part and parcel of a mental health system modeled as complex and dynamic. The systemic perspective outlined here should help both to clarify the value-based objectives that we hold for the system and, consequently, to plan for the strategic reforms that have so far eluded us.


Phillips, Helen. Private thoughts, public property — brain imaging can already see so deep into our private lives that we need to think long and hard about who has access to our personal secrets. New Scientist 2004 July 31-August 6; 183(2458): 38-41. NRCBL: 17.1; 5.1.


Seeman, Mary V. Therapy in the gray zone: psychiatry recalled. CMAJ/JAMC: Canadian Medical Association Journal 2004 December 7; 171(12): 1477-1479. NRCBL: 17.1; 17.7; 17.3.

Singer, Emily. They know what you want — If neuromarketers can find the key to our consumer desires, will they be able to manipulate what we buy? New Scientist 2004 July 31-August 6; 183(2458): 36-37. NRCBL: 17.1; 5.1.


Spinney, Laura. Why we do what we do — wouldn’t it be useful if you could predict the choices people were going to make? How close are we to a science of decision making. New Scientist 2004 July 31-August 6; 183(2458): 32-35. NRCBL: 17.1; 5.1.


Thomas, Philip; Cahill, Anne B. Compulsion and psychiatry — the role of advance statements: liberation cannot be handed to the oppressed by the oppressor [editorial]. BMJ: British Medical Journal 2004 July 17; 329(7458): 122-123. NRCBL: 17.1; 20.5.4.


MENTALLY DISABLED See CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MENTALLY DISABLED; INFORMED CONSENT/ INCOMPETENTS

MENTALLY HANDICAPPED See CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MENTALLY DISABLED; INFORMED CONSENT/ INCOMPETENTS

MENTALLY ILL See CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MENTALLY DISABLED; INFORMED CONSENT/ INCOMPETENTS; TREATMENT REFUSAL/ MENTALLY ILL

MERCY KILLING See EUTHANASIA AND ALLOWING TO DIE

MILITARY PERSONNEL See HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MILITARY PERSONNEL

MINORITIES See CARE FOR SPECIFIC GROUPS/ MINORITIES
MINORS See CARE FOR SPECIFIC GROUPS/ MINORS; DEATH AND DYING/ TERMINAL CARE FOR MINORS; EUTHANASIA AND ALLOWING TO DIE/ MINORS; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MINORS; INFORMED CONSENT/ MINORS

MISCONDUCT
See also BIOMEDICAL RESEARCH/ RESEARCH ETHICS AND SCIENTIFIC MISCONDUCT; MALPRACTICE


Dyer, Owen. GMC finds paediatrician guilty of abusing his position [news]. BMJ: British Medical Journal 2004 June 19; 328(7454): 1455. NRCBL: 7.4; 7.3; 1.3.5. Identifiers: General Medical Council.


Turone, Fabio. Italian doctors face criminal allegations over bribes [editorial]. BMJ: British Medical Journal 2004 June 5; 328(7452): 1333. NRCBL: 7.4; 9.7; 9.3.1; 1.3.5.


MORAL AND RELIGIOUS ASPECTS See ABORTION/ MORAL AND RELIGIOUS ASPECTS

NURSE PATIENT RELATIONSHIP See NURSING ETHICS AND PHILOSOPHY; PROFESSIONAL PATIENT RELATIONSHIP

NURSING CARE See CARE FOR SPECIFIC GROUPS; DEATH AND DYING/ TERMINAL CARE

NURSING ETHICS AND PHILOSOPHY
See also BIOETHICS AND MEDICAL ETHICS; CODES OF ETHICS; PROFESSIONAL ETHICS

A nurse’s ethical obligations toward candidates for the practice of the profession and nursing externs. Perspective Infermiere 2004 May-June; 1(5, Supplement): 6. NRCBL: 4.1.3.


Abstract: This article deals with nurses’ ethical concerns raised by the consequences of changes in governmental and institutional policies on nursing practice and patient care. The aims of this project were to explore perspectives of registered nurses who provide or manage direct patient care on policies that affect nursing and patient care, and to provide input to policy makers

NRCBL: National Reference Center for Bioethics Literature Classification Scheme
for the development of more patient-centred policies. Four focus groups were conducted with a total of 36 registered nurse participants. The project team identified major themes that emerged in the analysis of transcripts of the focus group discussions. The four major themes were: effects of policy focused on cost containment, effects on quality of care, effects on patient education and access to needed services, and effects on nurses and nursing. The participants identified primarily negative effects of changes in national health policy and legislation that influence institutional policies on patient care and nursing practice. The effects of identified policy changes raised concerns about meeting nurses’ ethical obligations to patients and families. Participants specified key points for consideration by legislators and other policy makers. They viewed nurses who are involved in direct patient care as a critical resource for legislators and other policy makers in the development of public and institutional policies that affect nursing and patient care.


Biedrzycki, Barbara A. Ethics in oncology nursing: realism and resources. ONS News 2004 August; 19(8): 1, 4-5, 7. NRCBL: 4.1.3; 20.4.1.


Bjorklund, Pamela. Invisibility, moral knowledge and nursing work in the writings of Joan Liaschenko and Patricia Rodney. Nursing Ethics 2004 March; 11(2): 110-121. NRCBL: 4.1.3; 1; 10. Abstract: The ethical ‘eye’ of nursing, that is, the particular moral vision and values inherent in nursing work, is constrained by the preoccupations and practices of the superordinate biomedical structure in which nursing as a practice discipline is embedded. The intimate, situated knowledge of particular persons who construct and attach meaning to their health experience in the presence of and with the active participation of the nurse, is the knowledge that provides the evidence for nurses’ ethical decision making. It is largely invisible to all but other nurses. Two nurse researchers, Joan Liaschenko of the University of Minnesota and Patricia Rodney of the University of Victoria, have investigated the ethical concerns of practising nurses and noted in their separate enquiries the invisible nature of critical aspects of nursing work. Noting the similarities in their respective observations, and with the feminist ethics of Margaret Urban Walker as a theoretical framework, this article examines the concept of ‘invisibility’ as it relates to nursing work and nursing ethics.


De Beer, T.; Gastmans, C.; Dierckx de Casterlé, B. Involvement of nurses in euthanasia: a review of the literature. Journal of Medical Ethics 2004 October; 30(5): 494-498. NRCBL: 4.1.3; 20.5.1; 21.1. SC: rv. Identifiers: Belgium; Australain; The Netherlands; Japan. Abstract: In ethical debates about euthanasia, the focus is often exclusively on the involvement of physicians and the involvement of nurses is seldom given much attention. Yet nurses occupy a central position in the care of terminal patients, where being confronted with a euthanasia request is an ever present possibility. To assess the involvement of nurses in euthanasia, this article provides an overview of relevant findings from the scientific literature. From this it becomes apparent that nurses are involved in various phases of the euthanasia process: observing the request for euthanasia, decision making, carrying out of euthanasia, and the aftercare for the patient’s family members.

Dierckx de Casterlé, Bernadette; Gypdonck, Mieke; Cannaearts, Nancy; Steeman, Els. Empirical ethics in action: lessons from two empirical studies in nursing ethics. Medicine, Health Care and Philosophy: A European Journal 2004; 7(1): 31-39. NRCBL: 4.1.3; 20.4.1; 20.5.1. SC: an; em. Abstract: Despite the burgeoning of publications in nursing ethics, only more recently has empirical evidence on nursing ethics been published. How nursing ethics can be empirically studied as well as enriched by empirical data will be the focus of this paper. Two empirical studies will be briefly presented and their contribution to ethics discussed. The first one is a qualitative research project about nurses’ ethical behavior in daily practice. Using an adapted version of Kohlberg’s theory of moral development, this study tried to describe and explore nurses’ responses to ethical dilemmas in daily nursing practice. The second study attempted to describe the specificity of residential palliative care. A qualitative approach was used to explore and describe the processes that take place on an inpatient palliative care unit, and the experiences of patients, relatives and palliative care team members. The analysis of the value of both research projects for ethics underlines the power of empirical understanding in the relationship between research and ethics. The need for integration of both qualitative and quantitative research methodologies is argued.

Doane, Gweneth; Pauly, Bernadette; Brown, Helen; McPherson, Gladys. Exploring the heart of ethical nursing practice: implications for ethics education. Nursing Ethics 2004 May; 11(3): 240-253. NRCBL: 4.1.3; 7.2. SC: em. Abstract: The limitations of rational models of ethical decision making and the importance of nurses’ human involvement as moral agents is increasingly being emphasized in the nursing literature. However, little is known about how nurses involve themselves in ethical decision making and action or about educational processes that support such practice. A recent study that examined the meaning and enactment of ethical nursing practice for three groups of nurses (nurses in direct care positions, student nurses, and nurses in advanced practice positions) highlighted that humanly involved ethical nursing practice is also simultaneously a personal process and a socially mediated one. Of particular significance was the way in which differing roles expectations and contexts shaped the nurses’ ethical practice. The study findings pointed to types of educative experiences that may help nurses to develop the knowledge and ability to live in and navigate their way through the complex, ambiguous and shifting terrain of ethical nursing practice.
SECTION I  NURSING ETHICS AND PHILOSOPHY


Abstract: This research project investigated the extent to which nurses engage in two important kinds of ethical behaviours: ethical activism (where they try to make hospitals more receptive to nurses’ participation in ethics deliberations) and ethical assertiveness (where they participate in ethics deliberations even when not formally invited). This research probed not only the extent to which nurses engage in these ethical behaviours but also whether this is influenced by professional, training and organizational factors. A random sample of 165 nurses from three major hospitals in Los Angeles provided the data. Regression analyses indicate that both ethical activism and ethical assertiveness are strongly influenced by nurses’ perceptions of the receptivity of hospitals to their inclusion in ethics deliberations.

In addition, nurses’ education in ethics is a significant predictor of ethical activism. The findings have important implications for the content of nurses’ ethics training as well as for expanding the boundaries of nurses’ participation in ethics deliberations. The authors define ethics deliberations as specific meetings of a number of people to discuss an ethical issue, such as one regarding the care of a patient.


Fraser, Kimberly D. Is personal choice an absolute right? [opinion]. Canadian Nurse 2004 April; 100(4): 12-14. NRCBL: 4.1.3; 1.1; 5.2. SC: cs.


Abstract: This article is based on an empirical study regarding ethical challenges in intercultural nursing. The focus is on autonomy and disclosure. Autonomy is a human capacity that has become an important ethical principle in nursing. Although the relationship between autonomy and patients’ possibly harmful choices is discussed, the focus is on ‘forced’ autonomy. Nurses seem to equate respect with autonomy; it seems to be hard to cope with the fact that there are patients who voluntarily undergo treatment but who actively participate neither in the treatment offered nor in making choices regarding that treatment. Nurses’ demand for patients to be autonomous may in some cases jeopardize the respect, integrity and human worth that the ethical principle of autonomy is meant to ensure. Even though respect for a person’s autonomy is also respect for the person, one’s respect for the person in question should not depend on his or her capacity or aptitude to act autonomously. Is autonomy necessarily a universal ethical principle? This article negates this question and, through the issues of culture, individualism versus collectivism, first- and second-order autonomy, communication and the use of family interpreters, and respect, an attempt is made to explain why.


Lemonidou, Chryssoulia; Papanathanassoglou, Elizabeth; Giannakopoulou, Margarita; Patiraki, Elisabeth; Papadatou, Danae. Moral professional personhood: ethical reflections during initial clinical encounters in nursing education. Nursing Ethics 2004 March; 11(2): 122-137. NRCBL: 4.1.3; 1.3.1; 7.2; 8.1. SC: em. Identifiers: Greece.

Abstract: Moral agency is an important constituent of the nursing role. We explored issues of ethical development in Greek nursing students during clinical practice at the beginning of their studies. Specifically, we aimed to explore students’ lived experience of ethics, and their perceptions and understanding of encountered ethical conflicts through phenomenological analysis of written narratives. The process of developing an awareness of personal values through empathizing with patients was identified as the core theme of the students’ experience. Six more common themes were identified. Development of the students’ moral awareness was conceptualized as a set of stages,
commencing with empathizing with patients and nurses, moving on to taking a moral stand and, finally, concluding by becoming aware of their personal values and showing evidence of an emerging professional moral personhood. The notions of empathy, caring and emotion were in evidence throughout the students’ experience. Implications for practice and nurse education are discussed.


Martin, Pam; Yarbrough, Susan; Alfred, Danita. Professional values held by baccalaureate and associate degree nursing students. *Journal of Nursing Scholarship* 2003; 35(3): 291-296. NRCBL: 4.1.3; 1.1; 7.2.


Meulenbergs, Tom; Verpeet, Ellen; Schotsmans, Paul; Gastmans, Chris. Professional codes in a changing nursing context: literature review. *Journal of Advanced Nursing* 2004 May; 46(3): 331-336. NRCBL: 4.1.3; 6.


Milton, Constance L. Stories: implications for nursing ethics and respect for another. *Nursing Science Quarterly* 2004 July; 17(3): 208-211. NRCBL: 4.1.3; 1.1; 7.1; 8.1.


Nädén, Dagfinn; Eriksson, Katie. Understanding the importance of values and moral attitudes in nursing care in preserving human dignity. *Nursing Science Quarterly* 2004 January; 17(1): 86-91. NRCBL: 4.1.3; 1.1. SC: em.


Peter, Elizabeth; Liaschenko, Joan. Whose morality is it anyway? Thoughts on the work of Margaret Urban Walker. *Nursing Philosophy* 2003 October; 4(3): 259-262. NRCBL: 4.1.3; 1.1.

Peter, Elizabeth; Lunardi, Valeria Lerch; Macfarlane, Amy. Nursing resistance as ethical action: literature review. *Journal of Advanced Nursing* 2004 May; 46(4): 403-416. NRCBL: 4.1.3; 1.1; 10.


Summers, Jim; Nowicki, Michael. System failures and ethical issues for rehabilitation nurses. *Rehabilitation
SECTION I

OCCUPATIONAL HEALTH


Touhy, Theris A. Dementia, personhood, and nursing: learning from a nursing situation. Nursing Science Quarterly 2004 January; 17(1): 43-49. NRCBL: 4.1.3; 4.4; 9.5.2; 17.1.


Varcoe, Colleen; Doane, Gweneth; Pauly, Bernadette; Rodney, Paddy; Storchi, Janet L.; Mahoney, Karen; McPherson, Gladys; Brown, Helen; Starzomski, Rosalie. Ethical practice in nursing: working the in-betweens. Journal of Advanced Nursing 2004 February; 45(3): 316-325. NRCBL: 4.1.3; 8.1. SC: em.


OCCUPATIONAL HEALTH

See also PUBLIC HEALTH


Ferber, Dan. Authors turn up heat over disputed paper [news]. Science 2004 June 25; 304(5679): 1891. NRCBL: 16.3; 1.3.2; 1.3.7. SC: le. Identifiers: IBM; Richard Clapp; Boston University; Rebecca Johnson; Epicenter in Circle Pines, Minnesota.


Nuwayhid, Iman A. Occupational health research in developing countries: a partner for social justice. American Journal of Public Health 2004 November; 94(11): 1916-1921. NRCBL: 16.3; 18.2; 21.1. Abstract: Occupational health remains neglected in developing countries because of competing social, economic, and political challenges. Occupational health research in developing countries should recognize the social and political context of work relations, especially the fact that the majority of developing countries lack the political mechanisms to translate scientific findings into effective policies. Researchers in the developing world can achieve tangible progress in promoting occupational health only if they end their professional isolation and examine occupational health in the broader context of social justice and national development in alliance with researchers from other disciplines. An occupational health research paradigm in developing countries should focus less on the workplace and more on the worker in his or her social context.


ORGAN AND TISSUE TRANSPLANTATION

See also BLOOD DONATION AND TRANSFUSION


Agich, George J.; Siemionow, Maria. Facing the ethical questions in facial transplantation. American Journal of


Clark, Jocalyn. Facial transplants technically possible, but “very hazardous” [news]. *CMAJ/JAMC: Canadian Medical Association Journal* 2004 February 3; 170(3): 323. NRCBL: 19.1; 5.2; 17.1; 18.1.

Concar, David. The boldest cut — the risks are considerable, and some say it shouldn’t be done. But one team of US surgeons is preparing to carry out the world’s first face transplant. *New Scientist* 2004 May 29-June 4; 182(2449): 32-37. NRCBL: 19.1; 18.1. Identifiers: United States.


Fox, Renée C.; Swazey, Judith P. “He knows that machine is his mortality”: old and new social and cultural patterns in the clinical trial of the AbioCor artificial heart. Perspectives in Biology and Medicine 2004 Winter; 47(1): 74-99. NRCBL: 19.2; 18.2; 18.3.


Gaines, Robin A. Identifiers: Composite Tissue Allotransplantation (CTA).


Mansell, M.A. The ethics of rewarded kidney donation [opinion]. BJU International 2004 June; 93(9): 1171-1172. NRCBL: 19.3; 9.3.1.


Abstract: HLA typing and the time a patient has spent on the waiting list are the primary criteria used to allocate cadaveric kidneys for transplantation in the United States. Candidates with no HLA-A, B, and DR mismatches are given top priority, followed by candidates with the fewest mismatches at the HLA-B and DR loci; this policy contributes to a higher transplantation rate among whites than nonwhites. We hypothesized that changing this allocation policy would affect graft survival and the racial balance among transplant recipients. METHODS: We estimated the relative rates of kidney transplantation according to race resulting from the current allocation policy and racial differences in HLA antigen profiles, using a Cox model for the time from placement on the waiting list to transplantation. Another model, also adjusted for HLA-B and DR antigen profiles, estimated the relative rates of kidney transplantation that would result if the distribution of these antigen profiles were identical among the racial and ethnic groups. We also investigated the effect of HLA matching on the risk of graft failure, using a Cox model for the time from the first transplantation to graft failure. The results of the two analyses were used to estimate the change in the racial balance of transplantation and graft-failure rates that would result from the elimination of HLA-B matching or HLA-A and DR matching as a means of assigning priority. RESULTS: Eliminating the HLA-B matching as a priority while maintaining HLA-DR matching as a priority would decrease the number of transplantations among whites by 4.0 percent (166 fewer transplantations over a one-year period), whereas it would increase the number among nonwhites by 6.3 percent and increase the rate of graft loss by 2.0 percent. CONCLUSIONS: Removing HLA-B matching as a priority for the allocation of cadaveric kidneys could reduce the existing racial imbalance by increasing the number of transplantations among nonwhites, with only a small increase in the rate of graft loss. Copyright 2004 Massachusetts Medical Society


Steinberg, David; Veatch, Robert M. The total artificial heart and the morality of killing [debate]. Medical Ethics Newsletter [Lahey Clinic] 2004 Spring; 11(2): 10-12. NRCBL: 19.2; 20.5.1.


Wiggins, Osborne P.; Barker, John H.; Martinez, Serge; Vossen, Marieke; Maldonado, Claudio; Grossi, Federico V.; Francois, Cedric G.; Cunningham, Michael; Perez-Abadia, Gustavo; Kon, Moshe; Banis, Joseph C. On the ethics of facial transplantation research. American Journal of Bioethics 2004 Summer; 4(3): 1-12. NRCBL: 19.1; 18.2; 18.3; 18.6; 5.2. SC: an. Identifiers: University of Louisville.

ORGAN AND TISSUE TRANSPLANTATION/ ALLOCATION


Johri, Mira; Ubel, Peter A. Setting organ allocation priorities: should we care what the public cares about? Liver Transplantation 2003 August; 9(8): 878-880. NRCBL: 19.6; 19.1.


McKneally, Martin F.; Sade, Robert M. The prisoner dilemma: should convicted felons have the same access to heart transplantation as ordinary citizens? Opposing views [editorial]. *Journal of Thoracic and Cardiovascular Surgery* 2003 March; 125(3): 451-453. NRCBL: 19.6; 9.5.1. SC: cs; le.


Moss, Alvin H. Too many patients who are too sick to benefit start chronic dialysis nephrologists need to learn to “just say no”. *American Journal of Kidney Diseases* 2003 April; 41(4): 723-727. NRCBL: 19.6; 2.2; 19.3. SC: le.


Pokorná, E.; Vitko, Š.; Lasziková, E. Compliance with kidney allocation criteria in the Czech Republic in 1997.


ceased-donor (DD) livers and was developed in response to “the final rule” mandate, whose stated principle is to allocate livers according to a patient’s medical need, with less emphasis on keeping organs in the local procurement area. However, in selected areas of the United States, organs are kept in organ procurement organizations (OPOs) with small waiting lists and transplanted into less-sick patients instead of being allocated to sicker patients in nearby transplant centers in OPOs with large waiting lists. OBJECTIVE: To determine whether there is a difference in MELD scores for liver transplant recipients receiving transplants in small vs large OPOs. DESIGN AND SETTING: Retrospective review of the US Scientific Registry of Transplant Recipients between February 28, 2002, and March 31, 2003. Transplant recipients (N = 4798) had end-stage liver disease and received DD livers. MAIN OUTCOME MEASURES: MELD score distribution (range, 6–40), graft survival, and patient survival for liver transplant recipients in small (d) and large (or = 100 on the waiting list) OPOs. RESULTS: The distribution of MELD scores was the same in large and small OPOs: 92% had a MELD score of 18 or less, 7% had a MELD score between 19 and 24, and only 2% of listed patients had a MELD score higher than 24 (P = .85). The proportion of patients receiving transplants in small OPOs and with a MELD score higher than 24 was statistically different (P = .59), and neither were graft survival rates in small OPOs (80.1%) and large OPOs (81.3%) (P = .80). CONCLUSIONS: There is a significant disparity in MELD scores in liver transplant recipients in small vs large OPOs; fewer transplant recipients in small OPOs have severe liver disease (MELD score 24). This disparity does not reflect the stated goals of the current allocation policy, which is to distribute organs according to a patient’s medical need, with less emphasis on keeping organs in the local procurement area.


ORGAN AND TISSUE TRANSPLANTATION/ DONATION AND PROCUREMENT


Ashkenazi, Tamar; Berman, Marius; Ben Ami, Sharona; Padilla, Abed; Aravot, Dan; Hoffenberg, Raymond. A bridge between hearts: mutual organ donation by Arabs and Jews in Israel. Transplantation 2004 January 15; 77(1): 151-157. NRCBL: 19.5; 1.2; 8.3.3; 21.1. SC: em.


Campbell, Courtney S. Harvesting the living?: separating “brain death” and organ transplantation. *Kennedy Institute of Ethics Journal* 2004 September; 14(3): 301-318. NRCBL: 19.5; 20.2.1; 20.5.1; 1.1; 7.1; 5.1; 1.2; 9.4; 2.1. Identifiers: technological imperative.

Clark, Peter A.; Deshmukh, Uday. Non-heart-beating organ donation and Catholic ethics. *National Catholic Bioethics Quarterly* 2004 Autumn; 4(3): 537-551. NRCBL: 19.5; 19.2; 8.3.1; 20.2.1; 9.7; 1.2; 1.1; 2.4.


Crowley-Matoka, Megan; Arnold, Robert M. The dead donor rule: how much does the public care... and how much should we care? *Kennedy Institute of Ethics Journal* 2004 September; 14(3): 319-332. NRCBL: 19.5; 20.2.1; 20.3.1; 20.5.1; 7.1. SC: em.


Dewar, S.; Bodington, P. Returning to the Alder Hey report and its reporting: addressing confusions and improving inquiries. *Journal of Medical Ethics* 2004 October; 30(5): 463-469. NRCBL: 19.5; 9.5.7; 8.3.2.


Dyer, Clare. Thousands of families to sue over retained organs [news]. *BMJ: British Medical Journal* 2004 January 24; 328(7433): 184. NRCBL: 19.5; 8.3.2; 8.5.


Fost, Norman C. Reconsidering the dead donor rule: is it important that organ donors be dead? *Kennedy Institute of Ethics Journal* 2004 September; 14(3): 249-260. NRCBL: 19.5; 20.2.1; 20.3.1; 7.1; 20.5.1.


Gill, Michael B. Presumed consent, autonomy, and organ donation. *Journal of Medicine and Philosophy* 2004 February; 29(1): 37-59. NRCBL: 19.5; 8.3.1. SC: an. Abstract: I argue that a policy of presumed consent for cadaveric organ procurement, which assumes that people do want to donate their organs for transplantation after their death, would be a moral improvement over the current American system, which assumes that people do not want to donate their organs. I address what I take to be the most important objection to presumed consent. The objection is that if we implement presumed consent we will end up removing organs from the bodies of people who did not want their organs removed, and that this situation is morally unacceptable because it violates the principle of respect for autonomy that underlies our concept of informed consent. I argue that while removing organs from the bodies of people who did not want them removed is unfortunate, it is morally no worse that not removing organs from the bodies of people who did want them removed, and that a policy of presumed consent will produce fewer of these unfortunate results than the current system.


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Abstract: Kidney donation by young children and the mentally retarded has been supported by court decisions, arguments based on obligations inherent in family relationships, an array of contextual factors, and the principle of beneficence. These justifications for taking organs from people who cannot protect themselves are problematic and must be weighed against our obligation to protect the vulnerable. A compromise solution is presented that strongly protects young children and the mentally retarded but does not abdicate all responsibility to relieve suffering. Guidelines are proposed that prohibit the retrieval of kidneys from young children and the mentally retarded but permit one exception. They would allow retrieval of a kidney when the consequence to a first order relative with whom the donor has a meaningful and valuable relationship is otherwise imminent death. This would be done in accordance with additional guidelines that minimize harm to the donor. Since most patients with end stage renal disease can be maintained on dialysis the need for a kidney to prevent death should be an uncommon occurrence. This compromise is proposed as a solution to a dilemma that exists because two ethical principles are in conflict and one cannot be honored without violating the other.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
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ORGAN AND TISSUE TRANSPLANTATION/ . . . / ECONOMIC ASPECTS

Bauer, Keith; Taub, Sara; Parsi, Kayhan. Ethical issues in tissue banking for research: a brief review of existing organizational policies. Theoretical Medicine and Bioethics 2004; 25(2): 113-142. NRCBL: 19.5; 8.4; 18.3; 18.2; 21.1; 9.3.1; 18.1. SC: rv.


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SECTION I ORGAN AND TISSUE TRANSPLANTATION/.../ECONOMIC ASPECTS


Jellinek, Samuel. Consideration for a donation — economic aspects. *Medicine and Law: World Association for Medical Law* 2004; 23(2): 453-470. NRCBL: 19.5; 9.3.1; 21.1. Abstract: This article considers the economic aspects involved in introducing and putting into operation the model proposed by the author of this article. It rests on the premise that it would be worthwhile to provide money or other economic consideration in order to encourage and hence increase donations of human organs for transplant, whether from living or deceased donors. The model is based on an official central body, which would coordinate receipt of organs from donors, payment to the donors and distribution of the organs to patients, who would not pay anything for receiving the organ and would not even have any contact with the seller-donor. The purpose of this article is to try to examine and prove, that increasing the supply of human organs, whether from living or deceased persons by providing money or some other economic incentive would not only save the lives of persons waiting for organs, but also bring about substantial financial saving to the social community in general and the health system in particular, and thereby make available additional resources for saving lives, shorten the queues and benefit the weaker levels of society. We will show this through examining the various financial costs. This covers both the expense of treating various patients who need transplants on the one hand and the estimated costs to the community, including the patients and their families, on the other hand—as well as the loss of work force to the economy, payment of pensions, care from welfare organizations, etc.


Sells, Robert A. Transplant ethics: altruism and materialism in organ donation. *Clinical Transplants* 2003; 293-305. NRCBL: 19.5; 9.3.1; 20.2.1. SC: le.

Sotiropoulos, Georgios C.; Brokalaki, Eirini I. Living organ donation: is there still place for altruism? *Hepato-Gastroenterology* 2004 January-February; 51(55): 6-8. NRCBL: 19.5; 1.1; 1.2; 9.3.1.

ORGAN AND TISSUE TRANSPLANTATION/ . . . / LEGAL ASPECTS

SECTION I


ORGAN AND TISSUE TRANSPLANTATION/ . . . / LEGAL ASPECTS


Caulfield, Timothy. Tissue banking, patient rights, and confidentiality: tensions in law and policy. Medicine and Law: World Association for Medical Law 2004; 23(1): 39-49. NRCBL: 19.5; 18.3; 8.4; 15.1. SC: le. Abstract: The collection, storage and analysis of tissue samples, including genetic data, has become an increasingly common part of biomedical research. Though there are many scientific justifications for the creation of tissue and DNA databanks, the storage and use of human tissue continues to create legal dilemmas. In this paper, the impact and relevance of existing common law principles are reviewed. It is noted that the Canadian common law rules covering consent and confidentiality may create challenges for the research community. Emerging health information legislation does, however, create a somewhat more lenient research environment, largely because these laws allow, in some circumstances, research on identifiable health information without consent. Nevertheless, conflicts between existing common law, research ethics policy and new health information legislation illustrate profound policy dilemmas created by research involving storage and use of tissue and genetic material.

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Jansen, Lynn A. Child organ donation, family autonomy, and intimate attachments. CQ: Cambridge Quarterly of Healthcare Ethics 2004 Spring; 13(2): 133-142. NRCBL: 19.5; 9.5.7; 8.3.2. SC: le.


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SECTION I

ORGAN AND TISSUE TRANSPLANTATION/ XENOTRANSPLANTATION

Ling, Amy. UCLA Willed Body program comes under scrutiny as companies sued for the purchase of body parts. *Journal of Law, Medicine and Ethics* 2004 Fall; 32(3): 532-534. NRCBL: 19.5; 4.4; 8.2; 18.1. SC: le.


Abstract: Advances in biological sciences and medicine have revolutionized current practice and opened new horizons. Tissue and organ transplantation is a miracle and an action of love and sacrifice for the sake of fellow human beings. Organ transplantation has been commonplace over the last decade but Greece still remains the lowest numerically among European countries in this field because of the lack of organ donation although it is highest in traffic accidents. Despite this, the legal framework regulating transplantation was enacted late in comparison to other European countries, and was not the only obstacle to the development of organ donation. Several other factors such as philosophy, culture, traditional and religious attitudes, lack of public information and lack of the relevant social fabric, have all contributed to the current sad situation. This article aims to present a critical view on the evolution of the legal framework in the field of tissue and organ transplantation in Greece. Issues that still deter organ donation are discussed along with an insight into the current situation in the Greek social context in order to make a constructive contribution to future perspectives.


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Sells, Robert A. Transplant ethics: altruism and materialism in organ donation. *Clinical Transplants* 2003; 293-305. NRCBL: 19.5; 9.3.1; 20.2.1. SC: le.


**ORGAN AND TISSUE TRANSPLANTATION/ XENOTRANSPLANTATION**


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**ORGAN DONATION See ORGAN AND TISSUE TRANSPLANTATION/ DONATION AND PROCUREMENT**

**OVUM DONORS See ARTIFICIAL INSEMINATION/ SURROGATE MOTHERS; HUMAN EXPERIMENTATION/ EMBRYOS AND FETUSES; REPRODUCTIVE TECHNOLOGIES**

**PALLIATIVE CARE See DEATH AND DYING/ TERMINAL CARE**

**PARENTAL CONSENT See HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ MINORS; INFORMED CONSENT/ MINORS**

**PATENTS**


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PATIENT ACCESS TO RECORDS See CONFIDENTIALITY; TRUTH DISCLOSURE

PATIENT CARE See CARE FOR SPECIFIC GROUPS; DEATH AND DYING/ TERMINAL CARE; PROFESSIONAL PATIENT RELATIONSHIPS

PATIENT PROFESSIONAL RELATIONSHIPS See PROFESSIONAL PATIENT RELATIONSHIPS

PATIENTS’ RIGHTS See CARE FOR SPECIFIC GROUPS; CONFIDENTIALITY; INFORMED CONSENT; RIGHT TO HEALTH CARE; TREATMENT REFUSAL; TRUTH DISCLOSURE

PERSONHOOD See QUALITY AND VALUE OF LIFE

PHILOSOPHY See BIOETHICS AND MEDICAL ETHICS/ PHILOSOPHICAL PERSPECTIVES; EUTHANASIA AND ALLOWING TO DIE/ PHILOSOPHICAL ASPECTS; NURSING ETHICS AND PHILOSOPHY; PHILOSOPHY OF MEDICINE

PHILOSOPHY OF MEDICINE


Abstract: Utilitarianism focuses on the optimization of personal well-being in ways that seems to make the practice of medicine irrelevant to the well-being of the practitioners, unless given external incentives such as money or honor. Care based on indirect incentives is considered inferior to care motivated internally. This leads to the paradox of utilitarian care. Following Nozick’s conceptual Pleasure Machine it is argued that in addition to the promotion of personal well-being, people care about fulfilling their well-being in a world which is real, just, good, and beautiful. Complete mechanization of social and personal life in accordance with a strict utilitarian regime is also incompatible with the kind of world people desire, even if it promises more fulfillment in terms of personal well-being. This explains the so-called Taurek-Parfit paradox, according to which sometimes ethics seems “to count the numbers” and sometimes not. The very pursuit of utilitarianism does not contribute to any personal life plan. The helping professions make the world a better place for us to live in, even though they do not necessarily bear directly on the well-being of any individual other than the recipients of care. This resolves the paradox of utilitarian care.


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Chervenak, Frank A.; McCullough, Laurence B. Neglected ethical dimensions of the professional liability crisis. American Journal of Obstetrics and Gynecology 2004 May; 190(5): 1198-1200. NRCBL: 4.1.2; 1.3.1; 9.3.1.

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Francis, Charles K. Professionalism and the medical student [editorial]. Annals of Internal Medicine 2004 November 2; 141(9): 735-736. NRCBL: 4.1.2; 7.2; 8.1.

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Ginsburg, Shipra; Regehr, Glenn; Lingard, Lorelei. Basing the evaluation of professionalism on observable behaviors: a cautionary tale. Academic Medicine 2004 October; 79(10, Supplement): S1-S4. NRCBL: 4.1.2; 1.3.1; 7.2; 8.2; 8.3.1. SC: em.

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O’Leary, J. Patrick. NRCBL: 4.1.2; 9.5.1; 21.1. response to acts of terrorism. 

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Sartin, Jeffrey S. J. Marion Sims: a defense of the father of gynecology [editorial]. *Southern Medical Journal* 2004 May; 97(5): 427-429. NRCBL: 4.1.2; 7.1; 18.5.3.

Sarin, Jeffrey S. J. Marion Sims, the father of gynecology: hero or villain? *Southern Medical Journal* 2004 May; 97(5): 427-429. NRCBL: 4.1.2; 7.1; 18.5.3.


Straus, Sharon E.; Wilson, Kumanan; Rambaldini, Gloria; Rath, Darlyne; Lin, Yulia; Gold, Wayne L.; Kapral, Moira K. Severe acute respiratory syndrome and its impact on professionalism: qualitative study of physicians’ behaviour during an emerging healthcare crisis. *BMJ: British Medical Journal* 2004 July 10; 329(7457): 83-85. NRCBL: 4.1.2; 1.3.1; 7.3; 16.3; 8.1.

Abstract: OBJECTIVE: To explore issues of professionalism in the context of severe acute respiratory syndrome (SARS), a new emerging health threat. DESIGN: Qualitative interviews analysed with grounded theory methodology. SETTING: University hospitals in Toronto, Canada, during the SARS outbreak in 2003. PARTICIPANTS: 14 staff physicians from divisions of infectious diseases, general internal medicine, and critical care medicine. RESULTS: Of 14 attending physicians, four became ill during the outbreak. Participants described their experiences during the outbreak and highlighted several themes about values inherent to medical professionalism that arose during this crisis including the balance between care of patients and accepted personal risk, confidentiality, appropriate interactions between physicians and patients, ethical research conduct, and role modelling of professionalism for junior doctors. CONCLUSION: Despite concerns raised by professional societies about the erosion of professionalism, participants in this study amply demonstrated the necessary qualities during the recent healthcare crisis. However, there were several examples of strained professional behaviour witnessed by the participants and these examples highlight aspects of medical professionalism that medical educators and professional organisations should address in the future, including the balance between personal safety and duty of care.


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PHILOSOPHY OF NURSING

See NURSING ETHICS AND PHILOSOPHY

PHYSICIAN PATIENT RELATIONSHIP

See BIOETHICS AND MEDICAL ETHICS; PROFESSIONAL PATIENT RELATIONSHIPS

POPULATION CONTROL

See also CONTRACEPTION; STERILIZATION


PRENATAL DIAGNOSIS See GENETIC COUNSELING; GENETIC SCREENING; SEX DETERMINATION

PRIORITIES IN HEALTH CARE See RESOURCE ALLOCATION

PRISONERS See HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ PRISONERS

PRIVILEGED COMMUNICATION See CONFIDENTIALITY

PROCUREMENT See ORGAN AND TISSUE TRANSPANTATION/ DONATION AND PROCUREMENT

PROFESSIONAL ETHICS

See also BIOETHICS AND MEDICAL ETHICS; CODES OF ETHICS; NURSES ETHICS AND PHILOSOPHY


Andrews, Gavin J.; Peter, Elizabeth; Hammond, Robin. Receiving money for medicine: some tensions and resolutions for community-based private complementary therapists. *Health and Social Care in the Community* 2003 March; 11(2): 155-167. NRCBL: 4.1.1; 9.3.1; 1.3.2; 7.1.

Ashcroft, Richard E. Ethical dimension was not discussed in theme issue [letter]. *BMJ: British Medical Journal* 2004 August 21; 329(7463): 458. NRCBL: 4.1.1; 2.1;


Dolan, Thomas C. A time for ethical leadership. ACHE affiliates can provide the moral leadership our nation’s healthcare system needs. Healthcare Executive 2004 January-February; 19(1): 6-8. NRCBL: 4.1.1; 6.


Egan, Mary; Swedersky, Jill. Spirituality as experienced by occupational therapists in practice. American Journal of Occupational Therapy 2003 September-October; 57(5): 525-533. NRCBL: 4.1.1; 1.2; 8.1; 16.3.


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Cantor, Harvey E.; Malani, Anup; Miller, Franklin G.; Emanuel, Ezekiel J.; Rosenstein, Donald L.; Straus, Stephen F. Ethical issues in research in complementary and alternative medicine [letter and reply]. JAMA: The Journal of the American Medical Association 2004 May 12; 291(18): 2192-2194. NRCBL: 4.1.1; 18.3.

SECTION I

PROFESSIONAL ETHICS

Abstract: Complementary and alternative medicine has become an important section of healthcare. Its high level of acceptance among the general population represents a challenge to healthcare professionals of all disciplines and raises a host of ethical issues. This article is an attempt to explore some of the more obvious or practical ethical aspects of complementary and alternative medicine.


Fleming, D. Duane; Scott, John F. The informed consent doctrine: what veterinarians should tell their clients. Journal of the American Veterinary Medical Association 2004 May 1; 224(9): 1436-1439. NRCBL: 4.1.1; 8.3.1; 22.1. SC: le.


Haegert, Sandra. The ethics of self. Nursing Ethics 2004 September; 11(5): 434-443. NRCBL: 4.1.1; 4.1.3; 8.1. Abstract: This article attempts to elucidate the ethical meaning behind the words “the ethics of self” and “an ethical self”, particularly in the light of Noddings’ “ethical self”, in order to show the relevance of these terms to the practice of ethical caring. It examines the relationship that Noddings believes exists between one’s actual self and the vision one has of one’s ideal self. I attempt to draw out a meaning derived from the texts in which this concept has been captured, while at the same time juxtaposing the concept “ethical of care” from my own research, together with the meaning given by philosophers Peta Bowden, Iris Murdoch and Simone Weil, who have written on the subject, albeit indirectly in some instances. A participant in a colleague’s research on care and patient satisfaction used similar expressions, and gave the impetus for this article.


Hasegawa, Thomas K., Jr.; Matthews, Merrill, Jr.; Grogan, David M. Ethical dilemma #47. “Friend or patient . . . or both?”. Texas Dental Journal 2004 April; 121(4): 329-331. NRCBL: 4.1.1; 8.1.


Jonas, Wayne B.; Goertz, Christine; Ives, John; Chez, Ronald A.; Walach, Harald; Miller, Franklin G.; Emanuel, Ezekiel J.; Rosenste, Donald L.; Straus, Stephen F. Ethical issues in research in complementary and alternative medicine. JAMA: The Journal of the American Medical Association 2004 May 12; 291(18): 2192-2194. NRCBL: 4.1.1; 18.3.

Kaptchuk, Ted J.; Lembo, Anthony; Emanuel, Ezekiel J.; Miller, Franklin G.; Rosenste, Donald L.; Straus, Stephen F. Ethical issues in research in complementary and alternative medicine [letter and reply]. JAMA: The Journal of the American Medical Association 2004 May 12; 291(18): 2193-2194. NRCBL: 4.1.1; 18.3.


Kerridge, Ian H.; McPhee, John R. Ethical and legal issues at the interface of complementary and conventional


Abstract: The realm of contemporary healthcare is pluralistic and complex. It is a blend of scientific promise, moral values, socio-economic constraints, cultural sensitivities, religious beliefs, political imperatives and commercial interests. Institutionalization of health care, with growing governmental control and the desire towards resource optimization, has widened the rift between individual and community perspectives. The quest for longer life-span, the urge to have ‘perfect’ babies, the curiosity to know our past and future, and many more expectations, have added new dimensions to human health and healthcare. In several areas ethical concepts are not clear and, at times, right and wrong contemplate redefinition posing serious challenge to the cultivators of law. The issue of biotechnological achievements and their social assimilation contemplates a much deeper dialogue than what is being done in contemporary ethical discussions. This paper is an attempt to identify and integrate the multiple roots of healthcare ethics in order to evolve holistic paradigms in the world of prevailing conceptual ambiguity.


Liebler, Michael; Devigus, Alessandro; Randall, Ros C.; Burke, F.J. Trevor; Pallesen, Ulla; Cerutti, Antonio; Putignano, Angelo; Cauchie, Didier; Kanzler, Reinhard; Koskinen, Kari P.; Skjerven, Henrik; Strand, Gunhild V.; Vermaas, Rob W.A. Ethics of esthetic dentistry. *Quintessence International* 2004 June; 35(6): 456-465. NRCBL: 4.1.1; 9.5.1. SC: cs.


Madorsky, M. David. When does ethical advertising cross the line? *Journal of the Michigan Dental Association* 2003 December; 85(12): 28-30, 61. NRCBL: 4.1.1; 8.1; 1.3.2; 9.3.1. SC: cs.


Abstract: A man with Alzheimer’s who wanders around, a caregiver who disconnects the alarm, a daughter acting on her own, and a doctor who is not consulted set the stage for a feminist reflection on capacity/competence assessment. Feminist theory attempts to account for gender inequality in the political and in the epistemological realm. One of its tasks is to unravel the settings in which actual practices, i.e. capacity/competence assessment take place and offer an alternative. In this article the focus will be on a feminist ethics of care in which relationality, care, vulnerability, and responsibility are privileged concepts and attitudes. The emphasis on these notions leads to a specific view of autonomy that has consequences for both care receivers (patients, clients) and caregivers (professional and not professional). These concepts constitute a default setting that shapes the context for capacity/competence assessment. Whereas this notion is meant to distinguish between those who need to be taken care of and those who do not, reflection on what it means to say ‘those who need to be taken care of is also required. The feminist analysis presented here emphasizes the necessity of the contextualization of assessment of competence. It sketches the multifold and complex grid that comprehends capacity assessment.


Marusic, Paul J.; Miller, Franklin G.; Emanuel, Ezekiel J.; Rosenstein, Donald L.; Straus, Stephen F. Ethical issues in research in complementary and alternative medicine [letter and reply]. *JAMA: The Journal of the American Medical Association* 2004 May 12; 291(18): 2193-2194. NRCBL: 4.1.1; 18.3.

Millea, Paul J.; Miller, Franklin G.; Emanuel, Ezekiel J.; Rosenstein, Donald L.; Straus, Stephen F. Ethical issues in research in complementary and alternative medicine [letter and reply]. *JAMA: The Journal of the American Medical Association* 2004 May 12; 291(18): 2193-2194. NRCBL: 4.1.1; 18.3.


Abstract: The use of complementary and alternative medicine (CAM) has grown dramatically in recent years, as has research on the safety and efficacy of CAM treatments. Minimal attention, however, has been devoted to the ethical issues relating to research on CAM. We argue that public health and safety demand rigorous research evaluating CAM therapies, research on CAM should adhere to the same ethical requirements for all clinical research, and randomized, placebo-controlled clinical trials should be used for assessing the efficacy of CAM treatments whenever feasible and ethically justifiable. In addition, we explore the legitimacy of providing CAM and conventional therapies that have been demonstrated to be effective only by virtue of the placebo effect.


Nichols, Polly S.; Winslow, Gerald R. Responding to faulty treatment. *General Dentistry* 2003 July-August; 51(4): 311-312. NRCBL: 4.1.1; 7.3; 8.2; 9.3.1; 9.8.


Peltier, Bruce. Some observations on truth claims in a profession. *Journal of the American College of Dentists* 2004 Summer; 71(2): 14-15. NRCBL: 4.1.1; 8.2; 1.3.1.


Thorne, Sally; Best, Allan; Balon, Jeffrey; Kelner, Merritjoy; Rickhi, Badri. Ethical dimensions in the borderland between conventional and complementary/alternative medicine. *Journal of Alternative and Complimentary Medicine* 2002 December; 8(6): 907-915. NRCBL: 4.1.1; 4.2; 7.1; 7.3.


**PROFESSIONAL PATIENT RELATIONSHIPS**

See also CARE FOR SPECIFIC GROUPS


Angelos, Peter; Lafreniere, Rene; Murphy, Timothy F.; Rosen, Wayne. Ethical issues in surgical treatment and research. *Current Problems in Surgery* 2003 July; 40(7): 353-448. NRCBL: 8.1; 2.1; 8.3.1; 8.3.4; 20.5.1; 18.5.1; 9.4; 19.5; 7.2. SC: rv.


Abstract: A number of dichotomies bedevil the concept of care, among them, the question of whether healthcare is posited on care or cure. On one side the question is whether it is enough to...
cure without caring (to cure is to care) and on the other whether caring is sufficient without a cure. This has received attention in recent years from feminists, particularly in the nursing profession, and from renewed interest in virtue ethics. This paper describes a study that was undertaken to explore what a group of experienced United Kingdom based osteopaths understand care to be. Following interviews and transcript analysis using Grounded Theory, a number of themes were identified: Care as communication; Care as understanding the patient; Care as the therapeutic relationship; Care as action; Care as most beneficial outcome. The relationships between the various themes were explored and a ‘model of osteopathic care’ was proposed. Most of the respondents put beneficial outcome of some kind at the heart of their understanding but the process of caring was not regarded as particularly important on its own. In fact the expressed intention of osteopathic care was to facilitate a beneficial outcome. However, beneficial outcome was described in very broad terms and was not confined to the resolution of patients’ presenting symptoms. In placing beneficial outcome at the heart of their model of care, respondents did not appear to recognize the dichotomy between care and cure, a finding that contrasts sharply with a number of nursing studies. The paper concludes by suggesting how it may be possible to differentiate between care and good practice.


Bedell, Susanna E.; Graboys, Thomas B.; Bedell, Elizabeth; Lown, Bernard. Words that harm, words that heal. Archives of Internal Medicine 2004 July 12; 164(13): 1365-1368. NRCBL: 8.1.

Beran, Roy G. Confidentiality and the management of patients with epilepsy who fail to comply with doctor’s advice not to drive: a survey of medical/legal opinions in Australia. Seizure 1998; 7: 459-468. NRCBL: 8.1; 8.4; 8.3.4; 9.1.


Cameron, Brenda L. Ethical moments in practice: the nursing ‘how are you?’ revisited. Nursing Ethics 2004 January; 11(1): 53-62. NRCBL: 8.1; 4.1.3.

Abstract: In seeking for an understanding of ethical practices in health care situations, our challenge is always both to recognize and respond to the call of individuals in need. In attuning ourselves to the call of the vulnerable other an ethical moment arises. Asking ‘how are you?’ in health care practice is our very first possibility to learn how a particular person finds herself or himself in this particular situation. Here, ‘how are you?’ shows itself as an ethical question that opens up a relational space that calls forth a response. It is a way to understand the situated moments in which we are already that enables us to act respectfully. Our ethical frameworks assist us in trying to decide what is the right thing to do given a set of circumstances. Yet there is a prior step that already calls us to ethical attention: this is when we ask ‘how are you?’, which transforms a seemingly small interaction into an ethical moment. ‘How are you?’ is a question that turns us back to who we are as health care professionals and calls us to be more deeply attentive to the moment. When we sincerely ask ‘how are you?’ we enact our ethical commitments to one another.

Cameron, Miriam E. Professional boundaries in nursing. Journal of Professional Nursing 1997 May-June; 13(3): 142. NRCBL: 8.1; 7.1; 4.1.3.

Ab stract: Cur rently, the com mon the o ret i cal mod els of pre -ferred decision-making relationships do not cor re spond well with clinical experience. This interview study of congestive heart failure (CHF) patients documents the variety of patient preferences for decision-making, and the necessity for attention to family involvement. In addition, these findings illustrate the confusion as to the designation of surrogate decision-makers and physicians in charge. We conclude that no single model of physician-patient decision-making should be preferred, and that physicians should first ask patients how they want medical information and decision-making to be handled.


Cronqvist, Agneta; Theorell, Töres; Burns, Tom; Lützén, Kim. Caring about — caring for: moral obligations and work responsibilities in intensive care nursing. Nursing Ethics 2004 January; 11(1): 63-76. NRCBL: 8.1; 4.1.3. SC: em. Abstract: The aim of this study was to analyse experiences of moral concerns in intensive care nursing. The theoretical perspective of the study is based on relational ethics, also referred to as ethics of care. The participants were 36 intensive care nurses from 10 general, neonatal and thoracic intensive care units. The structural characteristics of the units were similar: a high working pace, advanced technology, budget restrictions, recent reorganization, and shortage of experienced nurses. The data consisted of the participants’ examples of ethical situations they had experienced in their intensive care unit. A qualitative content analysis identified five themes: believing in a good death; knowing the course of events; feelings of distress; reasoning about physicians’ ‘doings’ and tensions in expressing moral awareness. A main theme was formulated as caring about—caring for: moral obligations and work responsibilities. Moral obligations and work responsibilities are assumed to be complementary dimensions in nursing, yet they were found not to be in balance for intensive care nurses. In conclusion there is a need to support nurses in difficult intensive care situations, for example, by mentoring, as a step towards developing moral action knowledge in the context of intensive care nursing.


Epstein, Ronald M.; Alper, Brian S.; Quill, Timothy E. Communicating evidence for participatory decision making. JAMA: The Journal of the American Medical Association 2004 May 19; 291(19): 2359-2366. NRCBL: 8.1; 9.8. Abstract: CONTEXT: Informed patients are more likely to actively participate in their care, make wiser decisions, come to a common understanding with their physicians, and adhere more fully to treatment; however, currently there are no evidence-based guidelines for discussing clinical evidence with...
patients in the process of making medical decisions. OBJECTIVE: To identify ways to communicate evidence that improve patient understanding, involvement in decisions, and outcomes. DATA SOURCES AND STUDY SELECTION: Systematic review of MEDLINE for the period 1966-2003 and review of reference lists of retrieved articles to identify original research dealing with communication between clinicians and patients and directly addressing methods of presenting clinical evidence to patients. DATA EXTRACTION: Two investigators and a research assistant screened 367 abstracts and 2 investigators reviewed 51 full-text articles, yielding 8 potentially relevant articles. DATA SYNTHESIS: Methods for communicating clinical evidence to patients include nonquantitative general terms, numerical translation of clinical evidence, graphical representations, and decision aids. Focus-group data suggest presenting options and/or equipoise before asking patients about preferred decision-making roles or formats for presenting details. Relative risk reductions may be misleading; absolute risk is preferred. Order of information presented and time-frame of outcomes can bias patient understanding. Limited evidence supports use of human stick figure graphics or faces for single probabilities and vertical bar graphs for comparative information. Less-educated and older patients preferred proportions to percentages and did not appreciate confidence intervals. Studies of decision aids rarely addressed patient-physician communication directly. No studies addressed clinical outcomes of discussions of clinical evidence. CONCLUSIONS: There is a paucity of evidence to guide how physicians can most effectively share clinical evidence with patients facing decisions; however, basing our recommendations largely on related studies and expert opinion, we describe means of accomplishing 5 communication tasks to address in framing and communicating clinical evidence: understanding the patient’s (and family members’) experience and expectations; building partnership; providing evidence, including a balanced discussion of uncertainties; presenting recommendations informed by clinical judgment and patient preferences; and checking for understanding and agreement.


Hall, Mark A. Law, medicine, and trust. Journal of Nursing Law 2003 May; 9(1): 33-84. NRCBL: 8.1; 8.2; 8.4; 4.1.2; 7.1; 1.3.8. SC: le.


Hasegawa, Thomas K., Jr.; Matthews, Merrill, Jr.; Rankin, K. Vendrell; Pollex, Sarah S. “Doc, if you can’t stop smoking, why should I?” Response to ethical dilemma #45. *Texas Dental Journal* 2003 October; 120(10): 991-993. NRCBL: 8.1; 8.3.1; 8.3.4; 9.5.9.


Howe, Edmund G. Death-defying empathy. *Journal of Clinical Ethics* 2003 Winter; 14(4): 233-245. NRCBL: 8.1; 8.3.4; 20.3.2; 9.6; 9.5.3; 8.2.


Jordens, Christopher F.C.; Little, Miles. “In this scenario, I do this, for these reasons”: narrative, genre and ethical reasoning in the clinic. *Social Science and Medicine* 2004 May; 58(9): 1635-1645. NRCBL: 8.1; 4.1.2. SC: em.


Abstract: BACKGROUND: Nearly half of all medical visits are to specialist physicians, yet little is known about patients’ outpatient experiences with specialists or how patients’ characteristics and experiences are related to trust in specialist physicians. METHODS: We surveyed patients who had a new patient visit with a cardiologist, neurologist, nephrologist, gastroenterologist, or rheumatologist practicing in hospital-based practices (response rate, 73%; N = 417) and inquired about their experiences with care and trust in the specialist physician. We used multivariable models to assess associations of patients’ characteristics and experiences with trust. RESULTS: Most patients reported good experiences, and 79% reported complete confidence and trust in the specialist. Black patients were less trusting than white patients (risk ratio [RR], 0.5; 95% confidence interval [CI], 0.2-0.8). Patients were more trusting if they reported that the consultant listened (RR, 1.8; 95% CI, 1.0-2.5), received as much information as they wanted (RR, 1.6; 95% CI, 1.1-1.9), were told what to do if problems or symptoms continued, got worse, or returned (RR, 1.4; 95% CI, 1.2-1.5), were involved in decisions as much as they wanted (RR, 1.5; 95% CI, 1.2-1.8), and spent as much time as they wanted with the specialist (RR, 1.8; 95% CI, 1.3-2.2). CONCLUSIONS: Patients reported high levels of trust in specialist physicians after an initial visit. Several specific experiences were associated with higher trust, suggesting that efforts to improve patient-physician interactions may be successful at achieving trust. Such efforts should especially aim to optimize physicians’ interactions with black patients, who were less trusting of specialist physicians.


Kvale, Gerd; Milgrom, Peter; Getz, Tracy; Weinstein, Philip; Johnsen, Tom Backer. Beliefs about professional ethics, dentist-patient communication, control and trust among fearful dental patients: the factor structure of the revised Dental Beliefs Survey. *Acta Odontologica*

Lacroix, Marc; Mintzes, Barbara; Bassett, Kenneth L.; Barer, Morris L. Direct-to-consumer advertising [letter and reply], CMAJ/JAMC: Canadian Medical Association Journal 2004 March 2; 170(5): 770-771. NRCBL: 8.1; 9.7; 9.3.1.


Levine, Joel S. Trust: can we create the time? [editorial]. Archives of Internal Medicine 2004 May 10; 164(9): 930-932. NRCBL: 8.1; 9.5.4.


Little, Paul; Dorward, Martina; Warner, Greg; Stephens, Katharine; Senior, Jane; Moore, Michael. Importance of patient pressure and perceived pressure and perceived medical need for investigations, referral, and prescribing in primary care: nested observational study. BMJ: British Medical Journal 2004 February 21; 328(7437): 444-446. NRCBL: 8.1; 9.6; 9.7.

Abstract: OBJECTIVE: To assess how pressures from patients on doctors in the consultation contribute to referral and investigation. DESIGN: Observational study nested within a randomised controlled trial. SETTING: Five general practices in three settings in the United Kingdom. PARTICIPANTS: 847 consecutive patients, aged 16-80 years. MAIN OUTCOMES MEASURES: Patient preferences and doctors’ perception of patient pressure and medical need. RESULTS: Perceived medical need was the strongest independent predictor of all behaviours and confounded all other predictors. The doctors thought, however, there was no or only a slight indication for medical need among a significant minority of those who were examined (89/580, 15%), received a prescription (74/394, 19%), or were referred (27/125, 22%) and almost half of those investigated (99/216, 46%). After controlling for patient preference, medical need, and clustering by doctor, doctors’ perceptions of patient pressure were strongly associated with prescribing (adjusted odds ratio 2.87, 95% confidence interval 1.16 to 7.08) and even more strongly associated with examination (4.38, 1.24 to 15.5), referral (10.72, 2.08 to 55.3), and investigation (3.18, 1.31 to 7.70). In all cases, doctors’ perception of patient pressure was a stronger predictor than patients’ preferences. Controlling for randomisation group, mean consultation time, or patient variables did not alter estimates or inferences. CONCLUSIONS: Doctors’ behaviour in the consultation is most strongly associated with perceived medical need of the patient, which strongly confounds other predictors. However, a significant minority of examining, prescribing, and referral, and almost half of investigations, are still thought by the doctor to be slightly needed or not needed at all, and perceived patient pressure is a strong independent predictor of all doctor behaviours. To limit unnecessary resource use and iatrogenesis, when management decisions are not thought to be medically needed, doctors need to directly ask patients about their expectations.


Luu, Nghe S. Dental students with hepatitis B: issues to be considered when defining policies. Journal of Dental Education 2004 March; 68(3): 306-315. NRCBL: 8.1; 4.1.1; 8.2. Identifiers: Canada.


Matiti, Milika Ruth; Torey, Gillian. Perceptual adjustment levels: patients’ perception of their dignity in the hospital setting. International Journal of Nursing Studies 2004 September; 41(7): 735-744. NRCBL: 8.1; 4.1.3; 4.4; 7.1. SC: em.


Meets Critics: Jodi Halpern’s From Detached Concern to Empathy, American Society of Bioethics and Humanities 2002 annual meeting.


Murphy, William M. Ethical issues in anatomic pathology — are we going the way of the financial sector? [editorial]. American Journal of Surgical Pathology 2003 March; 27(3): 392-395. NRCBL: 8.1; 7.1; 9.3.1.


Oppenheimer, Steven. Confronting child abuse. Journal of Halacha and Contemporary Society 2002 Fall; (44): 31-50. NRCBL: 8.1; 9.5.7; 1.2; 10.


Ozuna, Judy. To tell or not to tell: ethical dilemmas in people with epilepsy who drive. Clinical Nursing Practice in Epilepsy 1998; 5(1): 7-10. NRCBL: 8.1; 8.4; 9.1.


Petitfor, Jean; Crozier, Sharon; Chew, Judy. Recovered memories: ethical guidelines to support professionals. Journal of Child Sexual Abuse 2001; 10(2): 1-15. NRCBL: 8.1; 4.1.1; 9.5.7; 10.


Provis, Chris; Stack, Sue. Caring work, personal obligation and collective responsibility. Nursing Ethics 2004 January; 11(1): 5-14. NRCBL: 8.1; 4.1.1; 4.1.3; 9.4; 9.5.2. Abstract: Studies of workers in health care and the care of older people disclose tensions that emerge partly from their conflicting obligations. They incur some obligations from the personal relationships they have with clients, but these can be at odds with organizational demands and resource constraints. One implication is the need for policies to recognize the importance of allowing workers some discretion in decision making. Another implication may be that sometimes care workers can meet their obligations to clients only by taking collective action.


Santalucia, Carol; Michota, Franklin A., Jr. When and how is it appropriate to terminate the physician-patient re-
In particular, the function of imagination in hope is discussed in depth. Through an examination of the relationship between hope and vulnerability, I demonstrate how adequately describing hope can broaden the normative inquiry into the role of hope in healthcare. Three ways in which persons with hope can be vulnerable are illustrated, and the challenge of how healthcare providers can attend in moral ways to the hopes of patients is identified.

Sorlie, Venke; Larsson Kihlgren, Annica; Kihlgren, Mona. Meeting ethical challenges in acute care work as narrated by enrolled nurses. *Nursing Ethics* 2004 March; 11(2): 179-188. NRCBL: 8.1; 7.1; 9.5.1. SC: em.

Abstract: Five enrolled nurses (ENs) were interviewed as part of a comprehensive investigation into the narratives of registered nurses, ENs and patients about their experiences in an acute care ward. The ward opened in 1997 and provides patient care for a period of up to three days, during which time a decision has to be made regarding further care elsewhere or a return home. The ENs were interviewed concerning their experience of being in ethically difficult care situations and of acute care work. The method of phenomenological-hermeneutic interpretation inspired by the French philosopher Paul Ricoeur was used. The most prominent feature was the focus on relationships, as expressed in concern for society’s and administrators’ responsibility for health care and the care of older people. Other themes focus on how nurse managers respond to the ENs’ work as well as their relationships with fellow ENs, in both work situations and shared social and sports activities. Their reflections seem to show an expectation of care as expressed in their lived experiences and their desire for a particular level and quality of care for their own family members. A lack of time could lead to a bad conscience over the ‘little bit extra’ being omitted. This lack of time could also lead to tiredness and even burnout, but the system did not allow for more time.

Sorlie, Venke; Lindseth, Anders; Forde, Reidun; Norberg, Astrid. The meaning of being in ethically difficult care situations in pediatrics as narrated by male registered nurses. *Journal of Pediatric Nursing* 2003 October; 18(5): 350-357. NRCBL: 8.1; 9.5.7; 20.5.2; 21.1.


Abstract: OBJECTIVES: Evidence based patient choice seems based on a strong liberal individualist interpretation of patient autonomy; however, not all patients are in favour of such an interpretation. The authors wished to assess whether ideals of autonomy in clinical practice are more in accordance with alternative concepts of autonomy from the ethics literature. This paper describes the development of a questionnaire to assess such concepts of autonomy. METHODS: A questionnaire, based on six moral concepts from the ethics literature, was sent to aneurysm patients and their surgeons. The structure of the questionnaire was assessed by factor analysis, and item reduction was based on reliability. RESULTS: Ninety six patients and 58 surgeons participated. The questionnaire consisted of four scales. Two of the scales reflected the paternalistic and consumerist poles of the liberal individualist model, one scale reflected concepts of Socratic autonomy and of procedural independence, and the fourth scale reflected ideals of risk disclosure. DISCUSSION: The Ideal Patient Autonomy Scale is a 14


**Tzeng, Huey-Ming.** Nurses’ professional care obligation and their attitudes towards SARS infection control measures in Taiwan during and after the 2003 epidemic. *Nursing Ethics* 2004 May; 11(3): 277-289. NRCBL: 8.1; 9.1; 9.5.1. SC: em.

Abstract: This study investigated the relationship between hospital nurses’ professional care obligation, their attitudes towards SARS infection control measures, whether they had ever cared for SARS patients, their current health status, selected demographic characteristics, and the time frame of the data collection (from May 6 to May 12 2003 during the SARS epidemic, and from June 17 to June 24 2003 after the SARS epidemic). The study defines 172 nurses’ willingness to provide care for SARS patients as a professional obligation regardless of the nature of the disease. A conceptual model was developed and tested using ordinal logistic regression modelling. The findings showed that nurses’ levels of agreement with general SARS infection control measures and the lack of necessity for quarantining health care workers who provided care for SARS patients were statistically significant predictors of the nurses’ fulfilling of their professional care obligation. Suggestions and study limitations are discussed.

**van de Mortel, Thea F.** Registered and enrolled nurses’ knowledge of hepatitis C and attitudes towards patients with hepatitis C. *Contemporary Nurse* 2003 December-February; 16(1-2): 133-144. NRCBL: 8.1; 9.5.1; 16.3. SC: em.


Abstract: Enhancing patient choice is a central theme of medical ethics and law. Informed consent is the legal process used to promote patient autonomy; shared decision making is a widely promoted ethical approach. These processes may most usefully be seen as distinct in clinically and ethically important respects. The approach outlined in this article uses a model that arrays all medical decisions along 2 axes: risk and certainty. At the extremes of these continua, 4 decision types are produced, each of which constrains the principal actors in predictable ways. Shared decision making is most appropriate in situations of uncertainty, in which 2 or more clinically reasonable alternatives exist. When there is only 1 realistic choice, patient and physician may gather and exchange information; however, the patient cannot be empowered to make choices that do not exist. In contrast, informed consent does not require the presence of clinical choice; it is appropriate for all decisions of significant risk, even if there is only one option. When a clinical decision contains both risk and uncertainty, shared decision making and informed consent are both appropriate. For decisions of lower risk, consent should still be present, but it can be simple rather than informed. Clinicians may use this model as a guide to their own interactions with patients. In the continuing effort to provide patients with appropriate decisional authority over their own medical choices, shared decision making, informed consent, and simple consent each has a distinct role to play.

NRCBL: National Reference Center for Bioethics Literature Classification Scheme. See inside front cover for terms.

Abstract: BACKGROUND: The experimental method to acquire knowledge about efficacy and efficiency of medical procedures is well established in evidence-based medicine. A method to attain evidence about the significance of diseases and interventions from the patients’ perspectives taking into account their right to self-determination about their lives and bodies has however not been sufficiently characterized. DESIGN: Identification of a method to acquire evidence about the clinical significance of disease and therapeutic options from the patients’ perspectives. ARGUMENTS: Communication between patient and physician is analyzed as the method to attain evidence about what is at stake for individual patients in disease and therapy. It is the method that enables physicians to directly take into account patients’ disease experiences and their aims regarding treatments. These patients’ perspectives in turn determine the clinical significance of diagnoses and therapeutic options, if patient-autonomy is taken seriously. CONCLUSIONS: A full account of evidence-based medicine needs to include experimentation and communication between physician and patient as equally important methods to attain evidence necessary to practice patient-oriented medicine. The communicative method is especially important for primary physicians as they direct patients within the medical system to have their medical problems most effectively and efficiently addressed.


Wright, Emma Burkitt; Holcombe, Christopher; Salmon, Peter. Doctors’ communication of trust, care, and respect in breast cancer: qualitative study. *BMJ: British Medical Journal* 2004 April 10; 328(7444): 864-867. NRCBL: 8.1; 9.5.5; 8.2. SC: em.

Wynia, Matthew K.; VanGeest, Jonathan B.; Cummins, Deborah S.; Wilson, Ira B. Do physicians not offer useful services because of coverage restrictions? *Health Affairs* 2003 July-August; 22(4): 190-197. NRCBL: 8.1; 7.1; 8.2; 9.3.1. SC: em.

PROFESSIONAL PROFESSIONAL RELATIONSHIP


Allman, Richard L. The relationship between physicians and the pharmaceutical industry: ethical problems with the every-day conflict of interest. *HEC (Healthcare Ethics Committee) Forum* 2003 June; 15(2): 155-170. NRCBL: 7.3; 9.7; 7.2; 4.1.2; 1.3.1.


Council of Emergency Medicine Residency Directors [CORD] Board of Directors; Keim, Sam; Perina, Debra G. Council of Emergency Medicine Residency Directors position on interactions between emergency medicine residencies and the pharmaceutical industry. *Academic Emergency Medicine* 2004 January; 11(1): 78. NRCBL: 7.3; 1.3.2; 7.2; 9.7.


Diamond, Eugene F. Conflicts of interest in medical ethics [editorial]. *Ethics and Medicine* 2004 Fall; 20(3): 133-139. NRCBL: 7.3; 4.1.2; 4.4; 12.5.1; 10; 1.3.7.


Endocrine Society. Ethics Advisory Committee; Komesaroff, Paul A.; Bach, Mark A.; Danoff, Ann; Grumbach, Melvin M.; Kaplan, Selna; Lakoski, Jona M.; Leitman, Dale; Mellon, Synthia; Underwood, Louis E.; Leuen, Sarah. The Endocrine Society Ethics Advisory Committee: ethical aspects of conflicts of interests, October 2003. *Endocrinology* 2004 June; 145(6): 3032-3041. NRCBL: 7.3; 1.3.2; 1.3.9; 5.3; 9.3.1; 9.6; 9.7; 18.2.


Ferrand, Edouard; Lemaire, François; Regnier, Bernard; Kuteifan, Khalidoune; Badet, Michel; Asfar, Pierre; Jaber, Samir; Chagnon, Jean-Luc; Renault, Anne; Robert, René; Pochard, Frédéric; Herve, Christian; Brun-Buisson, Christian; Duvaldestin, Philippe. Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. *American Journal of Respiratory and Critical Care Medicine* 2003 May 15; 167(10): 1310-1315. NRCBL: 7.3; 20.5.1; 9.4; 7.1.


Hasegawa, Guy R. Full disclosure [editorial]. American Journal of Health-System Pharmacy 2002 October 1; 59(19): 1835. NRCBL: 7.3; 1.3.2; 9.7; 1.3.7.

Heaphy, David P.; Marrow, Victor B. Industry funding for continuing medical education: is it ethical? Archives of Ophthalmology 2004 May; 122(5): 771-773. NRCBL: 7.3; 7.2; 5.3; 9.7.


Jones, James W.; McCullough, Laurence B.; Richman, Bruce W. Ethics of serving as a plaintiff's expert medical witness. Surgery 2004 July; 136(1): 100-102. NRCBL: 7.3; 1.3.5; 8.5. SC: cs.


Keim, Samuel M.; Mays, Mary Z.; Grant, David. Interactions between emergency medicine programs and the pharmaceutical industry. Academic Emergency Medicine 2004 January; 11(1): 19-26. NRCBL: 7.3; 1.3.2; 7.2; 9.7. SC: em.


Moore, Nancy J. Regulating self-referrals and other physician conflicts of interest. HEC (Healthcare Ethics Committee) Forum 2003 June; 15(2): 134-154. NRCBL: 7.3; 1.3.2; 9.3.1; 1.3.5; 4.1.2; 1.3.1.


Moskowitz, Elliott M. Orthodontic “second opinions”: what they sometimes are, what they should be [editorial]. Angle Orthodontist 2004 February; 74(1): iv. NRCBL: 7.3; 4.1.1.


Packer, Samuel; Parke, David W., II. Ethical concerns in industry support of continuing medical education: the downside. Archives of Ophthalmology 2004 May; 122(5): 773-776. NRCBL: 7.3; 7.2; 5.3; 9.7.


Solyom, Antal E. Ethical challenges to the integrity of physicians: financial conflicts of interest in clinical research. Accountability in Research 2004 April-June; 11(2): 119-139. NRCBL: 7.3; 18.2; 5.3. SC: an.
PSYCHOPHARMACOLOGY

See also Behavior Control; Electroconvulsive Therapy; Care for Specific Groups/ Mentally Disabled; Involuntary Commitment; Mental Health Therapies; Psychotherapy


Daugherty, Kacie McCoy. “Synthetic sanity”: the ethics and legality of using psychotropic medications to render death row inmates competent for execution. Journal of Contemorary Health Law and Policy 2001 Summer; 17(2): 715-735. NRCBL: 17.4; 20.6; 8.3.4; 17.8; 4.3. SC: le.


Hall, Wayne. Feeling ‘better than well’ [opinion]. EMBO Reports 2004; 5(12); 1105-1109. NRCBL: 17.4; 4.5.

Irwin, Matt. Treatment of schizophrenia without neuroleptics: psychosocial interventions versus neuroleptic treatment. Ethical Human Psychology and Psychiatry 2004 Summer; 6(2); 99-110. NRCBL: 17.4; 7.1; 17.3. SC: em.


Miller, Greg. Learning to forget. Science 2004 April 2; 304(5667): 34-36. NRCBL: 17.4; 2.4; 9.7; 5.1.


Sparks, Jacqueline A.; Duncan, Barry L. The ethics and science of medicating children. Ethical Human Psychology and Psychiatry 2004 Spring; 6(1): 25-39. NRCBL: 17.4; 9.5.7; 17.3; 9.7; 1.3.9. SC: an.


PSYCHOTHERAPY

See also BEHAVIOR CONTROL; ELECTROCONVULSIVE THERAPY; CARE FOR SPECIFIC GROUPS/ MENTALLY DISABLED; INVOLUNTARY COMMITMENT; MENTAL HEALTH THERAPIES; PSYCHOPHARMACOLOGY


Fisher, Craig D. Ethical issues in therapy: therapist self-disclosure of sexual feelings. Ethics and Behavior 2004; 14(2): 105-121. NRCBL: 17.2; 10; 8.3.1; 6; 7.1. SC: em; cs.


McNeil-Haber, Fawn M. Ethical considerations in the use of nonerotic touch in psychotherapy with children. Ethics and Behavior 2004; 14(2): 123-140. NRCBL: 17.2; 10; 9.5.7; 8.1.


PUBLIC HEALTH

See also AIDS; CARE FOR SPECIFIC GROUPS; HEALTH CARE; OCCUPATIONAL HEALTH


NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.


Kessel, Anthony S. Public health ethics: teaching survey and critical review. *Social Science and Medicine* 2003 April; 56(7): 1439-1445. NRCBL: 9.1; 7.2; 2.3.


Lübbe, Andreas. No public health without public death — ethical considerations. *Supportive Care in Cancer* 2003 August; 11(8): 497-500. NRCBL: 9.1; 9.4; 20.3.1; 20.1; 20.5.1.

MacQueen, Graeme; Nagy, Thomas; Santa Barbara, Joanna; Raichle, Claudia. 'Iraq water treatment vulnerabilities': a challenge to public health ethics. Medicine, Conflict and Survival 2004 April-June; 20(2): 109-119. NRCBL: 9.1; 21.2; 2.1; 1.3.6.


Middaugh, John P.; Hodge, James G.; Cartter, Matthew L.; Fairchild, Amy L.; Bayer, Ronald. The ethics of public health surveillance [letter and reply]. Science 2004 April 30; 304(5671): 681-684. NRCBL: 9.1; 7.1; 9.6; 8.4; 5.3.


Abstract: In September 2003, the Association of Schools of Public Health administered an online survey to representatives of all 33 accredited US schools of public health. The survey assessed the extent to which the schools were offering curriculum content in the 8 areas recommended by the Institute of Medicine: communication, community-based participatory research, cultural competence, ethics, genomics, global health, informatics, and law/policy. Findings indicated that, for the most part, schools of public health are offering content in these areas through many approaches and have incorporated various aspects of a broad-based ecological approach to public health education and training. The findings also suggested the possible need for greater content in genomics, informatics, community-based participatory research, and cultural competence.


Abstract: The precautionary principle brings a special challenge to the practice of evidence-based public health decision-making, suggesting changes in the interpretative methods of public health used to identify causes of disease. In this paper, precautionary changes to these methods are examined: including discounting contrary evidence, reducing the number of causal criteria, weakening the rules of evidence assigned to the criteria, and altering thresholds for statistical significance. All such changes reflect the precautionary goal of earlier primary preventive intervention, i.e. acting on insufficient evidence, the least amount, or minimum level, of evidence for causation. Evaluating the impact of these changes will be difficult without a careful study of how well the current methods of causal inference work, their theoretical foundations, and the ethical implications of their applications. That research program will be most productive if it is jointly developed by public health professionals trained in the ethics and philosophy and by
bioethicists and philosophers trained in the theories, methods, and practice of public health.


PUBLISHING See JOURNALISM AND PUBLISHING

QUALITY AND VALUE OF LIFE


Anand, Paul. QALYS and the integration of claims in health-care rationing. Health Care Analysis: An International Journal of Health Care Philosophy and Policy 1999; 7(3): 239-253. NRCBL: 4.4; 1.1; 13.1; 9.2; 9.3.1; 9.4. Identifiers: Great Britain. Abstract: The paper argues against the polarizing of the health economics literature into pro- and anti-QALY camps. In particular, we suggest that a crucial distinction should be made between the QALY measure as a metric of health, and QALY maximization as an applied social choice rule. We argue against the rule but for the measure and that the appropriate conceptualization of health-care rationing decisions should see the main task as the integration of competing and possibly incommensurable normative claim types. We identify the main types as consequences, rights, social contracts, individual votes and community values and note situations in which the contribution of each claim type is limited. We go on to show that the integration of (at least some of) these claim types can be formalized within the mathematical framework provided by non-linear programming.


Dilcher, Amy J. Damned if they do, damned if they don’t: the need for a comprehensive public policy to address the inadequate management of pain. Annals of Health Law 2004 Winter; 13(1): 81-144. NRCBL: 4.4; 9.8; 9.5.9. SC: le.


Edgar, Andrew. A response to Nordenfelt’s “The Varieties of Dignity”. Health Care Analysis: An International
SECTION I: QUALITY AND VALUE OF LIFE


Gallagher, Ann. Dignity and respect for dignity — two key health professional values: implications for nursing practice. Nursing Ethics 2004 November; 11(6): 587-599. NRCBL: 4.4; 4.1.3. Abstract: It is argued that dignity can be considered both subjectively, taking into account individual differences and idiosyncrasies, and objectively, as the foundation of human rights. Dignity can and should also be explored as both an other-regarding and a self-regarding value: respect for the dignity of others and respect for one’s own personal and professional dignity. These two values appear to be inextricably linked. Aristotle’s doctrine of the mean enables nurses to reflect on the appropriate degree of respect for the dignity of others and of respect for themselves. To develop an understanding of the rationale for and the significance and implications of dignity in health care practice, a view of human nature is proposed that implies vulnerability and fallibility, and that urges that an ethic of aspiration is embraced. Anonymized vignettes are included to illustrate points about the everyday nature of dignity.


Koch, Tom. The difference that difference makes: bioethics and the challenge of “disability”. Journal of Medicine and Philosophy 2004 December; 29(6): 697-716. NRCBL: 4.4; 2.1; 15.5; 20.5.2. SC: an. Identifiers: Harriet McBryde Johnson; Peter Singer. Abstract: Two rival paradigms permeate bioethics. One generally favors eugenics, euthanasia, assisted suicide and other methods for those with severely restricting physical and cognitive attributes. The other typically opposes these and favors instead ample support for “persons of difference” and their caring families or loved ones. In an attempt to understand the relation between these two paradigms, this article analyzes a publicly reported debate between proponents of both paradigms, bioethicist Peter Singer and lawyer Harriet McBryde Johnson. At issue, the article concludes, are two distinct axiomatic sets of values resulting in not simply different styles of rhetoric but different vocabularies, in effect two different languages of ethics.


Lee, Patrick. The pro-life argument from substantial identity: a defence. Bioethics 2004 June; 18(3): 249-263. NRCBL: 4.4; 12.3. SC: an. Abstract: This article defends the following argument: what makes you and I valuable so that it is wrong to kill us now is what we are (essentially). But we are essentially physical organisms, who, embryology reveals, came to be at conception/fertilisation. I reply to the objection to this argument (as found in Dean Stretton, Judith Thomson, and Jeffrey Reiman), which holds that we came to be at one time, but became valuable as a subject of rights only some time later, in virtue of an acquired characteristic. I argue against this position that the difference between a basic, natural capacity and some degree of development of such a capacity is a mere difference in degree, that this position logically implies the denial of equal personal dignity, and that the selection of the required degree of development of a capacity is necessarily arbitrary.


SECTION I

QUALITY AND VALUE OF LIFE


Abstract: It is common to talk of wise physicians, but not so common to talk of wise patients. “Patient” is a word derived from the Latin patior—to suffer,—but also “to let be.” Suffering has been the universal lot of humanity, and medicine rightly tries to relieve suffering. Medical progress, like all technological progress, leads us more and more to hope that we can control our fate. However, we do well to ask whether our attempts to control our fate are wise. Wisdom played a major role in the philosophy of the ancient Stoics, and so I propose putting these questions into the context of a new stoicism. For the Stoic, happiness consists in living in accord with nature. Stoics are sometimes portrayed as apathetic fatalists, silently accepting whatever misfortune might come their way, but this is a misunderstanding. The Stoic sage, like the common person, wants to preserve life and health. The difference is that the sage’s wisdom brings knowledge about what actions are appropriate in the face of suffering. The sage sees suffering not as something that demands immediate control, but as something that might reasonably direct actions. Suffering brings turmoil to the common patient, who will take any possible steps to end the suffering. The wise patient possesses the knowledge that enables a correct assessment of the options in the face of the reality that we ultimately do not control our own fate.


Abstract: In “The Pro-Life Argument from Substantial Identity: A Defence”, Patrick Kee argues that the right to life is an essential property of those that possess it. On his view, the right arises from one’s ‘basic’ or ‘natural’ capacity for higher mental functions: since human organisms have this capacity essentially, they have a right to life essentially. Kee criticises an alternative view, on which the right to life arises from one’s ‘developed’ capacity for higher mental functions (or development of some other accidental property). I argue that his criticisms of this alternative view are misguided or self-defeating, and that there are good reasons to hold we have a right to life accidentally rather than essentially.


RATIONAL OF HEALTH CARE See RESOURCE ALLOCATION

RECOMBINANT DNA RESEARCH

Enserink, Martin. Activist throws a bright light on Institutes’ biosafety panels [news]. Science 2004 August 6; 305(5685): 768-769. NRCBL: 15.7; 21.3; 1.3.9.


Satava, Richard M. Biomedical, ethical, and moral issues being forced by advanced medical technologies. Proceedings of the American Philosophical Society 2003 September; 147(3): 246-258. NRCBL: 15.7; 5.2; 1.1; 5.3.


SECTION I  REPRODUCTIVE TECHNOLOGIES

Wynne, Brian. Expert discourses of risk and ethics on genetically manipulated organisms: the weaving of public alienation. *Notizie di Politeia* 2001; 17(62): 51-76. NRCBL: 15.7; 1.1; 5.2; 15.1; 1.3.11; 5.3; 21.1. SC: an.

**REFUSAL OF TREATMENT** See TREATMENT REFUSAL

**REGULATION** See HUMAN EXPERIMENTATION/REGULATION

**RELIGIOUS ASPECTS** See ABORTION/MORAL AND RELIGIOUS ASPECTS; BIOETHICS AND MEDICAL ETHICS/RELIGIOUS PERSPECTIVES; EUTHANASIA AND ALLOWING TO DIE/RELIGIOUS ASPECTS

**REPRODUCTIVE TECHNOLOGIES**

See also ARTIFICIAL INSEMINATION/SURROGATE MOTHERS; CLONING; IN VITRO FERTILIZATION; SEX DETERMINATION


Aksoy, S. Response to: a rational cure for pre-reproductive stress. *Journal of Medical Ethics* 2004 August; 30(4): 382-383. NRCBL: 14.1. Comments: comment on Journal of Medical Ethics 2004 August; 30(4): 377-378. Abstract: This response to “A rational cure for pre-reproductive stress syndrome” first suggests it exists, it is essential and prerequisite to everything good or bad, therefore it deserves to be protected and respected. Secondly, it argues that every life is worth living, even if it is worse than some other lives, if the only alternative is non-existence. Finally, it takes a critical view of and challenges Hayry’s suggestion that in a good clinical situation, the idea of the irrationality of having children could be a legitimate part of the guidance given, since it is not the counselor’s or doctor’s duty to advise a couple who wish to have children that it is irrational or even immoral to bring a child into life.


**Barnett, Stanley B.** Live scanning at ultrasound scientific conferences and the need for prudent policy. *Ultrasound in Medicine and Biology* 2003 August; 29(8): 1071-1076. NRCBL: 14.1; 9.5.5.


**Check, Erika.** Ethics council calls for probe into assisted reproduction [news]. *Nature* 2004 April 8; 428(6983): 590. NRCBL: 14.1; 2.4. Identifiers: President’s Council on Bioethics.


Dawson, Angus. The Human Fertilisation and Embryology Authority: evidence based policy formation in a contested context. Health Care Analysis: An International Journal of Health Care Philosophy and Policy 2004 March; 12(1): 1-6. NRCBL: 14.1; 5.3. SC: le. Abstract: This article briefly reviews the various papers contained in this volume. They were originally presented at a research workshop held at Keele University in the UK in February 2003. It is suggested that the different papers raise a series of related legal, social and ethical concerns and can be collectively seen to demonstrate the fact that policy formation in relation to reproductive matters is highly contested. It is concluded that ethical policy formation in this area needs to be based on actual evidence of harm rather than assumed harm and that this therefore entails more empirical research into reproductive matters.


Fielding, Dorothy; Handley, Sarah; Duquesno, Lindsay; Weaver, Sue; Lui, Steve. Motivation, attitudes and experience of donation: a follow-up of women donating eggs in assisted conception treatment. Journal of Commu-
trols. MAIN OUTCOME MEASURES: Very preterm birth, preterm birth, very low birth weight, low birth weight, small for gestational age, caesarean section, admission to neonatal intensive care unit, and perinatal mortality. RESULTS: For singletons, studies with matched controls indicated a relative risk of 3.27 (95% confidence interval 2.03 to 5.28) for very preterm (32 weeks) and 2.04 (1.80 to 2.32) for preterm (37 weeks) birth in pregnancies after assisted conception. Relative risks were 3.00 (2.07 to 4.36) for very low birth weight (1500 g), 1.70 (1.50 to 1.92) for low birth weight (2500 g), 1.40 (1.15 to 1.71) for small for gestational age, 1.54 (1.44 to 1.66) for caesarean section, 1.27 (1.16 to 1.40) for admission to a neonatal intensive care unit, and 1.68 (1.11 to 2.55) for perinatal mortality. Results of the non-matched studies were similar. In matched studies of twin gestations, relative risks were 0.95 (0.78 to 1.15) for very preterm birth, 1.07 (1.02 to 1.13) for preterm birth, 0.89 (0.74 to 1.07) for very low birth weight, 1.03 (0.99 to 1.08) for low birth weight, 1.27 (0.97 to 1.65) for small for gestational age, 1.21 (1.11 to 1.32) for caesarean section, 1.05 (1.01 to 1.09) for admission to a neonatal intensive care unit, and 0.58 (0.44 to 0.77) for perinatal mortality. The non-matched studies mostly showed similar trends. CONCLUSIONS: Singleton pregnancies from assisted reproduction have a significantly worse perinatal outcome than non-assisted singleton pregnancies, but this is less so for twin pregnancies. In twin pregnancies, perinatal mortality is about 40% lower after assisted compared with natural conception.


Holden, Constance. White House panel issues its final word on reproductive technology [news]. Science 2004 April 9; 304(5668): 188. NRCBL: 14.1; 14.5; 5.3; 2.4. SC: le.


Honke, Dina. Reproductive technologies and human experimentation: a Jewish perspective. Health Law in Canada 2001 May; 21(4): 103-106. NRCBL: 14.1; 1.2; 18.2; 14.4; 14.2; 14.6; 15.2; 18.5.4; 19.1. SC: le.


Kirkman, Maggie. Parents’ contributions to the narrative identity of offspring of donor-assisted conception. Social Science and Medicine 2003 December; 57(11): 2229-2242. NRCBL: 14.1; 9.5.5; 15.1.


Abstract: Technology is “unruly” because it operates in a social context where it is shaped by institutions, organisations and individuals in ways not envisaged when it was first developed. In the UK assisted reproductive technology has developed from strictly circumscribed beginnings as a treatment for infertility within the NHS, to a service which is more often offered by commercial clinics and purchased by clients who are not necessarily infertile. The article considers the process by which assisted reproductive technology has been created and developed, a process which is ideological rather than technical, and the social implications of its ever expanding use. In a society where the discourse around reproduction and family life, is one of choice and acceptance of diversity of life styles, the conditions are set for further “unruliness” supported by clinicians and commercial interests. The HFEA, public consultations and media coverage tend to subscribe to the way ethical issues are framed by those interested parties, an approach that favours increased liberalisation.


Luna, Florencia. Reproductive health and research ethics: hot issues in Argentina. CQ: Cambridge Quarterly of Healthcare Ethics 2004 Summer; 13(3): 267-274. NRCBL: 14.1; 18.6; 5.3; 1.2.


**REPRODUCTIVE TECHNOLOGIES**

**SECTION I**


Abstract: The Human Fertilisation & Embryology Authority (HFEA) is the UK’s statutory regulator of licensed assisted conception treatments. The past 10 years have, inevitably, drawn it further and deeper into this area of legal, moral and political controversy. It is opportune to consider how it has fared in the new climate of public accountability and critical scrutiny, and whether reform or revision of its role, mandate or operation may be called for. Through a close analysis of its published Annual Reports, it is possible to form a picture of a development of the HFEA which has not been consistent, coherent or comfortable.


Rigdon, Joan Indiana. To be, or not to be — the ethics of biotechnology — why we still lack a definitive national policy on cloning and assisted reproductive technologies. *Washington Lawyer* 2002 July-August; 18(11): 20-27. NRCBL: 14.1; 5.2; 1.3.5; 5.3.


Simpson, Bob. Ethical regulation and the new reproductive technologies in Sri Lanka: perspectives of ethics com-

SC (Subject Caption): an=analytical  cs=case studies  em=empirical  le=legal  po=popular  rv=review


**Westphal, Sylvia Pagan.** Dawn of a new kind of parenthood: the birth of one mouse shatters the notion that two mammals of the same sex can’t have healthy offspring. *New Scientist* 2004 April 24-30; 182(2444): 8-10. NRCBL: 14.1; 15.1; 10; 22.2.


**RESEARCH** See BEHAVIORAL RESEARCH; BIOMEDICAL RESEARCH; GENETIC RESEARCH; HUMAN EXPERIMENTATION; RECOMBINANT DNA RESEARCH

**RESEARCH ETHICS** See BIOMEDICAL RESEARCH/ RESEARCH ETHICS AND SCIENTIFIC MISCONDUCT

**RESEARCH ETHICS COMMITTEES** See HUMAN EXPERIMENTATION/ ETHICS COMMITTEES AND POLICY GUIDELINES

**RESOURCE ALLOCATION**

See also HEALTH CARE ECONOMICS; ORGAN AND TISSUE TRANSPLANTATION/ ALLOCATION


**Alexander, G Caleb; Werner, Rachel M.; Ubel, Peter A.** The costs of denying scarcity [opinion]. *Archives of Internal Medicine* 2004 March 22; 164(6): 593-596. NRCBL: 9.4; 7.1; 9.3.1.


**Bauer, Keith.** Distributive justice and rural healthcare: a case for e-health. *International Journal of Applied Philos-


Escher, Monica; Perneger, Thomas V.; Chevrolet, Jean-Claude. National questionnaire survey on what influences doctors’ decisions about admission to intensive care. BMJ: British Medical Journal 2004 August 21; 329(7463): 425-428. NRCBL: 9.4. SC: em. Abstract: OBJECTIVE: To determine what influences doctors’ decisions about admission of patients to intensive care. DESIGN: National questionnaire survey using eight clinical vignettes involving hypothetical patients. SETTING: Switzerland. PARTICIPANTS: 402 Swiss doctors specialising in intensive care. MAIN OUTCOME MEASURES: Rating of factors influencing decisions on admission and response to eight hypothetical clinical scenarios. RESULTS: Of 381 doctors agreeing to participate, 232 (61%) returned questionnaires. Most rated as important or very important the prognosis of the underlying disease (82%) and of the acute illness (81%) and the patients’ wishes (71%). Few considered important the socio-economic circumstances of the patient (2%), religious beliefs (3%), and emotional state (6%). In the vignettes, underlying disease (cancer versus non-cancerous disease) was not associated with admission to intensive care, but four other factors were: patients’ wishes (odds ratio 3.0, 95% confidence interval 2.0 to 4.6), “upbeat” personality (2.9, 1.9 to 4.4), younger age (1.5, 1.1 to 2.2), and a greater number of beds available in intensive care (1.8, 1.2 to 2.5). CONCLUSIONS: Doctors’ decisions to admit patients to intensive care are influenced by patients’ wishes and ethically problematic non-medical factors such as a patient’s personality or availability of beds. Patients with cancer are not discriminated against.


Hetemaa, Tiina; Keskimäki, Ilmo; Salomaa, Veikko; Mähönen, Markku; Manderbacka, Kristiina; Koskinen, Seppo. Socioeconomic inequities in invasive


**Hurst, Samia A.; Teagarden, J. Russell; Garrett, Elizabeth; Emanuel, Ezekiel J.** Conserving scarce resources: willingness of health insurance enrollees to choose cheaper options. *Journal of Law, Medicine and Ethics* 2004 Fall; 32(3): 496-499. NRCBL: 9.4; 9.3.1; 9.2.


**Jagai, Reshma; DeLANey, Thomas F.; Donelan, Karen; Tarbell, Nancy J.** Real-time rationing of scarce resources: the Northeast Proton Therapy Center experience. *Journal of Clinical Oncology* 2004 June 1; 22(11): 2246-2250. NRCBL: 9.4.


**Kahn, Jeffrey P.** Listening to the tin man [editorial]. *UNOS Update* 2001 August: 24. NRCBL: 9.4; 19.2; 18.1.


**Kapiriri, Lydia; Robbested, Bjarte; Norheim, Ole Frithjof.** The relationship between prevention of mother to child transmission of HIV and stakeholder decision making in Uganda: implications for health policy. *Health Policy* 2003 November; 66(2): 199-211. NRCBL: 9.4; 9.5.6; 21.1; 9.3.1; 9.5.5; 9.5.7. SC: em.


**Maynard, Alan; Bloor, Karen; Freemantle, Nick.** Challenges for the National Institute for Clinical Excellence. *BMJ: British Medical Journal* 2004 July 24; 329(7459): 227-229. NRCBL: 9.4; 9.3.1; 5.2; 1.3.1.

**McKie, John; Richardson, Jeff.** The rule of rescue. *Social Science and Medicine* 2003 June; 56(12): 2407-2419. NRCBL: 9.4; 1.1.
RESOURCE ALLOCATION


Abstract: Le Grand describes a situation where a drunk driver, who has medical insurance, is the cause of an accident in which he and a sober pedestrian, who has no medical insurance, are both equally and seriously injured. At the private hospital to which they are both taken, there is available emergency treatment for one of them only. Who should receive it? The issues raised by Le Grand’s example are shown to be more interesting, more complex and less cut-and-dried than Le Grand suggests and implies. In particular, it is not the case that, unequivocally, the drunkenness of the driver establishes that the pedestrian rather than he should be treated nor that, unequivocally, the driver’s possession of health insurance is morally irrelevant.

MOLINARI, VIC T; MCCOULLOUGH, LAURENCE B.; WORKMAN, RICHARD; COVERDALE, JOHN. Geriatric consent. Journal of Clinical Ethics 2004 Fall; 15(3): 261-268. NRCBL: 9.4; 9.5.2; 8.3.3.


Abstract: Implementing the new NHS and the 1997 NHS (Primary Care) Act will gradually extend cash-limiting into primary health care, especially general practice. UK policy-makers have avoided providing clear, unambiguous direction about how to ‘ration’ NHS resources. The ‘Child B’ case became an epitome of public debate about NHS rationing. Among many other decision-making processes which occurred, Cambridge and Huntingdon Health Authority applied an ethical code to this rationing decision. Using new data this paper analyses the rationing criteria NHS managers and clinicians used at local level in the Child B case; and the organisation structures which confronted them with such decisions. Primary Care Groups are likely to confront similar rationing decisions in respect of ‘gate-kept’ NHS services. However, such rationing processes are not so easily transposed to open-access services such as general practice. NHS rationing decisions, especially in PCGs, will require a much more specific ethical code than hitherto used.


Prior, Lindsay. Rationing through risk assessment in clinical genetics: all categories have wheels. Sociology of Health and Illness 2001 September; 23(5): 570-593. NRCBL: 9.4; 5.2; 15.1; 9.5.5; 7.1. SC: em.


Raithatha, Nick; Smith, Richard D. Paying for statins: should UK general practitioners be able to offer private prescriptions for statins to patients below 3% risk of heart disease? BMJ: British Medical Journal 2004 February 14; 328(7436): 400-402. NRCBL: 9.4; 9.3.1; 9.7; 21.1. Identifiers: United Kingdom.


Abstract: Despite the increasing focus on rationing, and rationing decisions in the NHS, little attention has been given to patient’s perceptions of rationing and the potential impact this might have on people’s use of services. Drawing on the qualitative findings of a study conducted in the North West of England which was concerned with the pattern and processes of primary care help seeking, this paper sets out to examine perceptions and experiences of rationing in primary care and the potential impact this has on people’s use of services. In relation to primary care services people had experienced rationing by deter-


Silveira, Maria J.; Rhodes, Lorna; Feudtner, Chris. Deciding how to decide: what processes do patients use when making medical decisions? *Journal of Clinical Ethics* 2004 Fall; 15(3): 269-281. NRCBL: 9.4; 8.3.1; 8.3.4.


Starfield, Barbara. Promoting equity in health through research and understanding. *Developing World Bioethics* 2004 May; 4(1): 76-95. NRCBL: 9.4; 4.2; 21.1. SC: an. Abstract: Developing strategies to reduce inequities in health requires an understanding of how inequities occur, determining the salient factors in their production, and deciding which ones are most amenable to change. The recognition of several principles regarding the manifestations and genesis of inequities can help to decide on strategies. In making decisions, it is important to consider whether the aim is to reduce disparities in the occurrence of ill health or to reduce disparities in the severity (including co-morbidity, disability, dysfunction and fatality) of ill health. Evidence shows that the major impact on equity of health services, particularly regarding their potential to reduce severity, is attributable to the strength of primary care resources and services in communities and countries. Virtually every influence on the genesis of inequities is determined by the political context in which policy is made. The issue of health services is not different in this regard from other types of strategies. There is no longer any doubt about the pervasive influence of social factors on health. Almost two centuries of descriptive research provides convincing evidence of associations between social structures and relationships and health status in all countries and in all societies; if there is anything new from recent research, it is that the association is not limited to differences between the lowest social strata and other social strata. Rather, the association is noted throughout the social spectrum. That is, there is a social gradient in health such that, for many if not most manifestations of ill health, the lower the social stratum, the worse the health. The challenge for the future is to understand why this is the case, to create a consensus that these inequalities are unnecessary and unacceptable, and to devise strategies that are both effective and possible. This paper will focus on the first of these aims, in a context that facilitates attention to the second and third aims.


Abstract: The issue of the allocation of resources in health care is here to stay. The goal of this study was to explore the views of physicians on several topics that have arisen in the debate on the allocation of scarce resources and to compare these with the views of policy makers. We asked physicians (oncologists, cardiologists, and nursing home physicians) and policy makers to participate in an interview about their practices and opinions concerning factors playing a role in decision making for patients in different age groups. Both physicians and policy makers recognised allocation decisions as part of their reality. One of the strong general opinions of both physicians and policy makers was the rejection of age discrimination. Making allocation decisions as such seemed to be regarded as a foreign entity to the practice of medicine. In spite of the reluctance to make allocation decisions, physicians sometimes do. This would seem to be only acceptable if it is justified in terms of the best interests of the patient from whom treatment is withheld.


Abstract: Kamm’s approach to patient selection qualifies the notion that fairness makes need for scarce, transplantable organs inversely proportional to age. She defines need as how much adequate conscious life a person will have had before death. Length of adequate conscious life correlates highly with age. If so, then younger persons are usually needier than older ones. Since Kamm allows for past periods of non-adequate conscious life, I argue that this correlation may be neither as close, nor as easy to apply, as she wants it to be. Fairness should require assessment of experiential content in determining how long one’s life has been adequately conscious. I argue that such assessments involve some of the goods of experience and quality of life judgements that Kamm thinks a reliance on adequate conscious life will avoid.


RESUSCITATION ORDERS See EU ThanASIA AND ALLOWING TO DIE

RIGHT TO DIE See ASSISTED SUICIDE; EU ThanASIA AND ALLOWING TO DIE

RIGHT TO HEALTH CARE


SECTION I

RIGHT TO HEALTH CARE


Abstract: Patient rights are universal values which we have to adopt. It is not so easy, however, to put such values and principles into effect. As approaches and attitudes differ from individual to individual, from society to society, and from country to country, a uniform application of these values is difficult. If we want to reach a general conclusion about the status of patient rights in the world as whole, we should examine the situation in individual countries. As far as Turkey is concerned, we can say that, although the idea of patient rights is accepted in principle, patient rights have yet to be adequately implemented.


Abstract: European health systems have experienced a “right-revolution” in the last 10 years’. The existence of a large number of policy trends and normative initiatives in European countries demonstrates a strong interest in patients’ rights. The increasing interest and involvement of the general public is also decisive and can favour further development and involvement by policy-makers and the legislators. Numerous measures exist to promote and enforce patients’ rights. It is now time for the anti-cancer associations to play an active role in this important event and to try to define a new mission for the benefit of the patients.


Abstract: OBJECTIVE: To determine whether access to cardiac procedures and drugs contributes to social and ethnic differences in coronary heart disease in a population setting. DESIGN: Prospective study with follow up over 15 years. Civil service employment grade was used as a measure of individual socioeconomic position. Need for cardiac care was determined by the presence of angina, myocardial infarction, and coronary risk factors. SETTING: 20 civil service departments originally located in London. PARTICIPANTS: 10,308 civil servants (3141 women; 560 South Asian) aged 35-55 years at baseline in 1985-8. MAIN OUTCOME MEASURES: Use of exercise electrocardiography, coronary angiography, and coronary revascularisation procedures and secondary prevention drugs. RESULTS: Inverse social gradients existed in incident coronary morbidity and mortality. South Asian participants also had higher rates than white participants. After adjustment for clinical need, social position showed no association with the use of cardiac procedures or secondary prevention drugs. For example, men in the low versus high employment grade had an age adjusted odds ratio for angiography of 1.87 (95% confidence interval 1.32 to 2.64), which decreased to 1.27 (0.83 to 1.94) on adjustment for clinical need. South Asians tended to be more likely to have cardiac procedures and to be taking more secondary prevention drugs than white participants, even after adjustment for clinical need. CONCLUSION: This population based study, which shows the widely observed social and ethnic patterning of coronary heart disease, found no evidence that low social position or South Asian ethnicity was associated with lower use of cardiac procedures or drugs, independently of clinical need. Differences in medical care are unlikely to contribute to social or ethnic differences in coronary heart disease in this cohort.


Abstract: It is accepted throughout the world today that a new approach is needed to health care, one that brings to the forefront the role of economic development. This situation has also increased the importance of the health care sector and health data have begun to take a significant place in countries’ development indicators. Health care services as a basic indicator of social and economic development in Turkey, as in the rest of the world, continue to gain in importance. However, there is a significant difference between health indicators for Turkey, which is a candidate for full membership of the European Union, and European Union countries.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme

See inside front cover for terms.


Ponte di Legno Group; Masera, Giuseppe; Eden, Tim; Schrappe, Martin; Nachman, James; Gadner, Helmut; Gaynon, Paul; Evans, William E.; Pui, Ching-Hon. Position statement by members of the Ponte di Legno Group on the right of children to have full access to essential treatment for acute lymphoblastic leukemia. *Pediatric Blood and Cancer* 2004 August; 43(2): 103-104. NRCBL: 9.2; 9.5.7.


Abstract: The aim of this paper is to describe the constitutional limits to the financing of health care and especially of public health insurance in the Czech Republic. It describes the current situation in the financing of health care on the basis of the Czech constitutional order as it has been interpreted by the Constitutional Court. Finally it presents an overview of the incorporation of the right to health into the constitutional documents of several European countries with the stress on the right to receive health care “free of charge”. It is not typical within the European region to specify in constitutional acts to what extent it is giving the right to health care free-of-charge or more precisely to what extent and for what groups health care is paid for by persons other than by the citizens (patients). The Czech Republic is one of the exceptional cases in which the basic right to health care free-of-charge on the basis of public insurance is given directly by the Constitution.

Rijlaarsdam, Janny. A reassessment of the right to health care. *Medicine and Law: World Association for Medical Law* 2004; 23(2): 219-224. NRCBL: 9.2; 9.4; 21.1. Abstract: This paper examines the right to health care in the Netherlands as provided for under the Constitution. The author discusses the relationships between human rights, economic forces and political choices in this connection and offers a view that these are due for reassessment.


Wilkinson, Stephen. Smokers’ rights to health care: why the ‘restoration argument’ is a moralising wolf in a liberal sheep’s clothing. *Journal of Applied Philosophy* 1999; 16(3): 255-269. NRCBL: 9.2; 9.4; 9.5.9; 9.3.1; 1.1. SC: an. Abstract: Do people who cause themselves to be ill (e.g. by smoking) forfeit some of their rights to healthcare? This paper examines one argument for the view that they do, the restoration argument. It goes as follows. Smokers need more health-resources than non-smokers. Given limited budgets, we must choose between treating everyone equally (according to need) or reducing smokers’ entitlements. This paper criticises the restoration argument on the following grounds. In order to avoid generating unpalatable conclusions elsewhere, it must be combined with a principle according to which activities which are sufficiently ‘socially valuable’ (e.g. parenting) are immune from restoration claims. This however means that what was supposed to be one of the argument’s most attractive features,
its compatibility with ‘liberal neutrality’ with respect to the values of different lifestyles, doesn’t really exist. Hence, the restoration argument is nowhere near as attractive as it first appears to be.

**RIGHTS** See INTERNATIONAL HUMAN RIGHTS; RIGHT TO HEALTH CARE

**SCIENCE AND TECHNOLOGY** See BIOMEDICAL RESEARCH/SOCIAL CONTROL OF SCIENCE AND TECHNOLOGY

**SCIENTIFIC MISCONDUCT** See BIOMEDICAL RESEARCH/RESEARCH ETHICS AND SCIENTIFIC MISCONDUCT

**SEX DETERMINATION**

See also GENETIC COUNSELING, GENETIC SCREENING


**Andreae, Michael; Dickens, B.M.** Prenatal sex and race determination is a slippery slope [letter and reply]. *Journal of Medical Ethics* 2004 August; 30(4): 376. NRCBL: 14.3; 15.2; 14.4; 9.5.4.

**Cadieux, Mary Martin; Gleicher, Norbert.** Sex preselection and full disclosure [letter and reply]. *Fertility and Sterility* 2003 August; 80(2): 469-470. NRCBL: 14.3.


**Flug, Joshua.** A boy or a girl? The ethics of preconception gender selection. *Journal of Halacha and Contemporary Society* 2004 Fall; (48): 5-27. NRCBL: 14.3; 1.2.


Abstract: This paper analyses the British Human Fertilisation and Embryology Authority’s 2002 public consultation on sex selection, a consultation that was mainly concerned with sex selection for non-medical reasons. Based on a close reading of the consultation document and questionnaire it is argued that the consultation is biased towards certain outcomes and can most plausibly be construed as an attempt not to investigate but to influence public opinion.


**Kalb, Claudia.** Brave new babies: parents now have the power to choose the sex of their children. But as technology answers prayers, it also raises some troubling questions. *Newsweek* 2004 January 26; 143(4): 44-53. NRCBL: 14.3; 15.2. SC: po.


**McMillan, John.** Reproductive technologies: II. Sex selection. *In: Post, Stephen G., ed. Encyclopedia of


Abstract: Although a preference for sons is reportedly a universal phenomenon, in some Asian societies daughters are considered financial and cultural liabilities. Increasing availability of ultrasonography and amniocentesis has led to widespread gender screening and selective abortion of normal female foetuses in many countries, including India. Feminists have taken widely divergent positions on the morality of this practice. Feminists from India have strongly opposed it, considering it as a further disenfranchisement of females in their patriarchal society, and have agitated successfully for legislative prohibitions. Libertarian feminists on the other hand, primarily from the United States, have argued that any prohibition of the use of this technology is a curtailment of a woman’s reproductive choices and a violation of her right to make autonomous decisions regarding procreation. Using India as an illustrative case, this paper argues that in the context of what prevails in some societies, an ethical argument that hinges on the principle of autonomy as understood in the West can be problematic. Furthermore, a liberal theoretical assumption that it is always better to have more rather than fewer choices may not hold up well against the realities of life for such women. Although feminists have little disagreement concerning substantive matters, it is in the area of strategy that differences of opinion have arisen, their moral reasoning and responses shaped by the culture, ethnicity, class and race to which they belong. A view that a single ‘orthodox’ feminism of any variety can embody the aspiration of all women reverts to the problematic issues in the evolution of the rationalistic, individualistic, ‘male’ ethics against which women have consistently raised objections.


Plummer, Kelly M. Ending parents’ unlimited power to choose: legislation is necessary to prohibit parents’ selection of their children’s sex and characteristics. *Saint Louis University Law Journal* 2003 Spring; 47(2): 517-560. NRCBL: 14.3; 4.4; 5.3; 10; 12.4.1; 15.2; 14.4. SC: an; le.


Abstract: This paper will examine the recent Human Fertilisation and Embryology Authority public consultation on sex selection. It will review the current regulation on sex selection in the United Kingdom and critically examine the outcomes of the HFEA consultation. The paper will argue that the current ban on embryo sex selection for social reasons and a proposed ban on sperm selection are not justified. There is no evidence for sex selection causing an increase in sex discrimination; creating a slippery slope towards selection for other non-disease characteristics; or promoting a consumerist attitude towards children. The HFEA recommendations to prohibit social sex selection techniques rely upon an unwarranted concern about the risk of the procedures used. Reproductive technologies should be made available to people unless a substantial risk of harm—to the child, the parents or to society—can be identified. There is no such evidence of harm in this case.


**SEX PRESELECTION** See **SEX DETERMINATION**

**SEXUALITY**

See also **MISCONDUCT**

SECTION I SEXUALITY

Carlton, Clark. Sexual reorientation therapy: an Orthodox perspective. *Christian Bioethics* 2004 August-December; 10(2-3): 137-153. NRCBL: 10; 17.3; 17.2; 1.2.


Frader, Joel; Alderson, Priscilla; Asch, Adrienne; Aspinall, Cassandra; Davis, Dena; Dreger, Alice; Edwards, James; Feder, Ellen K.; Frank, Arthur; Hedley, Lisa Abelow; Kittay, Eva; Marshall, Jeffrey; Miller, Paul Steven; Mouradian, Wendy; Nelson, Hilde; Parnes, Erik. Health care professionals and intersex conditions. *Archives of Pediatrics and Adolescent Medicine* 2004 May; 158(5): 426-428. NRCBL: 10; 9.5.7; 8.2.

Haas, Kate. Who will make room for the intersexed? *American Journal of Law and Medicine* 2004; 30(1): 41-68. NRCBL: 10; 8.3.2; 4.2; 4.3. SC: le.


Abstract: When a child is born with ambiguous genitalia it is declared a psychosocial emergency, and the policy first proposed by John Money (Johns Hopkins University) and adapted by the American Academy of Pediatrics (and more broadly accepted in Canada, the U.K., and Europe) requires determination of underlying condition(s), selection of gender, surgical intervention, and a commitment by all parties to accept the “real sex” of the patient, all no later than 18-24 months, preferably earlier. Ethicists have recently questioned this protocol on several grounds: lack of medical necessity, violation of informed consent, uncertainty of standards of success, among others. This suggests that the faults in the protocol can be addressed and improved. Through a rhetorical approach informed by Perelman/Olbrechts-Tyteca, the disciplinary pathologization and reconstruction of the body are explored as incidents of constraining rhetoric that enact their persuasion upon the body of intersexed children. This essay shows that the presumptions, judgments, values, and presuppositions brought by the physician to the identification, diagnosis, and curative procedures create a network of constraints that exclude alternative possibilities. The result is a situation wherein parents, physicians, and intersexed patients have “no choice” but to accept the medical treatment guidelines.

Hierholzer, Robert W. Are we ready for sexual reorientation therapy in the U.S. military? A response to David W. Lutz. *Christian Bioethics* 2004 August-December; 10(2-3): 227-238. NRCBL: 10; 17.3; 17.2; 1.2; 7.1.


Howsepiian, A.A. Treating homosexuality as a sickness: enlightenment is worrying [letter]. *BMJ: British Medical Journal* 2004 April 17; 328(7445): 955. NRCBL: 10; 4.2; 1.3.1.

Jensen, Steven. Is continence enough? *Christian Bioethics* 2004 August-December; 10(2-3): 161-175. NRCBL: 10; 17.3; 17.2; 1.2; 1.1.

Kaplan, Robert M. Treating homosexuality as a sickness: psychiatric abuses during apartheid era have not been brought to account [letter]. *BMJ: British Medical Journal* 2004 April 17; 328(7445): 956. NRCBL: 10; 17.1.


Koyama, Emi; Dreger, Alice; Wilson, Bruce. Intersex surgery [letter and reply]. *Hastings Center Report* 2004 March-April; 34(2): 4. NRCBL: 10; 9.5.7; 8.3.2; 21.7.

Lutz, David W. The Catholic Church, the American military, and homosexual reorientation therapy. *Christian Bioethics* 2004 August-December; 10(2-3): 189-226. NRCBL: 10; 17.3; 17.2; 1.2; 7.1.


Abstract: Cloacal exstrophy is a rare, complex defect of the entire pelvis and its contents that occurs during embryogenesis and is associated with severe phallic inadequacy or phallic absence in genetic males. For about 25 years, neonatal assignment to female sex has been advocated for affected males to over-
come the issue of phallic inadequacy, but data on outcome remain sparse. METHODS: We assessed all 16 genetic males in our cloacal-ectroscopy clinic at the ages of 5 to 16 years. Fourteen underwent neonatal assignment to female sex socially, legally, and surgically; the parents of the remaining two refused to do so. Detailed questionnaires extensively evaluated the development of sexual role and identity, as defined by the subjects’ persistent declarations of their sex. RESULTS: Eight of the 14 subjects assigned to female sex declared themselves male during the course of this study, whereas the 2 raised as males remained male. Subjects could be grouped according to their stated sexual identity. Five subjects were living as females; three were living with unclear sexual identity, although two of the three had declared themselves male; and eight were living as males, six of whom had reassigned themselves to male sex. All 16 subjects had moderate-to-marked interests and attitudes that were considered typical of males. Follow-up ranged from 34 to 98 months. CONCLUSIONS: Routine neonatal assignment of genetic males to female sex because of severe phallic inadequacy can result in unpredictable sexual identification. Clinical interventions in such children should be reexamined in the light of these findings. Copyright 2004 Massachusetts Medical Society

Riaz, Umair. Treating homosexuality as a sickness: time to rethink extent to which social norms determine disease [letter]. BMJ: British Medical Journal 2004 April 17; 328(7445): 955. NRCBL: 10; 4.2; 1.3.


Smith, Janet E. Are natural and unnatural appetites equally controllable? A response to Jensen’s “Is conti- nence enough?” Christian Bioethics 2004 August-December; 10(2-3): 177-188. NRCBL: 10; 17.3; 17.2; 1.2; 1.1.


Thomas, D.F.M. Gender assignment: background and current controversies. BJU International 2004 May; 93(Supplement 3): 47-50. NRCBL: 10; 9.5.7.

Yarhouse, Mark A. Homosexuality, ethics and identity synthesis. Christian Bioethics 2004 August-December; 10(2-3): 239-257. NRCBL: 10; 17.3; 17.2; 1.2; 1.1; 4.4.

SOCIAL WORK


SOCIOLOGY OF MEDICINE


Christiansen, Charles; Lou, Jennie Q. Ethical considerations related to evidence-based practice. American Jour-


Fadare, Oluwole; Murphy, William M. Ethical issues in anatomic pathology [letter and reply]. American Journal of Surgical Pathology. 2003 August; 27(8): 1174-1175. NRCBL: 7.1; 1.3.7; 9.8; 9.1.


Abstract: Malpractice insurance rates have created a crisis in American medicine. Rates are rising and reimbursements are not keeping pace. In response, physicians in the states hardest hit by this crisis are feeling compelled to take political action, and the current action of choice seems to be physician strikes. While the malpractice insurance crisis is acknowledged to be severe, does it justify the extreme action of a physician walkout? Should physicians engage in this type of collective action, and what are the costs to patients and the profession when such action is taken? I will offer three related arguments against physician strikes that constitute a prima facie prohibition against such action: first, strikes are intended to cause harm to patients; second, strikes are an affront to the physician-patient relationship; and, third, strikes risk decreasing the public’s respect for the medical profession. As with any prima facie obligation, there are justifying conditions that may override the moral prohibition, but I will argue that the current malpractice crisis does not rise to the level of such a justifying condition. While the malpractice crisis demands and justifies a political response on the part of the nation’s physicians, strikes and slow-downs are not an ethically justified means to the legitimate end of controlling insurance costs.


Abstract: Although leaders and other commentators have called for the medical profession’s greater engagement in improving systems of care and population health, neither medical education nor the practice environment has fostered such engagement. Missing have been a clear definition of physicians’ public roles, reasonable limits to what can be expected, and familiarity with tasks that are compatible with busy medical practices. We address these issues by proposing a definition and a conceptual model of public roles that require evidence of disease causation and are guided by the feasibility and efficacy of physician involvement. We then frame a public agenda for individual physicians and physician organizations that focuses on advocacy and community participation. By doing so, we aim to stimulate dialogue about the appropriateness of such roles and promote physician engagement with pressing health issues in the public arena.


Hayes, Robert. Epidemiological research and privacy protection. *Medical Journal of Australia* 1984 November 10; 141: 621-624. NRCBL: 7.1; 8.4; 18.5.1; 18.3.


Identifiers: American Medical Association [AMA].

Abstract: The threat of bioterrorism, the emergence of the SARS epidemic, and a recent focus on professionalism among physicians, present a timely opportunity for a review of, and renewed commitment to, physician obligations to care for patients during epidemics. The professional obligation to care for contagious patients is part of a larger “duty to treat,” which historically became accepted when 1) a risk of nosocomial infection was perceived, 2) an organized professional body existed to promote the duty, and 3) the public came to rely on the duty. Physicians' responses to epidemics from the Hippocratic era to the present suggests an evolving acceptance of the professional duty to treat contagious patients, reaching a long-held peak between 1847 and the 1950's. There has been some professional reenforcement against this duty to treat in the last 40 years but, we argue, conditions favoring acceptance of the duty are met today. A renewed embrace of physicians' duty to treat patients during epidemics, despite conditions of personal risk, might strengthen medicine’s relationship with society, improve society’s capacity to prepare for threats such as bioterrorism and new epidemics, and contribute to the development of a more robust and meaningful medical professionalism.


Kapocsy, Erzsébet. The medical profession, patients and society: a situation report from Hungary. *Bulletin of Medical Ethics* 2004 April; (197): 13-17. NRCBL: 7.1; 9.5.1; 5.3; 8.1; 9.3.1; 21.1.


Abstract: There has been increasing attention devoted to patient safety. However, the focus has been on system improvements rather than individual physician performance issues. The purpose of this study was to determine if there is an association between certain physician characteristics and the likelihood of medical board-imposed discipline. METHODS: Unmatched, case-control study of 890 physicians disciplined by the Medical Board of California between July 1, 1998, and June 30, 2001, compared with 2981 randomly selected, nondisciplined controls. Odds ratios (ORs) were calculated for physician discipline with respect to age, sex, board certification, international medical school education, and specialty. RESULTS: Male sex (OR, 2.76; P001), lack of board certification (OR, 2.22; P001), increasing age (OR, 1.64; P001), and international medical school education (OR, 1.36; P001) were associated with an elevated risk for disciplinary action that included license revocation, practice suspension, probation, and public reprimand. The following specialties had an increased risk for discipline compared with internal medicine: family practice (OR, 1.68; P =.002); general practice (OR, 1.97; P =.001); obstetrics and gynecology (OR, 2.25; P001); and psychiatry (OR, 1.87; P001). Physicians in pediatrics (OR, 0.62; P =.001) and radiology (OR, 0.36; P001) were less likely to receive discipline compared with those in internal medicine. CONCLUSION: Certain physician characteristics and medical specialties are associated with an increased likelihood of discipline.

La Puma, John; Szapary, Philippe; Maki, Kevin C. Physicians’ personal intake and prescription of weight loss products: are we practicing what we preach? [letter]. *Archives of Internal Medicine* 2004 April 12; 164(7): 806-807. NRCBL: 7.1; 8.1; 9.5.1; 9.7.


Malone, Ruth E.; Bero, L.A. Chasing the dollar: why scientists should decline tobacco industry funding [editorial]. *Journal of Epidemiology and Community Health* 2003 August; 57(8): 546-548. NRCBL: 7.1; 1.3.2; 9.3.1; 7.3.

Malpas, Phyllis; Schaffner, Marilyn. Managerial ethics: arriving at decisions we can live with. *Gastroenterology Nursing* 2000 September-October; 23(5): 239-240. NRCBL: 7.1; 4.1.3; 2.1.

Marshall, Mary Faith. The placebo effect in popular culture. *Science and Engineering Ethics* 2004 January; 10(1): 37-42. NRCBL: 7.1; 8.2; 18.3; 5.1. Conference: Placebo: Its Action and Place in Health Research Today, Warsaw, Poland, 12-13, April, 2003, meeting held under the auspices of the Secretary General, Council of Europe, Minister of Science and the Minister of Health, Poland.


Rodwin, Marc A. Financial incentives for doctors — have their place but need to be evaluated and used to promote appropriate goals [editorial]. *BMJ: British Medical Journal* 2004 June 5; 328(7452): 1328-1329. NRCBL: 7.1; 7.3.

Romyn, Donna M.; Allen, Marion N.; Boschma, Geertje; Duncan, Susan M.; Edgecombe, Nancy; Jensen, Louise A.; Ross-Kerr, Janet C.; March, Patricia; Salsali, Mahvash; Tourangeau, Ann E.; Warnock, Fay. The notion of evidence in evidence-based practice by the Nursing Ethics Working Group. *Journal of Professional Nursing* 2003 July-August; 19(4): 184-188. NRCBL: 7.1; 4.1.3; 9.8. Identifiers: Institute for Philosophic Nursing Research; Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada.


Sieber, Joan E. Empirical research on research ethics. *Ethics and Behavior* 2004; 14(4): 397-412. NRCBL: 7.1; 18.2; 18.3; 1.3.5; 8.4; 5.2; 1.1. SC: em.


Stewart, J.A.D. What should a suspended doctor do when his actions could save a patient’s life? *Postgraduate Medical Journal* 2003 April; 79(930): 204-205. NRCBL: 7.1; 1.3.8; 8.1. SC: le.

Tabrizi, S.J.; Elliott, C.L.; Weissmann, C. Ethical issues in human prion diseases. *British Medical Bulletin* 2003; 66: 305-316. NRCBL: 7.1; 9.1; 15.3; 18.2; 18.6.


Werner, Rachel M.; Alexander, G. Caleb; Fagerlin, Angela; Ubel, Peter A. Lying to insurance companies: the desire to deceive among physicians and the public. *American Journal of Bioethics* 2004 Fall; 4(4): 53-59. NRCBL: 7.1; 9.3.1; 8.1; 9.3.2. SC: em.

Whiteway, Dean E. Physicians and the pharmaceutical industry: a growing embarrassment and liability. *WMJ (Wisconsin Medical Journal)* 2001; 100(9): 39-44, 57. NRCBL: 7.1; 9.7; 7.3; 9.3.1.


Wilson, Chris. Intersecting discourses: MMR vaccine and BSE. *Science as Culture* 2004 March; 13(1): 75-88. NRCBL: 7.1; 9.7; 22.3; 1.3.11; 9.1; 21.1; 5.2. SC: an. Identifiers: United Kingdom; measles, mumps, rubella; bovine spongiform encephalopathy.


**SPECIAL POPULATIONS** See CARE FOR SPECIFIC GROUPS; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS

**STERILIZATION**

See also CONTRACEPTION; POPULATION CONTROL


Gillam, Lynn. In that case . . . response [case study]. *New Zealand Bioethics Journal* 2004 February; 5(1): 35-36. NRCBL: 11.3; 9.5.3; 8.1; 8.3.3.


Spota, Kate. In good conscience: the legal trend to include prescription contraceptives in employer insurance plans and Catholic charities’ “conscience clause” objection. *Catholic University Law Review* 2003 Summer; 52(4): 1081-1113. NRCBL: 11.3; 1.2; 9.3.1. SC: le.


**SUBSTANCE ABUSERS** See CARE FOR SPECIFIC GROUPS/ SUBSTANCE ABUSERS
TELEMEDICINE AND INFORMATICS


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TERMINAL CARE See DEATH AND DYING/ TERMINAL CARE

TERRORISM See WAR AND TERRORISM

TERMINALLY ILL See DEATH AND DYING/ TERMINAL CARE; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ AGED AND TERMINALLY ILL

TEST TUBE FERTILIZATION See IN VITRO FERTILIZATION

THERAPEUTIC RESEARCH See HUMAN EXPERIMENTATION

THIRD PARTY CONSENT See HUMAN EXPERIMENTATION/ INFORMED CONSENT; INFORMED CONSENT

TISSUE DONATION See ORGAN AND TISSUE TRANSPLANTATION/ DONATION AND PROCUREMENT

TRANSPLANTATION See ORGAN AND TISSUE TRANSPLANTATION

TORTURE, GENOCIDE, AND WAR CRIMES See also WAR AND TERRORISM


Ernst, Edzard. Dr. Reiter: the “Third” and “Fourth” Reich [opinion]. Seminars in Arthritis and Rheumatism 2003 February; 32(4): 244-245. NRCBL: 21.4; 15.5; 7.1; 1.3.9.


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Mayor, Susan. AMA calls for inquiry into doctors’ role in abuse of prisoners [news]. BMJ: British Medical Journal
**SECTION I**


**McKie, Andrew.** ‘The demolition of a man’: lessons from Holocaust literature for the teaching of nursing ethics. *Nursing Ethics* 2004 March; 11(2): 138-149. NRCBL: 21.4; 4.1.3; 7.1; 7.2; 15.5.


**Schmidt, Ulf.** German medical war crimes, medical ethics and post-war justice: a symposium to mark the 50th anniversary of the Nuremberg Medical Trial, held at the University of Oxford, 14 March 1997. *German History: The Journal of the German History Society* 1997; 15(3): 385-391. NRCBL: 21.4; 15.5; 1.3.5; 1.1.


**Zofka, Zdenek.** Der KZ-Arzt Josef Mengele Zur Typologie eines NS-Verbrechers/The concentration camp physician Josef Mengele: the typology of a National Socialist criminal. *Vierteljahrshefte fur Zeitgeschichte* 1986 April; 34(2): 245-267. NRCBL: 21.4; 2.2; 1.3.5; 15.5; 18.5.5. Identifiers: Germany.

**TREATMENT REFUSAL**

See also ADVANCE DIRECTIVES; EUTHANASIA AND ALLOWING TO DIE; INFORMED CONSENT


**Ariga, Tomonori; Hayasaki, Shiro.** Medical, legal and ethical considerations concerning the choice of bloodless medicine by Jehovah’s Witnesses. *Legal Medicine* 2003 March; 5(Supplement 1): S72-S75. NRCBL: 8.3.4; 1.2; 19.4.


NRCBL: National Reference Center for Bioethics Literature Classification Scheme See inside front cover for terms.
TREATMENT REFUSAL


Abstract: Minors are generally considered incompetent to provide legally binding decisions regarding their health care, and parents or guardians are empowered to make those decisions on their behalf. Parental authority is not absolute, however, and when a parent acts contrary to the best interests of a child, the state may intervene. The best interests standard is the threshold most frequently employed in challenging a parent’s refusal to provide consent for a child’s medical care. In this paper, I will argue that the best interest standard provides insufficient guidance for decision-making regarding children and does not reflect the actual standard used by medical providers and courts. Rather, I will suggest that the Harm Principle provides a more appropriate threshold for state intervention than the Best Interest standard. Finally, I will suggest a series of criteria that can be used in deciding whether the state should intervene in a parent’s decision to refuse medical care on behalf of a child.
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**Hurst, Samia A.** When patients refuse assessment of decision-making capacity — how should clinicians respond? *Archives of Internal Medicine* 2004 September 13; 164(16): 1757-1760. NRCBL: 8.3.4; 8.3.3. Abstract: When patients refuse beneficial treatment, the assessment of decision-making capacity plays a key role in determining the best course of action. However, situations in which patients refuse to explain their reasons occur. This can make an assessment of capacity impossible. In such cases, clinicians find themselves in difficult situations without clear ethical guidance. Refusal to give reasons for refusing beneficial treatment has been seen as pointing to the absence of decision-making capacity. However, the reasons given for this are either unsatisfactory or insufficient to eliminate cases of genuine uncertainty. This article argues that although it cannot be concluded that such patients are incompetent, there are reasons to treat them as if they were. The basis of this possibility, however, points to several obligations for clinicians before such a situation can be said to exist.

**Johnson, Kirk.** Harm to fetuses becomes issue in Utah and elsewhere. *New York Times* 2004 March 27; p. A9. NRCBL: 8.3.4; 9.5.8; 9.5.5. SC: po; le.

**Haydon, Joseph; Franklin, Cory.** Enigmatic refusals: the difference between a potential problem and one in a patient under our care. *Chest* 2004 August; 126(2): 337-339. NRCBL: 8.3.4.


**Marwick, Charles.** Mother accused of murder after refusing caesarean section [news]. *BMJ: British Medical Journal* 2004 March 20; 328(7441): 663. NRCBL: 8.3.4; 9.5.5; 1.3.5. SC: le.

**Melamed, Yuval; Mester, Roberto; Margolin, Jacob; Kalian, Moshe.** Involuntary treatment of anorexia nervosa. *International Journal of Law and Psychiatry* 2003 November-December; 26(6): 617-626. NRCBL: 8.3.4; 17.7; 21.5. SC: le.


**Rich, Ben A.** Possible limits to the surrogate’s role: when a patient lacks decisionmaking capacity, is the surrogate’s role absolute? Commentary. *CQ: Cambridge Quarterly of Healthcare Ethics* 2004 Winter; 13(1): 100-104. NRCBL: 8.3.4; 4.4; 9.8; 20.4.1; 8.3.3.


**Smith, George P., II.** “Just say no!”: the right to refuse psychotropic medication in long-term care facilities. *Annals of Health Law* 2004 Winter; 13(1): 1-35. NRCBL: 8.3.4; 17.4; 9.5.2. SC: le.


**Tan, Jacinta; Hope, Tony; Stewart, Anne.** Competence to refuse treatment in anorexia nervosa. *International Journal of Law and Psychiatry* 2003 November-December; 26(6): 697-707. NRCBL: 8.3.4; 9.5.5; 4.3. SC: em.


**van Kleeffs, Titia; van Baarsen, Berna; van Leeuwen, Evert.** The medical practice of patient autonomy and cancer treatment refusals: a patients’ and physicians’ perspective. *Social Science and Medicine* 2004 June; 58(11): 2325-2336. NRCBL: 8.3.4; 1.1; 9.5.1. SC: em.


**Zupan, Daniel; Solis, Gary; Schoonhoven, Richard; Annas, George.** Dialysis for a prisoner of war [case study and commentaries]. *Hastings Center Report* 2004 November-December; 34(6): 11-12. NRCBL: 8.3.4; 21.2; 9.5.1. SC: cs.

## TREATMENT REFUSAL/ MENTALLY ILL

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Tannsjo, T. The convention on human rights and biomedicine and the use of coercion in psychiatry. *Journal of Medical Ethics* 2004 October; 30(5): 430-434. NRCBL: 17.8; 8.3.4; 17.7; 21.1. Abstract: According to a recent convention on human rights and biomedicine, coercive treatment of psychiatric patients may only be given if, without such treatment, serious harm is likely to result to the health of the patient; it must not be given in the interest of other people. In the present article a discussion is undertaken about the implication of this stipulation for the use of coercion in psychiatry in general and in forensic psychiatry in particular.

**TRUTH DISCLOSURE**


Bogardus, Sidney T., Jr.; Geist, David E.; Bradley, Elizabeth H. Physicians’ interactions with third-party payers — is deception necessary? * Archives of Internal Medicine* 2004 September 27; 164(17): 1841-1844. NRCBL: 8.2; 7.1; 8.1; 9.3.1. Abstract: Published reports indicate that physicians sometimes use deceptive tactics with third-party payers. Many physicians appear to be willing to deceive to secure care that they perceive as necessary, particularly when illnesses are severe and appeals procedures for care denials are burdensome. Physicians whose practices include larger numbers of Medicaid or managed care patients seem more willing to deceive third-party payers than are other physicians. The use of deception has important implications for physician professionalism, patient trust, and rational health policy development. If deception is as widespread as these studies suggest, there may be serious problems in the medical profession and the health care financing systems at the interface between physicians and third-party payers. Deception may be a symptom of a flawed system, in which physicians are asked to implement financing policies that conflict with their primary obligation to the patient.


Briley, Laura D. A physician’s professional duty to inform despite personal ethical objections. *Current Surgery* 2003 November-December; 60(6): 594-595. NRCBL: 8.2; 8.1; 12.5.3.


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SECTION I

TRUTH DISCLOSURE


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Fan, Ruiping; Li, Benfu. Truth telling in medicine: the Confucian view. Journal of Medicine and Philosophy 2004 April; 29(2): 179-193. NRCBL: 8.2; 21.7; 1.1. Abstract: Truth-telling to competent patients is widely affirmed as a cardinal moral and biomedical obligation in contemporary Western medical practice. In contrast, Chinese medical ethics remains committed to hiding the truth as well as to lying when necessary to achieve the family’s view of the best interests of the patient. This essay intends to provide an account of the framing commitments that would both justify physician deception and have it function in a way authentically grounded in the familial moral concerns of Confucianism. It reflects on the moral conditions and possibilities for sustaining a Confucian understanding of truth-telling and consent in mainland China.

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Hamdy, Ronald C. Alzheimer’s disease: to tell or not to tell [editorial]. Southern Medical Journal 2004 January; 97(1): 1. NRCBL: 8.2; 17.1; 9.5.2.


Hu, Wen-Yu; Chiu, Tai-Yuan; Chuang, Rong-Bin; Chen, Ching-Yu. Solving family-related barriers to truthfulness in cases of terminal cancer in Taiwan — a professional perspective. Cancer Nursing 2002 December; 25(6): 486-492. NRCBL: 8.2; 20.4.1; 8.1; 7.1. SC: em.


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Kunin, Joshua. Should patients be told the truth about their illnesses: Jewish perspectives. Israel Medical Association Journal 2002 September; 4(9): 737-741. NRCBL: 8.2; 1.2; 8.1.


Abstract: While discussions of the ethics of the placebo have usually dealt with their use in a research context, the authors address here the question of the placebo in clinical practice. It is argued, firstly, that the placebo can be an effective treatment. Secondly, it is demonstrated that its use does not entail deception. Finally, guidelines are presented according to which the placebo may be used for clinical purposes. It is suggested that in select cases, use of the placebo may even be morally imperative. The argument is illustrated by three case vignettes.

Macnaghten, A. A patients [sic; patient’s] right to know? *Lancet Oncology* 2002 April; 3(4): 206. NRCBL: 8.2; 9.5.5.


Lancet Oncology 2002 April; 3(4): 206. NRCBL: 8.2; 9.5.5.

Abstract: BACKGROUNd: Various authorities and national organizations encourage disclosing medical errors, but there is little information on how patients respond to disclosure. OBJECTIVE: To examine how the type of error, severity of adverse clinical outcome, and level of disclosure affect patients’ responses to error and disclosure. DESIGN: Mail questionnaire survey (8 versions were developed) varying 3 factors in a completely crossed, randomized, factorial design. Each questionnaire included a vignette describing (1) a medical error (failure to check for penicillin allergy or inadequate monitoring of antiepileptic medication); 2) an associated clinical outcome (life-threatening or less serious); and 3) a physician-patient dialogue, with either full disclosure (acceptance of responsibility and an apology) or nondisclosure (expression of regret without acceptance of responsibility or an apology). SETTING: New England-based health plan. PARTICIPANTS: Random sample of 1500 adult members received the questionnaire, with a 66% response rate. MEASUREMENTS: Likelihood of changing physicians, likelihood of seeking legal advice, ratings of patient satisfaction, trust and emotional reaction in response to a vignette and dialogue, and views on medical error and disclosure. RESULTS: Full disclosure reduced the reported likelihood of changing physicians and increased patient satisfaction, trust, and positive emotional reaction. Full disclosure reduced the reported likelihood of seeking legal advice in only 1 error-and-outcome vignette. In the other vignettes, the percentage of patients indicating that they would seek legal advice was relatively high even with full disclosure. Almost all respondents (98.8%) wanted to be told of errors, most (83%) favored financial compensation if harm occurred, and few (12.7%) favored compensation if no harm occurred. LIMITATIONS: Since the study was done in the context of a managed care plan in one geographic area, it could not assess whether the results are generalizable to other populations. In addition, it could not determine whether responses to the simulated situations used predict responses to real situations. CONCLUSIONS: Patients will probably respond more favorably to physicians who fully disclose medical errors than to physicians who are less forthright, but the specifics of the case and the severity of the clinical outcome also affect patients’ responses. In some circumstances, the desire to seek legal advice may not diminish despite full disclosure.


Abstract: BACKGROUND: Ethical and professional guidelines recommend disclosure of medical errors to patients. The objective of this study was to review the empirical literature on disclosure of medical errors with respect to (1) the decision to disclose, (2) the process of informing the patient and family, and (3) the consequences of disclosure or nondisclosure. METHODS: We searched 4 electronic databases (MEDLINE, CINAHL, PsycINFO, and Social Sciences Citation Index) and the reference lists of relevant articles in English-language studies on disclosure of medical errors. From more than 800 titles reviewed, we identified 17 articles reporting original empirical data on disclosure of medical errors to patients and families. We examined methods and results of the articles and extracted study designs, data collection procedures, populations sampled, response rates, and definitions of error. RESULTS: Available research findings suggest that patients and the public support disclosure. Physicians also indicate support for disclosure, but often do not disclose. We found insufficient empirical evidence to support conclusions about the disclosure process or its consequences. CONCLUSIONS: Empirical research on disclosure of medical errors to patients and families has been limited, and studies have focused primarily on the decision stage of disclosure. Fewer have considered the disclosure process, the consequences of disclosure, or the relationship between the two. Additional research is needed to understand how disclosure decisions are made, to provide guidance to physicians on the process, and to help all involved anticipate the consequences of disclosure.

Mazor, Kathleen M.; Simon, Steven R.; Yood, Robert A.; Martinson, Brian C.; Gunter, Margaret J.; Reed, George W.; Gurwitz, Jerry H. Health plan members’ views about disclosure of medical errors. *Annals of Internal Medicine* 2004 March 16; 140(6): 409-418. NRCBL: 8.2; 8.1; 8.5; 9.8. SC: em.


Monaghan, Catherine; Begley, Ann. Dementia diagnosis and disclosure: a dilemma in practice. *Journal of Clinical Nursing* 2004 March; 13(3a): 22-29. NRCBL: 8.2; 4.1.3; 8.1; 8.4; 9.5.3.


Abstract: OBJECTIVES: To gauge the frequency and circumstances of use of placebo in clinical practice and the attitudes towards its use among those who administer it. DESIGN: Retrospective questionnaire. SETTING: Two large hospitals and various community clinics in the Jerusalem area. PARTICIPANTS: 31 physicians working in hospital inpatient and outpatient departments, 31 head nurses working in hospital inpatient departments, and 27 family physicians working in community clinics. MAIN OUTCOME MEASURES: Self report of frequency and circumstances of, and attitudes towards, use of placebo. RESULTS: Among the 89 respondents, 53 (60%) used placebo (95% confidence interval 49% to 70%). Among users, 33 (62%) prescribed a placebo as often as once a month or more; 36 (68%) told patients they were receiving actual medication; 15 (28%) considered that placebos were a diagnostic tool; and 48/51 (94%) reported that they found placebos generally or occasionally effective. CONCLUSION: Most practitioners questioned in this study continue to use placebos. Used wisely, placebos might have a legitimate place in therapeutics. Wider recognition of the practice and debate about its implications are imperative.


Ozdogan, Mustafa; Samur, Mustafa; Bozuk, Hakan Sat; Coban, Erkan; Artac, Mehmet; Savas, Burhan; Kara, Arzu; Topcu, Zekiye; Sualp, Yeliz. “Do not tell!”: what factors affect relatives’ attitudes to honest disclosure of diagnosis to cancer patients? *Supportive Care in Cancer* 2004 July; 12(7): 497-502. NRCBL: 8.2; 8.1; 9.5.1. SC: em. Identifiers: Turkey.


Abstract: In general, most, but not necessarily all, patients want truthfulness about their health. Available evidence indicates that truth-telling practices and preferences are, to an extent, a cultural artefact. It is the case that practices among nurses and doctors have moved towards more honest and truthful disclosure to their patients. It is interesting that arguments both for and against truth-telling are established in terms of autonomy and physical and psychological harm. In the literature reviewed here, there is also the view that truth-telling is essential because it is an intrinsic good, while it is argued against on the grounds of the uncertainty principle. Based on this review, it is recommended that practitioners ought to ask patients and patients’ families what informational requirements are preferred, and research should continue into truth-telling in clinical practice, particularly to discover its very nature as a cultural artefact, and the other conditions and contexts in which truth-telling may not be preferred.


**VALUE OF LIFE** See **QUALITY AND VALUE OF LIFE**
WAR AND TERRORISM

See also TORTURE, GENOCIDE, AND WAR CRIMES


Galbraith, S.N. Medico-legal issues surrounding medical countermeasures used in the Gulf War — part 1. Journal of the Royal Army Medical Corps 2000 February; 146(1): 33-36. NRCBL: 21.2; 8.3.4; 9.5.1; 9.7; 21.3.


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Richardson, Louise. Buying biosafety — is the price right? New England Journal of Medicine 2004 May 20; 350(21): 2121-2123. NRCBL: 21.3; 5.1; 5.2; 5.3.


Seligld, M.J. Bioterrorism and smallpox planning: information and voluntary vaccination. Journal of Medical Ethics 2004 December; 30(6): 558-560. NRCBL: 21.3; 9.5.1; 9.7; 8.3.

Abstract: Although smallpox was declared eradicated in 1980, there are fears that stocks of the virus manufactured for military purposes by the Soviet Union may have fallen into the hands of "rogue nations" or terrorists. Worries about bioterrorism have thus sparked debate about whether or not the smallpox vaccine, which can be dangerous, should be offered to the general public. Meaningful public debate on this issue requires expert information about the likelihood that the virus will in fact be used as a weapon. Informed voluntary individual decision making, about whether to get vaccinated if vaccine is made available to the public, would similarly require appreciation of the likelihood of attack. Public deliberation and private deliberation thus both require briefing by the intelligence community.


Abstract: Were terrorists ever to effectively deploy weapons of mass destruction, medical practice would be quickly transformed. Many ordinary clinicians would be asked or required to treat unfamiliar yet serious medical conditions in a setting of overwhelming urgency and impossible odds. Clinical focus would shift from doing good things for a succession of individual patients to considering many patients at once, a change that could beget loss of trust and rapport with patients. Clinicians might also experience restrictions in personal liberties and appropriation of their property. The purpose of this essay is to develop a teleological framework for undertaking this transformation. In ordinary clinical medicine, the elusiveness of the individual telos (i.e.,the good for the individual) is acknowledged in procedures (such as social history taking, informed consent and outpatient scheduling) designed to protect patients' (and clinicians') prerogatives to interpret the telos for themselves. In mass casualty scenarios, on the other hand, the telos is standardized and regarded as an Immediate Object (usually as a state of affairs in which survival is maximized and permanent disability is minimized). Clinicians who provide mass casualty care will face a number of ethical challenges that can be negotiated by appealing to the political and ethical rationale, and limits, pertaining to the pursuit of aggregate survival as an Immediate Object.


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**WITHHOLDING TREATMENT** See EUThANA1SIA AND ALLOWING TO DIE

**WOMEN** See CARE FOR SPECIFIC GROUPS/ WOMEN; HUMAN EXPERIMENTATION/ SPECIAL POPULATIONS/ WOMEN

**WRONGFUL BIRTH** See CONTRACEPTION

**XENOTRANSPLANTATION** See ORGAN AND TISSUE TRANSPLANTATION/ XENOTRANSPLANTATION
SECTION II:
PERIODICAL LITERATURE
AND ESSAYS

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Aaron, Henry J.; Bach, Peter B.; Schrag, Deborah. Primary care physicians who treat blacks and whites [letter and reply]. *New England Journal of Medicine* 2004 November 11; 351(20): 2126-2127. Subject: 9.5.4


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See SUBJECT HEADING KEY FOR SECTION II on inside back cover


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<tr>
<th>Author(s)</th>
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<td>Asai, Atsushi; Ohnishi, Motoki; Nishigaki, Etsuyo; Sekimoto, Miho; Fukuhara, Shunichi; Fukui, Tsuguya.</td>
<td>Focus group interviews examining attitudes towards medical research among the Japanese: a qualitative study.</td>
<td>Bioethics 2004 September; 18(5): 448-470. Subject: 18.1</td>
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<td>Ashcroft, Richard E.</td>
<td>Ethical dimension was not discussed in theme issue [letter].</td>
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<td>Arnold, Beth E.; Ogielska-Zei, Eva.</td>
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<td>Arnos, Kathleen S.</td>
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Friedman, Lester D., ed. CULTURAL SU TURES: MEDICINE AND MEDIA. Frankfurt/Main: Campus Verlag, 2001. 196 p. ISBN 3-593-36549-7. (1.3.11; 1.3.7; 1.1; 1.3.5; 1.3.8)

Health Care Communication Group. WRITING, SPEAKING, & COMMUNICATION SKILLS FOR HEALTH PROFESSIONALS. New Haven, CT: Yale University Press, 2001. 338 p. ISBN 0-300-08862-0. [R118 .W77 2001] (1.3.7; 1.3.9; 7.2; 8.1)


1.3.8 APPLIED AND PROFESSIONAL ETHICS: LAW


Rudinow, Joel and Graybosch, Anthony, [eds.]. ETHICS AND VALUES IN THE INFORMATION AGE. South Melbourne, Australia/[Belmont, CA]: Wadsworth Thomson Learning, 2002. 483 p. ISBN 0-507956-5. [P94 .E793 2002] (1.3.12; 1.1; 1.3.7; 5.3; 10; 21.2)

1.3.9 APPLIED AND PROFESSIONAL ETHICS: SCIENTIFIC RESEARCH

Dawson, John and Peart, Nicola, eds. THE LAW OF RESEARCH: A GUIDE. Dunedin, New Zealand: University of Otago Press, 2003. 382 p. ISBN 1-877276-50-2. (Publisher’s address: PO Box 56, 56 Union Street West, Dunedin, New Zealand.) (1.3.9; 5.3; 8.4; 16.1; 16.3; 18.2; 18.3; 18.5.2; 18.5.4; 22.2; LE)


Wootton, Richard; Yellowlees, Peter; and McLaren, Paul, eds. TELEPSYCHIATRY AND E-MENTAL HEALTH. London: Royal Society of Medicine Press, 2003. 368 p. ISBN 1-85315-549-7. (Publisher’s address: 1 Wimpole Street, postal code W1G 0AE.) (1.3.12; 8.1; 9.1; 9.5.7; 17.1; 17.2; 21.1)

2.1 BIOETHICS (GENERAL)

Bioethics and Science in the New Epoch. SYNTHESIS PHILOSOPHICA 2002; 17(1): 111-170. (ISSN 0352-7875. Special Issue.) (2.1; 1.3.11; 2.3; 4.4; 8.1; 15.1; 15.7; 17.1; 20.5.1; 20.7; 21.7)

SECTION III

2.1 BIOETHICS (GENERAL)

3-593-36854-4. (Kultur der Medizin series; Bd. 2. Habilitationsschrift—Georg-August Universität Göttingen, 2000.) (2.1; 1.1; 10)


Card, Robert F. CRITICALLY THINKING ABOUT MEDICAL ETHICS. Upper Saddle River, NJ: Pearson Prentice Hall, 2004. 496 p. ISBN 0-13-182484-8. (On Trial WITH CASES, LAWS, AND DOCUMENTS Cawthon, Elisabeth A. 2004. 496 p. ISBN 0-13-182484-8. (2.1; 1.1; 2.3; 8.1; 8.4; 9.4; 9.5.6; 12.1; 14.2; 15.1; 18.1; 20.5.1; 20.3.2; 20.4.1; 20.5.1; 20.5.4; LE)

Cawthon, Elisabeth A. MEDICINE ON TRIAL: A HANDBOOK WITH CASES, LAWS, AND DOCUMENTS. Santa Barbara, CA: ABC-CLIO, 2004. 333 p. ISBN 1-85109-564-0. (2.1; 1.3.5; 1.3.12; 8.3.1; 8.4; 9.5.2; 18.2; 20.2.1; 20.5.1; 20.5.4; LE)

Conference: Religious Values and Legal Dilemmas in Bioethics. FORDHAM URBAN LAW JOURNAL 2002 November; 30(1): 1-275. (ISSN 0199-4646.) (2.1; 1.1; 1.2; 1.3.8; 4.4; 5.1; 8.1; 8.3.1; 8.3.3; 8.3.4; 9.1; 9.5.3; 14.4; 18.5.4; 20.2.1; 20.3.2; 20.4.1; 20.5.1; 20.5.4; LE)

Crawford, S. Cromwell. HINDU BIOETHICS FOR THE TWENTY-FIRST CENTURY. Albany: State University of New York Press, 2003. 226 p. ISBN 0-7914-5780-X. (SUNY Series in Religious Studies.) [QH332 .C73 2003] (2.1; 1.2; 1.3.5; 2.2; 7.3; 8.3.2; 8.3.4; 8.5; 12.4.2; 14.2; 14.5; 18.5.4; 20.5.1; 20.7; Reference; LE)


Diamond, Eugene F. A CATHOLIC GUIDE TO MEDICAL ETHICS: CATHOLIC PRINCIPLES IN CLINICAL PRACTICE. Palos Park, IL: Lincare Institute of the Catholic Medical Association, 2001. 393 p. ISBN 0-89555-690-1. (Publisher’s address: 8706 W. 121st Street, zip 60464.) (2.1; 1.2)

Draper, Heather and Scott, Wendy E., eds. ETHICS IN ANESTHESIA AND INTENSIVE CARE. Edinburgh/New York: Butterworth-Heinemann, 2003. 251 p. ISBN 0-7506-5353-1. [RD82 .E87 2003] (2.1; 1.1; 2.3; 8.1; 8.3.1; 8.4; 9.5.2; 18.2; 20.2.1; 20.5.1; 21.7; LE)

Flight, Myrtle. LAW, LIABILITY, ETHICS FOR MEDICAL OFFICE PROFESSIONALS. Clifton Park, NY: Thomson/Delmar Learning, 2004. 350 p. ISBN 1-4018-4033-7. (Fourth edition.) [KF2914 .F58 2004] (2.1; 1.1; 1.3.5; 1.3.12; 8.3.1; 8.4; 8.5; 9.1; 9.3.2; 9.4; 9.5.7; 9.5.9; 14.1; 15.1; 16.3; LE)

Garrison, Marsha and Schneider, Carl E. THE LAW OF BIOETHICS: INDIVIDUAL AUTONOMY AND SOCIAL REGULATION. St. Paul, MN: Thomson/West, 2003. 1103 p. ISBN 0-314-25221-5. (American Casebook Series.) [KF3823 .A7 G37 2003] (2.1; 1.1; 4.3; 4.4; 8.1; 8.3.3; 8.4; 9.3.2; 9.4; 9.5.5; 9.5.7; 14.1; 19.5; 20.5.1; 20.7; LE)

Gillett, Grant R. BIOETHICS IN THE CLINIC: HIPPOCRATIC REFLECTIONS. Baltimore, MD: Johns Hopkins University Press, 2004. 309 p. ISBN 0-8018-7843-8. (Gift of the publisher.) [R724 .G549 2004] (2.1; 4.1.2; 8.1; 8.3.1; 8.4; 9.5.6; 14.5; 15.1; 18.5.4; 20.5.1)


Hilliard, Bryan. THE U.S. SUPREME COURT AND MEDICAL ETHICS: FROM CONTRACEPTION TO MANAGED HEALTH CARE. St. Paul, MN: Paragon House, 2004. 425 p. ISBN 1-55778-831-6. (Paragon Issues in Philosophy series. Gift of the publisher.) [KF3821 .H55 2004] (2.1; 1.2; 1.3.5; 8.1; 8.3.4; 8.4; 9.3.2; 9.5.3; 9.5.5; 9.5.8; 11.1; 12.4.1; 14.1; 17.1; 17.7; 20.5.1; 20.7)


Holm, Søren and Jonas, Monique F., eds. ENGAGING THE WORLD: THE USE OF EMPIRICAL RESEARCH IN BIOETHICS
AND THE REGULATION OF BIOTECHNOLOGY. Amsterdam/Washington, DC: IOS Press, 2004. 157 p. ISBN 1-58603-400-6. (Biomedical and Health Research series; Vol. 58. ISSN 0929-6743. “The papers in this book are all the result of work performed as part of the Empirical Methods in Bioethics [EMPIRE] project.”) [R724 .E533 2004] (2.1; 1.1; 1.3.12; 2.3; 5.3; 7.1; 7.3; 9.6; 15.1; 18.3; 18.5.4; LE)

Honnfelder, Ludger and Strefler, Christian, eds. JAHRBUCH FÜR WISSENSCHAFT UND ETHIK, BAND 7. 2002. Berlin/New York: Walter de Gruyter, 2002. 512 p. ISBN 3-11-017639-4. (Jahrbuch für Wissenschaft und Ethik series; Bd. 7. ISSN 1430-9017. Gift of Warren Reich.) (2.1; 1.1; 2.3; 4.1.2; 4.1.3; 8.1; 8.3.1; 8.4; 8.5; 9.1; 9.2; 9.5.5; 9.5.7; 10; 11.1; 11.3; 12.1; 14.1; 15.1; 16.1; 18.2; 18.5.4; 19.5; 20.4.1; 20.5.1)


Kelly, David F. CONTEMPORARY CATHOLIC HEALTH CARE ETHICS. Washington, DC: Georgetown University Press, 2004. 336 p. ISBN 1-58901-030-2. (Gift of the publisher.) [R725.5 .K438 2003] (2.1; 1.2; 4.4; 8.1; 9.7; 10; 11.1; 11.3; 12.1; 14.1; 15.1; 18.2; 18.5.4; 19.5; 20.4.1; 20.5.1)

Khushf, George, ed. HANDBOOK OF BIOETHICS: TAKING STOCK OF THE FIELD FROM A PHILOSOPHICAL PERSPECTIVE. Dordrecht/Boston: Kluwer Academic, 2004. 568 p. ISBN 1-4020-1870-3. (Philosophy and Medicine Series; Vol. 78.) [R725.5 .H36 2004] (2.1; 1.1; 2.2; 4.1.2; 4.1.3; 8.1; 8.3.1; 9.1; 9.3.1; 9.4; 9.5.2; 9.6; 10; 15.3; 17.1; 18.1; 20.4.1; 20.5.1; 20.5.4)


Macer, Darryl R.J., ed. CHALLENGES FOR BIOETHICS FROM ASIA: THE PROCEEDINGS OF THE FIFTH ASIAN BIOETHICS CONFERENCE. Christchurch, New Zealand/Ibaraki, Japan: Eubios Ethics Institute, 2004. 646 p. ISBN 0-908897-22-7. (Proceedings of the Fifth Asian Bioethics Conference held 13-16 February 2004 in Tsukuba Science City, Japan. Publisher’s address: 31 Colwyn Street, Christchurch 8005, New Zealand [or] PO Box 125, Tsukuba Science City, Ibaraki 305-8691, Japan. Gift of the editor.) (2.1; 1.2; 1.3.12; 2.3; 4.1.3; 5.3; 14.1; 15.1; 15.2; 15.3; 15.4; 15.5; 15.8; 15.10; 16.1; 21.1)


McMahon, Kevin T. MORAL ISSUES IN CATHOLIC HEALTH CARE. Wynnewood, PA: The John Cardinal Krol Chair of Moral Theology, Saint Charles Borromeo Seminary, 2004. 182 p. ISBN 0-9753171-0-5. (Publisher’s address: 100 East Wynnewood Road, zip 19096.) [2.1; 1.1; 4.4; 8.1; 9.7; 10; 11.1; 11.3; 12.1; 14.1; 15.1; 18.2; 18.5.4; 19.5; 20.4.1; 20.5.1)


Montgomery, Jonathan. HEALTHCARE LAW. Oxford/New York: Oxford University Press, 2003. 515 p. ISBN 0-19-876574-6. (Second edition.) [KD3395 .M66 2003] (2.1; 8.3.1; 8.4; 8.5; 9.1; 9.2; 9.5.5; 9.5.7; 12.1; 14.1; 17.1; 18.1; 19.1; 20.5.1; LE)

Morgan, Derek. ISSUES IN MEDICAL LAW AND ETHICS. London: Cavendish, 2001. 281 p. ISBN 1-85941-591-1. (KD3395 .M67 2001) (2.1; 1.3.8; 4.4; 5.2; 9.4; 10; 14.1; 14.3; 15.1; LE)


Numbers in ( ) = NRCBL Classification Numbers
2.3 BIOETHICS: EDUCATION/PROGRAMS

2.3 BIOETHICS: EDUCATION/PROGRAMS

Section III

1.4020-1053-2. (Philosophy and Medicine Series; Vol. 77.) [RT725.5 .C668 2002] (2.1; 1.1; 1.2; 4.4; 5.1; 9.5.7; 20.5.1; 20.5.2)


Wear-Finkle, Deborah. LEGAL PRINCIPLES OF MEDICAL PRACTICE EXPLAINED. Port Huron, MI/London, Ontario: Rapid Psychler Press, 2003. 128 p. ISBN 1-894328-27-2. (Publisher’s address: 3560 Pine Grove Avenue, Suite 374, zip 48060 [or] 1673 Richmond Street, Suite 203, postal code N6G 2N3.) (2.1; 4.3; 8.1; 8.3.1; 8.3.2; 8.3.4; 8.4; 9.6; 9.8; 18.2; 20.5.1; 20.7; LE)


2.3 BIOETHICS: EDUCATION/PROGRAMS

Dubler, Nancy N. and Liebman, Carol B. BIOETICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS. New York: United Hospital Fund of New York, 2004. 236 p. ISBN 1-881277-70-4. (Publisher’s address: 350 Fifth Avenue, 23rd Floor, zip 10118-2399. Gift of the publisher.) [RT723.5 .D83 2004] (2.1; 4.3; 8.1; 8.3.1; 8.3.2; 8.3.4; 8.4; 9.6; 9.8; 18.2; 20.5.1; 20.7; LE)

Levinson, Ralph and Reiss, Michael J., eds. KEY ISSUES IN BIOETICS: A GUIDE FOR TEACHERS. London/New York: RoutledgeFalmer, 2003. 182 p. ISBN 0-415-27068-5. (2.3; 1.3.11; 14.2; 14.4; 14.5; 15.3; 22.2; 22.3)


3.1 PHILOSOPHY OF BIOLOGY

(GENERAL)


3.2 EVOLUTION AND CREATION


Dembski, William A., ed. UNCOMMON DISSENT: INTELLECTUALS WHO FIND DARWINISM UNCONVINCING. Wilmington, DE: ISI Books, 2004. 366 p. ISBN 1-932236-31-7. (Publisher’s address: 3901 Centerville Road, PO Box 4431, zip 19807-0431. Gift of the publisher.) (3.2; 1.2; 5.1)

Falk, Darrel R. COMING TO PEACE WITH SCIENCE: BRIDGING THE WORLDS BETWEEN FAITH AND BIOLOGY. Downers Grove, IL: InterVarsity Press, 2004. 235 p. ISBN 0-8208-2742-0. (Gift of the publisher.) (3.2; 1.2; 15.1)


Russell, Robert John; Stoeger, William R.; and Ayala, Francisco J., eds. EVOLUTIONARY AND MOLECULAR BIOL-

Ryan, Frank X., ed. DARWIN’S IMPACT: SOCIAL EVOLUTION IN AMERICA. 1880–1920. Bristol: Thoemmes Press, 2001. 3 volumes. ISBN 1-85506-910-5 [set]. (History of American Thought series. Volume 1: Social Darwinism and its Critics; Volume 2: Race, Gender, and Supremacy; Volume 3: Evolution, Law, and Economics. Publisher’s address: 11 Great George Street, postal code BS1 5RR.) (3.2; 1.1; 1.3.2; 1.3.5; 1.3.8; 10; 15.5; 15.9; 21.2)

4.1.1 PHILOSOPHY OF MEDICINE, NURSING, ETC. (GENERAL)


Johnston, Robert D., ed. THE POLITICS OF HEALING: HISTORIES OF ALTERNATIVE MEDICINE IN TWENTIETH-CENTURY NORTH AMERICA. New York: Routledge, 2004. 388 p. ISBN 0-415-93339-0. (4.1.1; 7.1; 9.1; 9.5.1; 9.5.5; 9.7; 10; 21.1)


4.1.2 PHILOSOPHY OF MEDICINE


Cutter, Mary Ann G. REFRAMING DISEASE CONTEXTUALLY. Dordrecht/Boston: Kluwer Academic, 2003. 189 p. ISBN 1-4020-1796-0. (Philosophy and Medicine series; Vol. 81.) [R723 .C88 2003] (4.1.2; 4.2; 9.5.5; 9.5.6; 10; 15.1)


Steen, Win J. van der; Ho, Vincent K.Y.; and Karmelk, Ferry J. BEYOND BOUNDARIES OF BIOMEDICINE: PRAGMATIC PERSPECTIVES ON HEALTH AND DISEASE. Amsterdam/New York: Rodopi, 2003. 292 p. ISBN 90-420-0816-4. (At the Interface/Probing the Boundaries series; Vol. 4.) (4.1.2; 1.2; 4.1.1; 4.2; 7.1; 9.7; 17.1; 17.4; 21.7)

4.1.3 PHILOSOPHY OF NURSING

4.3 CONCEPT OF MENTAL HEALTH

Bourgeault, Ivy; Benoit, Cecilia; and Davis-Floyd, Robbie, eds. RECONCEIVING MIDWIFERY. Montreal/Ithaca, NY: McGill-Queen’s University Press, 2004. 335 p. ISBN 0-7735-2690-0. (4.1.3; 1.3.5; 4.1.1; 7.1; 7.2; 7.3; 9.5.1; 1.3.5)

Cady, Rebecca F. and Carcio, Helen A. THE ADVANCED PRACTICE NURSE’S LEGAL HANDBOOK. Philadelphia: Lippincott Williams & Wilkins, 2003. 304 p. ISBN 0-7817-2337-X. [RT86 .C33 2003] (4.1.3; 2.1; 4.1.1; 8.1; 8.3.1; 8.5; 9.3.1; 9.5.6; LE)

Cusveller, Bart; Sutton, Agneta; and O’Mathúna, Dónal, eds. COMMITMENT AND RESPONSIBILITY IN NURSING: A FAITH-BASED APPROACH. Sioux Center, IA: Dordt College Press, 2004. 174 p. ISBN 0-932914-51-9. (Publisher’s address: 498 4th Avenue, NE, zip 51250-1606. Gift of the publisher.) [RT85 .C65 2004] (4.1.3; 2.1; 4.1.1; 7.3; 8.1; 10; 20.4.1; 20.5.1)


Ellis, Janice Rider and Hartley, Celia Love. NURSING IN TODAY’S WORLD: TRENDS, ISSUES & MANAGEMENT, Philadelphia: Lippincott Williams & Wilkins, 2004. 576 p. ISBN 0-7817-4108-X. (Eighth edition.) [RT85 .C51 2004] (4.1.3; 1.3.5; 4.1.1; 7.1; 7.2; 7.3; 9.5.1; 15.1; 19.1; 20.5.1; 21.1; 22.2)


Storch, Janet L.; Rodney, Patricia; and Starzomski, Rosalie, eds. TOWARDS A MORAL HORIZON: NURSING ETHICS FOR LEADERSHIP AND PRACTICE. Toronto: Pearson/Prentice Hall, 2004. 575 p. ISBN 0-13-139716-8. (Gift of the publisher.) (4.1.3; 1.1; 1.2; 6.7; 9.5.5; 9.5.7; 15.1; 19.1; 20.5.1; 21.1; 22.2)


4.3 CONCEPT OF MENTAL HEALTH


Numbers in ( ) = NRCBL Classification Numbers

620
4.4 QUALITY/VALUE OF LIFE/PERSOHNHOOD


Bainham, Andrew; Sclater, Shelley Day and Richards, Martin, eds. BODY LORE AND LAWS. Oxford/Portland, OR: Hart Publishing, 2002. 346 p. ISBN 1-84113-197-0. (Distributed in North America by: Hart Publishing, c/o International Specialized Book Services, 5804 NE Hassalo Street, Portland, OR 97213-3644; distributed in The Netherlands, Belgium and Luxembourg by: Intersentia, Churchillaan 108, B2900 Schoten, Antwerpen, Belgium.) (4.4; 1.2; 7.2; 9.5.5; 9.5.7; 10; 15.3; 15.5; 15.7; 15.8; 20.5.1; LE)


4.5 ENHANCEMENT

Fuchs, Michael; Lanzerath, Dirk; Hillebrand, Ingo; Runkel, Thomas; Balcerak, Magdalena; and Schmitz, Barbara. ENHANCEMENT: DIE ETHISCHE DISKUSSION ÜBER BIOMEDIZINISCHE VERBESSERUNGEN DES MENSCHEN. Bonn: Deutsches Referenzzentrum für Ethik in den Biowissenschaften, 2002. 132 p. ISBN 3-400-010038-5. (DRZE-Sachstandsbericht series; Heft 1. ISSN 1611-3195. Gift of Deutsches Referenzzentrum für Ethik in den Biowissenschaften [DRZE].) (4.5; 1.1; 9.5.1; 9.5.7; 15.1; 17.4)


5.1 SCIENCE, TECHNOLOGY AND SOCIETY

5.3 SOCIAL CONTROL OF SCIENCE/TECHNOLOGY


Biagioli, Mario and Galison, Peter, eds. SCIENTIFIC AUTHORITY: CREDIT AND INTELLECTUAL PROPERTY IN SCIENCE. New York: Routledge, 2003. 384 p. ISBN 0-415-94293-4. (Papers from a symposium held in March 1997 in Cambridge, MA. Gift of the publisher.) [K1401.G3 C67 2004] (5.3; 1.3.4; 1.3.7; 1.3.9; 3.2; 5.1; 21.7)


Eaton, Margaret L. ETHICS AND THE BUSINESS OF BIOSCIENCE. Stanford, CA: Stanford University Press, 2004. 534 p. ISBN 0-8046-4250-2. (Gift of the publisher.) (5.3; 1.1; 1.3.2; 9.5.6; 9.7; 18.3; 18.5.1; 18.6; 21.1; 22.2)


6 CODES OF/POSITION STATEMENTS ON PROFESSIONAL ETHICS


American Psychiatric Association [APA]. OPINIONS OF THE ETHICS COMMITTEE ON THE PRINCIPLES OF MEDICAL
7.1 SOCIOLOGY OF HEALTH CARE (GENERAL)


Conrad, Peter and Leiter, Valerie, eds. HEALTH AND HEALTH CARE AS SOCIAL PROBLEMS. Lanham, MD: Rowman & Littlefield, 2003. 369 p. ISBN 0-7425-2857-X. (Understanding Social Problems series.) (7.1; 7.4; 8.1; 8.5; 9.5.2; 9.5.4; 9.5.5; 9.5.6; 9.5.7; 9.5.9; 10; 12.1; 17.3; 17.4; 18.5.2)


Knatterud, Mary Ellen.  FIRST DO NO HARM: EMPATHY AND THE WRITING OF MEDICAL JOURNAL ARTICLES. New York: Routledge, 2002. 161 p. ISBN 0-415-93387-0. (American Popular History and Culture series. “This qualitative descriptive study examines how various members of a certain discourse community of academic physicians have constructed patients on paper over time—with emphasis on the classical concept of pathos, of its modern equivalent, empathy. The most pertinent lexical and syntactic choices made with disregard to patients are delineated in five editions of the New England Journal of Medicine (NEJM), spaced 30 years apart—March 25, 1828; March 25, 1858; March 29, 1888; March 28, 1918; and March 25, 1948.”) [R119. K56 2002] (7.1; 1.3.7)


Lancaster, J., guest ed.  Ethical Issues in Interventions in Family and Community Health. FAMILY & COMMUNITY HEALTH 2001 January; 23(4): 1-83. (ISSN 0160-6379.) (7.1; 7.2; 9.5.1; 9.5.4; 20.3.3)


Miller, Julia R.; Lerner, Richard M.; Schiamberg, Lawrence B.; and Anderson, Pamela M., eds.  THE ENCYCLOPEDIA OF HUMAN ECOLOGY. Santa Barbara, CA: ABC-CLIO, 2003. 2 volumes. [760 p.] ISBN 1-57607-852-3. (Gift of the publisher.) [GF4 .E53 2003] (7.1; 1.3.1; 9.5.1; 9.5.7; 9.5.9; 16.1; 17.1; 20.1)


Scambler, Graham, ed.  SOCIOLOGY AS APPLIED TO MEDICINE. Edinburgh/New York: Saunders, 2003. 328 p. ISBN 0-7202-2665-4. (Fifth edition. Gift of the publisher.) [RA418 .S67373 2003] (7.1; 2.1; 4.2; 8.1; 9.1; 9.3.1; 9.5.2; 9.5.4; 9.5.5)


Smith, George Davey, ed.  HEALTH INEQUALITIES: LIFECOURSE APPROACHES. Bristol: Polity Press, 2003. 548 p. ISBN 1-86134-322-1. (Studies in Poverty, Inequality and Social Exclusion series.) (7.1; 9.3.1; 9.4; 9.5.1; 9.5.4; 9.5.10; 10; 13.1)


Smith, George Davey, ed.  HEALTH INEQUALITIES: LIFECOURSE APPROACHES. Bristol: Polity Press, 2003. 548 p. ISBN 1-86134-322-1. (Studies in Poverty, Inequality and Social Exclusion series.) (7.1; 9.3.1; 9.4; 9.5.1; 9.5.4; 9.5.10; 10; 13.1)


7.2 EDUCATION FOR HEALTH CARE PROFESSIONALS


Weiss, Gregory L. and Lonnquist, Lynne E. **368 p. ISBN 1-55728-756-2.** (7.1; 7.2; 9.5.4)

Weiss, Gregory L. and Lonnquist, Lynne E. **SOUTH.** New York: Basic Books, 2002. 1-84046-373-2.) [RB153 .W34 2002] (7.1; 4.2; 5.3; 9.5.1)

ISBN 0-231-13150-X. (Revolutions in Science series. EASE YEARS THAT TRANSFORMED THE WAY WE THINK ABOUT DISEASE. Upper Saddle River, NJ: Prentice Hall, 2003. 401 p. ISBN 0-13-098137-0. (Fourth edition.) [RA418.3 .U6 W45 2003] (7.1; 2.1; 4.1.1; 5.1; 7.2; 7.3; 8.1; 8.3.4; 9.1; 9.3.1; 9.3.2; 9.4; 14.1; 19.5; 21.1)

7.2 EDUCATION FOR HEALTH CARE PROFESSIONALS


Welie, Jos V.M. and Kissell, Judith Lee, eds. **INTO THE SOUL OF MEDICINE** (JESUIT STUDIES IN THEOLOGY SERIES; NO. 42. Gift of the publisher.) [R118 .M39 2003] (8.1; 1.2; 1.3.12; 4.1.1; 14.1; 18.5.1; 19.5.10)

7.3 PROFESSIONAL-PROFESSIONAL RELATIONSHIP

Cassidy, Barry Allen. **DIFFERENCES IN PHILOSOPHICAL, PROFESSIONAL, AND INTERPERSONAL ATTITUDES BETWEEN NURSES AND PHYSICIANS IN CRITICAL CARE.** Ann Arbor, MI: University Microfilms International [UMI], 1995. 223 p. (Publication Order No. AAT-9537918. Dissertation, (Ph.D.)—The Union Institute, 1995.) (7.3; 4.1.2; 4.1.3; 7.1; 8.1; 9.3.1; 9.4; 9.6; 17.1; 20.5.1)


Klass, Perri. **THE MYSTERY OF BREATHING.** Boston: Houghton Mifflin, 2004. 344 p. ISBN 0-618-10961-7. ("Dr. Maggie Claymore is a leading neonatologist at a bustling Boston hospital. She works with the smallest and sickest patients: premature babies so ill that other doctors might give up on them. Maggie is fiercely devoted, despite the ethical conundrums that arise daily on the highest-tech edge of medicine—and in spite of colleagues who feel she often risks too much... Maggie’s orderly life begins to unravel when she gets an anonymous note calling her ethics and reputation into question. At first she is able to ignore the increasingly virulent letters, but when her accuser goes public—putting up hate-filled warning posters around the hospital implicating her in a child’s death—Maggie finds herself mired in a personal and professional hell.”) (7.3; 2.1; 8.1; 9.5.7; 14.1; 20.1; Fiction)

8.1 PROFESSIONAL-PATIENT RELATIONSHIP (GENERAL)

Crawshaw, Ralph. **COMPASSION’S WAY: A DOCTOR’S QUEST INTO THE SOUL OF MEDICINE.** Bloomington, IL: Medi-Ed Press, 2002. 646 p. ISBN 0-936741-15-5. (Publisher’s address: #5 White Place, zip 61701; Web: http://www.Medi-EdPress.com.) [R153 .C73 2002] (8.1; 1.1; 2.1; 2.2; 4.1.2; 4.4; 6; 7.2; 7.4; 20.7; Biography)

Ethical Issues in Surgical Treatment and Research. CURRENT PROBLEMS IN SURGERY 2003 July; 40(7): 353-448. (ISSN 0011-3840.) (8.1; 2.1; 7.2; 8.3.1; 8.3.4; 9.4; 18.5.1; 19.5; 20.5.1)


Mazur, Dennis J. **THE NEW MEDICAL CONVERSATION: MEDIA, PATIENTS, DOCTORS, AND THE ETHICS OF SCIENTIFIC COMMUNICATION.** Lanham, MD: Rowman & Littlefield, 2003. 187 p. ISBN 0-7425-2029-3. (Gift of the publisher.) [R118.M39 2003] (8.1; 1.3.7; 1.3.9; 5.2; 5.3; 8.3.1; 18.2)

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Numbers in ( ) = NRCBL Classification Numbers
8.3.1 INFORMED CONSENT (GENERAL)


8.4 CONFIDENTIALITY

Koggel, Christine M.; Furlong, Allannah; and Levin, Charles, eds. CONFIDENTIAL RELATIONSHIPS: PSYCHOANALYTIC, ETICAL, AND LEGAL CONTEXTS. Amsterdam/New York: Rodopi, 2003. 263 p. ISBN 90-420-0835-0. (Value Inquiry Book Series; Vol. 141.) [RC455.2 .E8 C655 2003] (8.4; 1.1; 1.3.12; 9.5.5; 10; 17.2; LE)

Privacy and the Law: A Symposium. GEORGE WASHINGTON LAW REVIEW 1999 June-August; 67(5-6): 1097-1322. (ISSN 0016-8076.) (8.4; 1.1; 1.3.5; 1.3.7; 10; 11.2; 21.1; LE)


REVIEW 1999 Symposium; 36(5): 1597-1864. (ISSN 0018-6694.) (9.1; 1.3.5; 4.2; 5.2; 7.1; 8.4; 8.5; 9.5.6; 9.5.9; 9.7; LE)

Exworthy, Mark; Stuart, Marian; Blane, David; and Marmot, Michael [and] Joseph Rowntree Foundation. TACKLING HEALTH INEQUALITIES SINCE THE ACHESON INQUIRY. Bristol, UK: Policy Press, 2003. 68 p. ISBN 1-86134-504-6. (“Published for the Joseph Rowntree Foundation.”) (9.1; 7.1; 9.5.4; 9.5.10)


Healthcare and the Law. OKLAHOMA CITY UNIVERSITY LAW REVIEW 2002 Fall; 27(3): 773-944. (ISSN 0364-9458.) (9.1; 8.3.3; 9.3.2; 9.5.5; 10; 20.4.1; 20.5.1; 20.5.4; LE)

Herzlinger, Regina E., ed. CONSUMER-DRIVEN HEALTH CARE: IMPLICATIONS FOR PROVIDERS, PAYERS, AND POLICYMAKERS. San Francisco: Jossey-Bass, 2004. 892 p. ISBN 0-7879-5258-3. (Gift of the publisher.) (9.1; 1.3.12; 5.3; 7.1; 9.3.1; 9.3.2; 9.7; 9.8; 15.1; 21.1)


Kronenfeld, Jennie Jacobs. HEALTH CARE POLICY: ISSUES AND TRENDS. Westport, CT: Praeger, 2002. 203 p. ISBN 0-275-97465-0. (9.1; 9.2; 9.3.1; 9.3.2; 9.5.2; 9.5.7; 12.1; 14.1; 17.1)

LeBow, Robert H. HEALTH CARE MELTDOWN: CONFRONTING THE MYTHS AND FIXING OUR FAILING SYSTEM. Chambersburg, PA: Alan C. Hood, 2004. 281 p. ISBN 0-911469-23-0. (Publisher’s address: PO Box 775, zip 17201.) (9.1; 7.1; 9.3.1; 9.3.2; 9.7; 21.1)


9.3.1 HEALTH CARE ECONOMICS (GENERAL)


Feldman, Penny Holland, guest ed. From Philosophy to Practice: Selected Issues in Financing and Coordinating Long-Term Care. JOURNAL OF AGING AND HEALTH 2003 February; 15(1): 5-291. (ISSN 0898-2643.) (9.3.1; 9.3.2; 9.5.10)


Hammer, Peter J.; Haas-Wilson, Deborah; Peterson, Mark A.; and Sage, William M., eds. UNCERTAIN TIMES: KEN-
9.3.2 MANAGED CARE

SECTION III

NETH ARROW AND THE CHANGING ECONOMICS OF HEALTH CARE. Durham, NC: Duke University Press, 2003. 339 p. ISBN 0-8223-3248-5. (Gift of the publisher.) (9.3.1; 1.3.2; 2.1; 7.1; 9.3.2; 9.8)


9.3.2 MANAGED CARE


Symposium [Managed Care]. SAINT LOUIS UNIVERSITY LAW JOURNAL 2003 Spring; 47(2): 217-421. (ISSN 0036-3030.) (9.3.2; 8.5; 9.4; 9.7; LE)

Numbers in ( ) = NRCBL Classification Numbers

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SECTION III 9.4 ALLOCATION OF HEALTH CARE RESOURCES


Light, Donald and Hughes, David, guest eds. SPECIAL ISSUE: SOCIOLOGICAL PERSPECTIVES ON HEALTH CARE RATIONING. SOCIOLOGY OF HEALTH & ILLNESS 2001 September; 23(5): 551-746. (ISSN 0141-9889.) (9.4; 5.2; 7.1; 9.1; 9.3.1)


Shaw, George Bernard. THE DOCTOR’S DILEMMA. Boston: IndyPublish.com, 2003. 107 p. ISBN 1-4043-4803-4. (“A well-respected physician is forced to choose whom he shall save: A bumbling friend or the ne’er-do-well artist husband of the woman he loves.”) [PR5365 .D63 2003] (9.4; 7.1; Fiction)


Beran, Roy G., ed. EPILEPSY AND LAW. Tel-Aviv: YOZMOT Heiliger, 1996. 266 p. ISBN 965-7077-01-X. (“International Center for Health, Law & Ethics Library.”) The papers included in this publication were initially presented at the 21st International Epilepsy Congress [1995] in Sydney, Australia. Publisher’s address: PO Box 56055, Tel Aviv 61560. Gift of the publisher.) [RC372 .A2 E64 1996] (9.5.1; 1.3.7; 8.1; 8.3.1; 8.3.3; 9.7; 18.5.1; 19.4; LE)


Denniston, George C.; Hodges, Frederick Mansfield; Milos, Marilyn Fayre, eds. UNDERSTANDING CIRCUMCI-
9.5.2 HEALTH CARE FOR THE AGED

SECTION III


Hay, M. Cameron. REMEMBERING TO LIVE: ILLNESS AT THE INTERSECTION OF ANXIETY AND KNOWLEDGE IN RURAL INDONESIA. Ann Arbor: University of Michigan Press, 2001. 345 p. ISBN 0-472-06785-0. (Southeast Asia: Politics, Meaning, Memory series.) [DS632 .S38 H38 2001] (9.5.1; 1.3.2; 4.1.1; 7.1; 9.5.2; 9.5.5; 9.7; 16.3)


Levine, Carol and Murray, Thomas H., eds. THE CULTURES OF CAREGIVING: CONFLICT AND COMMON GROUND AMONG FAMILIES, HEALTH PROFESSIONALS, AND POLICY MAKERS. Baltimore, MD: Johns Hopkins University Press, 2004. 187 p. ISBN 0-8018-7863-2. (Gift of the publisher.) (9.5.1; 7.1; 7.3; 8.1; 9.5.2; 17.1)


Siegler, Eugenia L.; Mirafzali, Saeid; and Foust, Janice B., eds. AN INTRODUCTION TO HOSPITALS AND INPATIENT CARE. New York: Springer Publishing Company, 2003. 351 p. ISBN 0-8261-2194-2. [RA981 .A2 I5526 2003] (9.5.1; 1.3.12; 7.3; 8.1; 9.6; 9.8; 17.3; 18.2; 20.5.1; 21.7)

Swain, John; French, Sally; Barnes, Colin; and Thomas, Carol, eds. DISABLING BARRIERS—ENABLING ENVIRONMENTS. London/Thousand Oaks, CA: Sage, 2004. 306 p. ISBN 0-7619-4265-3. (Second edition. Gift of the publisher.) (9.5.1; 1.3.7; 4.2; 5.3; 7.1; 9.3.1; 9.5.2; 9.5.5; 9.5.7; 15.1; 15.5; 21.1; LE)


9.5.3 HEALTH CARE FOR MENTALLY DISABLED PERSONS


Disability Law Symposium: Legal and Treatment Issues. THOMAS M. COOLEY LAW REVIEW 2000; 17(1): 1-181. (ISSN 1060-1007.) (9.5.3; 1.3.8; 2.2; 8.3.4; 9.2; 9.3.2; 9.5.7; 17.7; 17.8)

Health care and the Americans with Disabilities Act. HOUSTON LAW REVIEW 2000 Symposium; 37(4): 979-1248. (ISSN 0018-6694.) (9.5.3; 4.2; 8.1; 9.3.2; 9.5.1; 9.5.6; 17.7)


Hogenboom, Marga. LIVING WITH GENETIC SYNDROMES ASSOCIATED WITH INTELLECTUAL DISABILITY. London/Philadelphia: Jessica Kingsley, 2001. 143 p. ISBN 1-85302-984-X. [RC570.2.H64 2001] (9.5.3; 9.5.7; 15.6)

Noll, Steven and Trent, Jr., James W., eds. MENTAL RETARDATION IN AMERICA: A HISTORICAL READER. New York: New York University Press, 2004. 513 p. ISBN 0-8147-8248-5. (The History of Disability series. Gift of the publisher.) [HV3006 .A4 M435 2004] (9.5.3; 1.3.5; 2.2; 4.3; 7.1; 9.5.7; 11.3; 15.5; 20.6; LE)


Symposium: Joint Conference on Legal/Ethical Issues in the Progression of Dementia. GEORGIA LAW REVIEW 2001 Winter; 35(2): 451-834. (ISSN 0016-8300. Special Issue.) (9.5.3; 1.3.8; 4.3; 8.3.3; 8.5; 9.1; 9.3.1; 9.5.2; 15.3; 20.4.1; 20.5.1; 20.5.4; 21.7; LE)


9.5.4 HEALTH CARE FOR MINORITIES

Coker, Naaz. RACISM IN MEDICINE: AN AGENDA FOR CHANGE. London: King’s Fund, 2001. 241 p. ISBN 1-85717-407-0. (Publisher’s address: 11-13 Cavendish Square, postal code W1G 0AN.) [RA563 .M56 R335 2001] (9.5.4; 7.1; 7.2; 7.3; 8.1; 9.1; 21.7)


9.5.5 HEALTH CARE FOR WOMEN


Minkin, Mary Jane and Wright, Carol V. THE YALE GUIDE TO WOMEN'S REPRODUCTIVE HEALTH: FROM MENARCHE TO MENOPAUSE. New Haven, CT: Yale University Press, 2003. 448 p. ISBN 0-300-09820-0. (Rose Fitzgerald Kennedy Collection on Women, Infants and Children. Gift of the publisher.) [RG121 .M667 2003] (9.5.5; 10; 11.1; 12.1; 14.1)


9.5.6 HIV INFECTION AND AIDS

9.5.6 HIV INFECTION AND AIDS


Klitzman, Robert and Bayer, Ronald. MORTAL SILENCES: TRUTH AND LIES IN THE AGE OF AIDS. Baltimore, MD: Johns Hopkins University Press, 2003. 218 p. ISBN 0-8018-7427-0. (“Drawing from interviews with more than seventy gay men and women, intravenous drug users, sex workers, bisexual men, and heterosexual men and women. . .”) (9.5.6; 7.1; 8.4; 9.1; 10)


Messer, Donald E. BREAKING THE CONSPIRACY OF SILENCE: CHRISTIAN CHURCHES AND THE GLOBAL AIDS CRISIS. Minneapolis, MN: Fortress, 2004. 192 p. ISBN 0-8006-3641-4. (Prisms series. Gift of the publisher.) (9.5.6; 1.2; 7.1; 9.5.1; 9.5.5; 9.5.7; 10; 21.1)


Symposium on Health Care Policy: What Lessons Have We Learned From the AIDS Pandemic? ALBANY LAW REVIEW 1998; 61(3): 671-1158. (ISSN 0002-4678.) (9.5.6; 1.3.2; 1.3.8; 7.1; 8.1; 8.4; 9.2; 9.3.2; 9.4; 9.5.3; 9.5.10; 16.3; 20.1; LE)


Willinger, Barbara I. and Rice, Alan, eds. A HISTORY OF AIDS SOCIAL WORK IN HOSPITALS: A DARING RESPONSE TO AN EPIDEMIC. New York: Haworth Press, 2003. 360 p. ISBN 0-7890-1587-0. [RA643.83.H57 2003] (9.5.6; 1.3.10; 2.2; 7.1; 9.1; 9.3.2; 9.5.7; 17.1; 20.4.1)
9.5.7 HEALTH CARE FOR MINORS

D’Antonio, Michael. THE STATE BOYS REBELLION. New York: Simon & Schuster, 2004. 308 p. ISBN 0-7432-4512-1. (Rose Fitzgerald Kennedy Collection on Women, Infants and Children. Gift of the publisher.) (9.5.7; 9.5.3; 11.3; 15.5; 15.6; 16.2; 17.4; 17.5; 17.6; 18.5.2)


9.5.8 HEALTH CARE FOR EMBRYOS AND FETUSES

Carrera, José M.; Chervenak, Frank A.; and Kurjak, Asim, eds. CONTROVERSY IN PERINATAL MEDICINE: STUDIES ON THE FETUS AS A PATIENT. New York: Parthenon Publishing Group, 2003. 306 p. ISBN 1-84214-230-5. [RG626 .C66 2003] (9.5.8; 5.1; 7.1; 9.5.5; 14.1; 15.2; 15.3)

Chervenak, Frank A.; Kurjak, Asim; Papp, Zoltan, eds. FETUSES AS A PATIENT: THE EVOLVING CHALLENGE. New York: Parthenon, 2002. 344 p. ISBN 1-84214-157-0. [RG628 .3 .U58 F49 2002] (9.5.8; 8.3.1; 9.5.5; 9.5.9; 12.1; 15.2; 18.5.4)

9.5.9 HEALTH CARE FOR SUBSTANCE ABUSERS/USERS OF CONTROLLED SUBSTANCES


9.5.10 HEALTH CARE FOR INDIGENTS


Grell, Ole Peter; Cunningham, Andrew; and Jütte, Robert. HEALTH CARE AND POOR RELIEF IN 18TH AND 19TH CENTURY NORTHERN EUROPE. Aldershot, Hants/Burlington, VT: Ashgate, 2002. 337 p. ISBN 0-7546-2075-3. (The History of Medicine in Context series.) (9.5.10; 1.3.5; 7.1; 9.3.1)

9.6 ETHICS

COMMITTEES/CONSULTATION


9.7 DRUGS AND PHARMACEUTICAL INDUSTRY


Numbers in ( ) = NRCBL Classification Numbers
SECTION III

9.8 QUALITY OF HEALTH CARE


Quadros, Ciro A. de, ed. VACCINES: PREVENTING DISEASE AND PROTECTING HEALTH. Washington, DC: Pan American Health Organization [PAHO], 2004. 398 p. ISBN 92-75-11596-6. (Scientific and Technical Publication series; No. 596. Also published in Spanish in 2004 as: Vacunas: Prevención de enfermedades y protección de la salud; ISBN 92-75-31596-5.) (9.7; 1.3.11; 5.2; 9.1; 9.3.1; 9.5.1; 9.5.6; 15.1; 21.1; 21.2; 21.3)


9.8 QUALITY OF HEALTH CARE


Association of American Medical Colleges [AAMC]. Joint Committee of the Group on Resident Affairs and Organization of Resident Representatives. PATIENT SAFETY AND GRADUATE MEDICAL EDUCATION: A REPORT AND ANNOTATED BIBLIOGRAPHY. Washington, DC: Association of American Medical Colleges [AAMC], 2003. 22 p. (February 2003. Publisher’s address: 2450 N Street, NW, zip 20037-1127.) (9.8; 7.2)


Youngberg, Barbara J. and Hatlie, Martin, eds. THE PATIENT SAFETY HANDBOOK. Sudbury, MA: Jones and Bartlett, 2004. 779 p. ISBN 0-7637-3147-1. [HQ76.3 .U5 H6443 2004] (10; 1.1; 1.2; 15.6; 17.1; LE)

10 SEXUALITY/GENDER


11.1 CONTRACEPTION (GENERAL)


11.3 STERILIZATION


12.1 ABORTION (GENERAL)


12.3 ABORTION: MORAL AND RELIGIOUS ASPECTS


12.4.1 ABORTION: LEGAL ASPECTS (GENERAL)


12.5.1 ABORTION: SOCIAL ASPECTS (GENERAL)


Ferree, Myra Marx; Gans, William Anthony; Jürgen Gerhards; and Rucht, Dieter. SHAPING ABORTION DISCOURSE: DEMOCRACY AND THE PUBLIC SPHERE IN GERMANY AND THE UNITED STATES. Cambridge/New York: Cambridge University Press, 2002. 350 p. ISBN 0-521-79384-X. (Communication, Society, and Politics series.) (12.5.1; 1.2; 1.3.5; 1.3.7; 7.1; 12.3; 21.1)


12.5.2 ABORTION: DEMOGRAPHIC SURVEYS

Herring, Mark Y. THE PRO-LIFE/CHOICE DEBATE. Westport, CT: Greenwood Press, 2003. 200 p. ISBN 0-313-31710-0. (Historical Guide to Controversial Issues in America series. ISSN 1541-0021.) (12.5.2; 2.2; 7.1; 12.3; 12.4.2)


13.3 POPULATION POLICY


Tobin, Kathleen A. POLITICS AND POPULATION CONTROL: A DOCUMENTARY HISTORY. Westport, CT: Greenwood Press, 2004. 171 p. ISBN 0-313-32279-1. (Documentary Reference Collection series. Gift of the publisher.) (13.3; 1.2; 1.3.2; 5.3; 10; 11.1; 15.5; 21.1)
14.1 REPRODUCTION/REPRODUCTIVE TECHNOLOGIES (GENERAL)


Gerris, Jan; Olivennes, François; and Sutter, Petra De, eds. ASSISTED REPRODUCTIVE TECHNOLOGIES: QUALITY AND SAFETY. Boca Raton: Parthenon; Distributed by: Taylor & Francis, 2004. 290 p. ISBN 1-84214-313-1. (14.1; 1.1; 5.2; 7.1; 9.3.1; 9.8; 14.4; 15.2; 17.1; 21.1)


Lorber, Caroline. EXPERIENCES OF DONOR CONCEPTION: PARENTS, OFFSPRING AND DONORS THROUGH THE YEARS. London/Philadelphia: Jessica Kingsley, 2003. 208 p. ISBN 1-84310-122-X. (14.1; 7.1; 8.2; 8.4; 9.5.5; 9.5.7; 14.2; 17.1; 19.5)

Merrick, Janna C. and Blank, Robert H. REPRODUCTIVE ISSUES IN AMERICA: A REFERENCE HANDBOOK. Santa Barbara, CA: ABC-CLIO, 2003. 241 p. ISBN 1-57607-816-7. (Contemporary World Issues series. Gift of the publisher.) [RG133.5 .M47 2003] (14.1; 1.1; 11.3; 12.4.1; 12.5.2; 14.2; 14.5; 15.2; 18.5.4; Biography; Reference; LE)

Mullings, Leith and Wali, Alaka. STRESS AND RESILIENCE: THE SOCIAL CONTEXT OF REPRODUCTION IN CENTRAL HARI


Odent, Michel. THE FARMER AND THE OBSTETRICIAN. London: Free Association Press, 2002. 159 p. ISBN 1-85343-565-1. (“While interchangeing ideas the farmer and the obstetrician realise to what extent they both manipulate the laws of nature. They analyse the striking similarities between the industrialisation of farming and the industrialisation of childbirth, which developed side by side during the twentieth century.”) (14.1; 1.3.11; 5.3; 9.5.5; 16.1)


Pearson, Yvette E. PROCREATION AND OBLIGATION. Ann Arbor, MI: University Microfilms International [UMI], 2002. 221 p. (Publication Order No. AAT-3056625. Dissertation, (Ph.D.)—University of Miami, 2002.) (14.1; 1.1; 5.3; 9.3.1; 11.4; 14.2; 14.4)


14.2 ARTIFICIAL INSEMINATION AND SURROGACY

Cook, Rachel; Sclater, Shelley Day; and Kaganas, Felicity; eds. SURROGATE MOTHERHOOD: INTERNATIONAL PERSPECTIVES. Oxford/Portland, OR: Hart, 2003. 308 p. ISBN 1-84113-255-1. (14.2; 1.1; 1.2; 5.3; 9.3.1; 9.5.5; 14.4; 17.1; 21.1; LE)
14.4 IN VITRO FERTILIZATION AND EMBRYO TRANSFER


14.5 CLONING


Morgan, Sally. BODY DOUBLES: CLONING PLANTS AND ANIMALS. Chicago: Heinemann Library, 2002. 64 p. ISBN 1-58810-698-5. (Science at the Edge series. Juvenile literature.) [QH442.2 .M67 2002] (14.5; 1.3.11; 14.1; 15.1; 18.5.4; 19.1; 22.2; 22.3; POP)

Pence, Gregory E. CLONING AFTER DOLLY: WHO’S STILL AFRAID? Lanham, MD: Rowman & Littlefield, 2004. 211 p. ISBN 0-7425-3408-1. (Gift of the publisher.) [QH442.2 .P458 2004] (14.5; 1.2; 5.2; 14.1; 15.1; 18.5.4; 22.2)

SYMPOSIUM ON CLONING. SOUTHERN CALIFORNIA INTERDISCIPLINARY LAW JOURNAL 1998 Winter; 8(1): 87-284. (14.5; 1.1; 1.2; 1.3.8; 4.4; 5.2; 5.3; 14.2; 14.4; 18.1; 18.6; LE)

search, or therapeutic cloning, differs from human reproductive cloning and the ethical and public-policy issues related to both, and related issues of S. 1853 to ban human cloning while protecting stem cell research.” Available from: Superintendent of Documents, U.S. Government Printing Office, Stop SSOP, Washington, DC 20402-0001. Available on the Web at: http://www.senate.gov. (14.5; 1.3.5; 15.1; 19.1; 19.5; 18.5.3; 18.5.4)


15.1 GENETICS, MOLECULAR BIOLOGY AND MICROBIOLOGY (GENERAL) AND MICROBIOLOGY (GENERAL)

Agricultural Biotechnology: The Public Policy Challenges. ABS. AMERICAN BEHAVIORAL SCIENTIST 2000 November; 44(3): 310-522. ISBN 0-7619-0172-0. (ISSN 0002-7642.) (15.1; 1.3.11; 5.3; 15.7; 15.8; 16.1; 21.1)

Ahrens Torts Seminar: Genomic Torts. WASHBURN LAW JOURNAL 2003 Spring; 42(3): 413-628. (Special Issue.) (15.1; 4.4; 8.4; 8.5; 9.3.1; 9.7; 15.3; 16.3; LE)


Avise, John C. THE HOPE, HYPE, & REALITY OF GENETIC ENGINEERING: REMARKABLE STORIES FROM AGRICULTURE, INDUSTRY, MEDICINE, AND THE ENVIRONMENT. Oxford/New York: Oxford University Press, 2004. 242 p. ISBN 0-19-516950-6. (Gift of the publisher.) (15.1; 1.3.11; 9.7; 14.5; 15.4; 15.7; 16.1; 18.5.2; 18.5.4; 19.1; 22.2; 22.3; POP)


Bear, Greg. DARWIN’S RADIO. New York: Ballantine, 1999. 430 p. ISBN 0-345-42333-X. (“A Del Rey Book.” “Molecular biologist Kaye Lang, a specialist in retrovirus research, believes that ancient diseases encoded in the DNA of humans can again come to life. But her theory soon becomes chilling reality. For Christopher Dicken—a “virus hunter” at the Epidemic Intelligence Service—has pursued an elusive flu-like disease that strikes down expectant mothers and their offspring. The shocking link: something that has slept in our genes for millions of years is waking up.”) [PS3552 .E157 D43 1999] (15.1; 9.5.5; 9.5.8; Fiction)

Berry, Roberta Marie. RE-CREATING ADAM: A PHILOSOPHICAL INVESTIGATION OF THE GENETIC ENGINEERING OF HUMAN BEINGS. Ann Arbor, MI: UMI/ProQuest, 2003. 353 p. (Publication No. AAT-3108186. Dissertation, Ph.D.)—University of Notre Dame, 2003. Publisher’s address: 300 North Zeeb Road, PO Box 1346, zip 48106-1346.) (15.1; 1.1; 15.5; 15.6)


Bevington, Linda K.; Bohlin, Ray G.; Stewart, Gary P.; Kilner, John F.; and Hook, C. Christopher. BASIC QUESTIONS ON GENETICS, STEM CELL RESEARCH, AND CLONING: ARE THESE TECHNOLOGIES OKAY TO USE? Grand Rapids, MI: Kregel Publications, 2004. 125 p. ISBN 0-8254-3075-5. (BioBasic Series. Published for: The Center for Bioethics and Human Dignity [Bannockburn, IL]. Publisher’s address: PO Box 2607, Grand Rapids, MI 49501.) [R725.56 .B37 2004] (15.1; 1.2; 14.5; 15.2; 15.3; 15.4; 15.5; 15.6; 15.7; 15.10; 18.5.4)


Canadian Biotechnology Advisory Committee [CBAC] = Comité consultatif canadien de la biotechnologie [CCCB]. ANNUAL REPORT 2002 = RAPPORT ANNUEL DE 2002. Ottawa, Ontario, Canada: Canadian Biotechnology Advisory Committee [CBAC], 2003. [29 p.+ 33 p.] ISBN 0-662-67233-X. (ISSN 1497-8741; ISSN 1497-9969. Text in English and French on inverted pages. Available from: Canadian Biotechnology Advisory Committee [CBAC], 240 Sparks Street, Ottawa, Ontario K1A 0H5. Also available on the Web at: http://www.cbac-cccb.ca.) [TP249.195 .C2 C36 2002] (15.1; 1.3.11; 5.3; 8.4; 14.5; 15.8; 18.5.1; 18.5.4; 19.1; 22.2)


Eaglesham, Allan; Ristow, Sandra; and Hardy, Ralph W.F., eds. BIOTECHNOLOGY: SCIENCE AND SOCIETY AT A CROSROAD. Ithaca, NY: National Agricultural Biotechnology Council [NABC], 2003. 292 p. (NABC Report series; No. 15. Publisher’s address: Boyce Thompson Institute Rm. 419, Tower Road, zip 14853. Gift of the publisher.) (15.1; 1; 1.3.11; 5.2; 5.3; 15.7; 21.1; LE)


Glasner, Peter, ed. RECONFIGURING NATURE: ISSUES AND DEBATES IN THE NEW GENETICS. Aldershot, Hampshire/Burlington, VT: Ashgate, 2004. 330 p. ISBN 0-7546-3237-7. (Cardiff Papers in Qualitative Research series. Gift of the publisher.) [QH438.7 .R43 2004] (15.1; 1.3.12; 4.2; 5.3; 8.3.1; 9.3.1; 9.5.1; 14.5; 15.3; 15.6; 17.1; 22.2)


Genetic Technology: Social Values and Personal Autonomy in the 21st Century. WAKE FOREST LAW REVIEW 1999 Fall; 34(3): 557-913. (ISSN 0043-003X. Special Issue.) (15.1; 1.1; 1.3.5; 4.4; 5.3; 8.4; 8.5; 9.3.2; 11.4; 15.4; 15.5; 15.8; LE)


Guides series.) (15.1; 3.2; 5.3; 13.1; 14.5; 15.4; 15.7; 15.10; LE; POP)

Halford, Nigel G. GENETICALLY MODIFIED CROPS. London: Imperial College Press, 2003. 112 p. ISBN 1-86094-353-5. (Publisher’s address: 57 Shelton Street, Covent Garden, postal code WC2H 9HE.) [SB123.57 .H35 2003] (15.1; 1.3.11; 15.7; LE)


Honnefelder, Ludger; Mieth, Dietmar; Propping, Peter; Siep, Ludwig; and Weisemann, Claudia, eds. DAS GENETISCHE WISSEN UND DIE ZUKUNFT DES MENSCHEN. Berlin/New York: Walter de Gruyter, 2003. 418 p. ISBN 90-0413-678-9. (Consulting editors: Dirk Lanzerath, Rimas Cuplinskas and Rudolf Teuwsen. Gift of Deutsches Referenzzentrum für Ethik in den Biowissenschaften [DRZE].) (15.1; 4.4; 5.3; 9.7; 15.2; 15.3; LE)


Khoury, Muin J.; Little, Julian; and Burke, Wylie, eds. HUMAN GENOME EPIDEMIOLOGY: A SCIENTIFIC FOUNDATION FOR USING GENETIC INFORMATION TO IMPROVE HEALTH AND PREVENT DISEASE. Oxford/New York: Oxford University Press, 2004. 549 p. ISBN 0-19-514674-3. (15.1; 7.1; 9.1; 9.7; 13.1; 15.1; 15.3; 16.1; 16.3; 18.2)

Knoppers, Bartha Maria, ed. POPULATIONS AND GENETICS: LEGAL AND SOCIO-ETHICAL PERSPECTIVES. Leiden/Boston: Martinus Nijhoff, 2003. 648 p. ISBN 90-0413-678-9. (Proceedings of the Third International DNA Sampling Conference held in Montreal, Québec, 2002. Distributed in North America by: Brill Academic Publishers, PO Box 605, Herndon, VA20172; distributed elsewhere by: Turpin Distribution Services Limited, Blackhorse Road, Letchworth, Herts SG6 1HN, United Kingdom.) (15.1; 1.3.2; 1.3.12; 5.3; 8.3.1; 8.4; 9.3.1; 9.7; 13.1; 15.8; 21.1; LE)


Magill, Gerard. GENETICS AND ETHICS: AN INTERDISCIPLINARY STUDY. Saint Louis, MO: Saint Louis University Press, 2004. 360 p. ISBN 0-9652929-7-5. [QH438.7 .G445 2004] (15.1; 1.1; 1.3.2; 2.1; 4.4; 5.3; 7.2; 9.5.2; 9.7; 10; 14.5; 15.2; 15.3; 15.4; 18.5.2; 18.5.4; Reference; LE)


McGrath, Alister. DAWKIN’S GOD: GENES, MEMES, AND THE MEANING OF LIFE. Malden, MA: Blackwell, 2005. 202 p. ISBN 0-14501-2539-X. (Gift of the publisher.) (15.1; 1.2; 3.2; 5.1; 15.6)


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Borlaug. Prologue by John H. Moore. Gift of the publisher.) (15.1; 1.3.2; 1.3.5; 13.11; 5.3; 13.1; 15.7; 21.1; LE)


Notes on Moral Theology: Issues in Genetics. THEOLOGICAL STUDIES 1999 March; 60(1): 109-147. (ISSN 0040-5639.)(15.1; 1.2; 2.2; 5.2; 8.4; 14.5; 15.2; 15.3; 15.4; 15.8)


Scully, Jackie Leach. QUAKER APPROACHES TO MORTAL ISSUES IN GENETICS. Lewiston, NY: Edwin Mellen Press, 2002. 276 p. ISBN 0-7734-7064-6. (Quaker Studies series; Vol. 4.) [QH438.7 .S36 2002] (15.1; 1.2; 2.2; 4.4; 8.1; 8.4; 9.3.1; 15.8)

Shannon, Thomas A., ed. GENETICS, SCIENCE, ETHICS, AND PUBLIC POLICY: A READER. Lanham, MD: Rowman & Littlefield, 2005. 200 p. ISBN 0-7425-3238-0. (Readings in Bioethics series. “A Sheed & Ward Book.” Gift of the publisher.) (15.1; 8.3.2; 9.5.1; 9.5.3; 10.1; 13.1; 14.4; 14.5; 15.2; 15.3; 15.8; 18.5.4; 19.1; 19.5)


Sherwin, Byron L. GOLEM AMONG US: HOW A JEWISH LEGEND CAN HELP US NAVIGATE THE BIOTECH CENTURY. Chicago: Ivan R. Dee, 2004. 237 p. ISBN 1-56663-568-3. (Gift of the publisher. Max M. and Marjorie B. Kampelman Collection of Jewish Ethics.) (15.1; 1.1; 1.2; 1.3.2; 1.3.5; 1.3.11; 14.5; 18.5.4)
Smith, David H. and Cohen, Cynthia B., eds. A CHRISTIAN RESPONSE TO THE NEW GENETICS: RELIGIOUS, ETHICAL, AND SOCIAL ISSUES. Lanham, MD: Rowman & Littlefield, 2003. 190 p. ISBN 0-7425-1499-4. (Gift of Cynthia B. Cohen.) (15.1; 1.2; 4.4; 5.3; 9.3.1; 15.3; 15.4)

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Symposium: Legal and Ethical Issues in Genetic Research on Indigenous Populations. JURIMETRICS 2002 Winter; 42(2): 119-220. (ISSN 0022-6793. Special Issue.) (15.1; 2.1; 4.2; 4.4; 5.2; 9.5.4; 9.7; 13.1; 15.10; 18.3; 21.1; 21.7; LE)

Symposium: The Evaluation of Forensic DNA Evidence. JURIMETRICS 1997 Summer; 37(4): 395-506. (ISSN 0897-1277.) (15.1; 1.3.5; 5.1; LE)

Symposium: The Human Genome Project, DNA Science and the Law: The American Legal System's Response to Breakthroughs in Genetic Science. AMERICAN UNIVERSITY LAW REVIEW 2002 February; 51(3): 367-484. (ISSN 0003-1453. Special Issue.) (15.1; 1.3.5; 8.4; 9.3.1; 15.3; 15.8; 15.10; 18.3; LE)

Thomson, Jennifer A. GENES FOR AFRICA: GENETICALLY MODIFIED CROPS IN THE DEVELOPING WORLD. Landsdowne: UCT [University of Cape Town] Press, 2002. 197 p. ISBN 1-919-71357-3. (Publisher’s address: PO Box 24309, Landsdowne 7779, South Africa.) [SB123.57 .T49 2002] (15.1; 1.3.11; 5.2; 15.7; 15.8)

Tudge, Colin. SO SHALL WE REAP: HOW EVERYONE WHO IS LIKELY TO BE IN SERIOUS TROUBLE. London: Allen Lane, 2003. 437 p. ISBN 0-713-99640-4. (15.1; 1.3.2; 1.3.11; 5.3; 22.3)

Twenty-First Annual Health Law Symposium: “Human Genetics: Legal, Medical and Ethical Perspectives”. WHITTIER LAW REVIEW 2002 Winter; 24(2): 361-490. (ISSN 0195-7643.) (15.1; 4.4; 8.4; 15.2; 15.5; 15.8; 18.2; 18.3)


Wertz, Dorothy C. and Fletcher, John C. GENETICS AND ETHICS IN GLOBAL PERSPECTIVE. Dordrecht/Boston: Kluwer Academic, 2004. 474 p. ISBN 1-4020-1768-5. (International Library of Ethics, Law, and the New Medicine series; Vol. 17.) [QH438.7 .W47 2004] (15.1; 1.1; 1.3.5; 7.1; 8.4; 9.1; 14.3; 15.2; 15.3; 15.5; 15.11; 21.1; 21.7; LE)


Zimmer, Marc. GLOWING GENES: A REVOLUTION IN BIOTECHNOLOGY. Amherst, NY: Prometheus Books, 2005. 221 p. ISBN 1-59102-253-3. (Gift of the publisher.) (15.1; 1.3.11; 22.2; POP)

15.2 GENETIC COUNSELING/PRENATAL DIAGNOSIS

Düwell, Marcus and Mieth, Dietmar, eds. ETHIK IN DER HUMANGENETIK: DIE NEUEREN ENTWICKLUNGEN DER GENETISCHEN FRÜHDIAGNOSTIK AUS ETHISCHER Sicht. Augsburg Fortress, tel: 800-328-4648 [U.S. and Canada only]. Also available on the Web at: http://www.elca.org/dcs/genetics.study.html.) (15.1; 1.3.11; 22.2; POP)
SECTION III

15.3 GENETIC SCREENING/TESTING


15.3 GENETIC SCREENING/TESTING


Olsen, Sharon J.; Baxendale-Cox, Lynn; and Mock, Victoria, guest eds. Clinical Genetics. NURSING CLINICS OF NORTH AMERICA 2000 September; 35(3): 583-828. (ISSN 0029-6465. Special Issue.) (15.3; 4.1.3; 8.4; 9.3.1; 9.3.2; 16.1; 18.3; 18.5.1; 18.5.7; 16; LE)

Patenaude, Andrea Farkas. GENETIC TESTING FOR CANCER: PSYCHOLOGICAL APPROACHES FOR HELPING PATIENTS AND FAMILIES. Washington, DC: American Psychological Association, 2005. 305 p. ISBN 1-59147-110-9. (15.3; 1.1; 8.4; 8.3.1; 9.5.1; 9.5.2; 9.5.3; 9.5.4; 9.5.5; 9.5.7; 15.2; 15.3; 15.4; 16.1; 18.3; 18.5.1; 18.5.7; 19.2; LE)


15.4 GENE THERAPY/TRANSFER

Brehaney, John F. GERM-LINE GENETIC ENGINEERING: AN ANALYSIS OF PRINCIPLED ARGUMENTATION IN LIGHT OF A CRITICAL THEOLOGY OF THE BODY. Ann Arbor, MI: University Microfilms International [UMI], 2003. 319 p. (Publication No. AAT-3102873. Dissertation, (Ph.D.)—Saint Louis University, 2003.) (15.4; 1.1; 1.2; 2.2; 4.4; LE)


Rehmam-Sutter, Christoph and Müller, Hansjakob, eds. ETHIK UND GENTHERAPIE: ZUM PRAKTISCHEN DISKURS UM DIE MOLEKULARE MEDIZIN. Tübingen: Francke Verlag, 2003. 309 p. ISBN 3-7720-2617-6. (Second, revised and expanded edition. Ethik in den Wissenschaften series; Bd. 7.) (15.4; 2.1; 15.7)


15.5 EUGENICS


section III

15.5 EUGENICS


Evans, Suzanne E. FORGOTTEN CRIMES: THE HOLOCAUST AND PEOPLE WITH DISABILITIES. Chicago: Ivan R. Dee, 2004. 201 p. ISBN 1-56663-565-9. (Gift of the publisher.) [D804 .5 .H35 E93 2004] (15.5; 1.3.5; 9.5.1; 9.5.3; 9.5.7; 11.3; 20.5.1; 20.5.2; 21.4)

Falk, Raphael; Paul, Diane; and Allen, Garland, guest eds. EUGENIC THOUGHT AND PRACTICE: A REAPPRAISAL. SCIENCE IN CONTEXT 1998 Autumn-Winter; 11(3-4); 329-367. (ISSN 0269-8897. Special Issue.) (15.5; 1.3.5; 2.2; 4.2; 7.1; 8.4; 9.1; 9.3.1; 15.2; 15.3; 15.4; 15.6; 21.1; 21.7)


Llobetra, Josep R. MAKING OF TOTALITARIAN THOUGHT, Oxford/New York: Berg, 2003. 175 p. ISBN 1-85973-790-0. [JC480 .L596 2003] (15.5; 1.3.5; 2.2; 3.2)


RACE AND MEMBERSHIP IN AMERICAN HISTORY: THE EUGENICS MOVEMENT. Brookline, MA: Facing History and Ourselves National Foundation, 2002. 356 p. ISBN 0-9615841-9-K. (Publisher’s address: 16 Hurd Road, zip 02445.) (15.5; 1.3.5; 5.3; 11.3; 15.6; 15.11; 21.1; 21.4)


Richter, Ingrid. KATOLICISMUS UND EUGENIK IN DER WEIMARER REPUBLIK UND IM DRITTHEN REICH: ZWISCHEN SITTILICHKEITSREFORM UND RASSENHYGIENE. Paderborn: Ferdinand Schöningh, 2001. 572 p. ISBN 3-506-79993-2. (Veröffentlichungen der Kommission für Zeitgeschichte series; Reihe B; Forschungen; Bd. 88. Originally presented as the author’s thesis (Doctoral)—Universität Münster, under the title: Katholische Eugenik in der Weimarer Republik und im Dritten Reich: Zwischen Rassenhygiene und Sittlichkeitsparänese.) [HQ755.5 .G3 R53 2001] (15.5; 1.2; 1.3.5; 2.2; 11.3; 21.1)


Schütz, Horst. GESUNDHEITSFÜRSORGE ZWISCHEN HUMANITÄREM ANSPRUCH UND EUGENISCHER VERPF LICHTUNG: ENTWICKLUNG UND KONTINUITÄT SOZIALHYGIENISCHER ANSCHAUUNGEN ZWISCHEN 1920 UND 1960 AM BEISPIEL VON PROF. DR. CARL COERPER. Husum: Matthiesen Verlag, 2004. 270 p. ISBN 3-7868-4098-9. (Abhandlungen zur Geschichte der Medizin und der Naturwissenschaften series; Heft 98.) (15.5; 1.3.5; 2.2; 7.1; 9.1)

Selgelid, Michael J. NEUROGENICS: GENETICALLY-INFORMED REPRODUCTIVE DECISION MAKING. Ann Arbor, MI: University Microfilms International [UMI], 2001. 291 p. (Publication Order No. AAT-3015841. Dissertation, (Ph.D.)—University of California-San Diego, 2001.) (15.5; 4.4; 9.3.1; 9.4; 12.3; 14.1; 15.2; 15.3; 21.7)


Symposium: Genes and Disability: Defining Health and the Goals of Medicine. FLORIDA STATE UNIVERSITY LAW REVIEW 2003 Winter; 30(2); xi- xxiii, 191-410. (ISSN 0096-3070.) (15.5; 2.2; 4.3; 4.4; 8.5; 9.1; 9.3.1; 9.4; 12.3; 12.5.1; 14.4; 15.2; LE)

Numbers in ( ) = NRCBL Classification Numbers
BRAIN, AND GENOME

Kaplan, Gisela and Rogers, Lesley J. (publishers.) [BF698.95 .G73 2004] (15.6; 3.2; 17.1)

DEBATE: CHALLENGES TO THE NATURE-VS.-NURTURE DISCUSSION

Gander, Eric M. [E157 D39 2003] (15.6; 13.5; 9.5.7; 15.5; Fiction)

BEHAVIORAL GENETICS


Bear, Greg. DARWIN’S CHILDREN. New York: Ballantine Books, 2003. 383 p. ISBN 0-345-44835-9. (“A Del Rey Book.” “Eleven years have passed since SHEVA, an ancient retrovirus, was discovered in human DNA—a retrovirus that caused mutations in the human genome and heralded the arrival of a new wave of genetically enhanced humans. Now these changed children have reached adolescence...and face a world that is outraged about their very existence. For these special youths, possessed of remarkable, advanced traits that mark a major turning point in human development, are also ticking time bombs harboring hosts of viruses that could exterminate the “old” human race. Fear and hatred of the virus children have made them a persecuted underclass, quarantined by the government in special “schools,” targeted by federally sanctioned bounty hunters, and demonized by hysterical segments of the population. But pockets of resistance have formed among those opposed to treating the children like dangerous diseases—and who fear the worst if the government’s draconian measures are carried to their extremes.”) [PS3552 .E157 D39 2003] (15.6; 13.5; 9.5.7; 15.5; Fiction)


Lynn, Richard and Vanhanen, Tatu. IQ AND THE WEALTH OF NATIONS. Westport, CT: Praeger, 2002. 298 p. ISBN 0-275-97510-X. (Human Evolution, Behavior, and Intelligence series. ISSN 1063-2158.) (15.6; 1.3.2; 1.3.5; 21.1)


Somit, Albert and Peterson, Steven A., eds. HUMAN NATURE AND PUBLIC POLICY: AN EVOLUTIONARY APPROACH. New York: Palgrave Macmillan, 2003. 266 p. ISBN 1-4039-6285-5. (15.6; 1.3.5; 1.3.11; 9.5.9; 10; 15.1; 16.1; 17.1; 20.5.1; 21.1)


15.7 BIOHAZARDS OF GENETIC RESEARCH

15.8 GENETIC PATENTS


Benarde, Melvin A. YOU’VE BEEN HAD! HOW THE MEDIA AND ENVIRONMENTALISTS TURNED AMERICA INTO A NATION OF HYPOCHONDRIACS. New Brunswick, NJ: Rutgers University Press, 2002. 308 p. ISBN 0-8135-3050-4. (16.1; 1.3.7; 5.3; 7.1; 9.5.1; 15.7; 16.2)


Numbers in ( ) = NRCBL Classification Numbers


16.2 NUCLEAR POWER/RADIATION


16.2 NUCLEAR POWER/RADIATION


16.3 OCCUPATIONAL HEALTH


17.1 THE NEUROSCIENCES AND MENTAL HEALTH THERAPIES

(GENERAL)


Numbers in ( ) = NRCBL Classification Numbers
17.2 PSYCHOTHERAPY

Columbus, Frank, ed. ADVANCES IN PSYCHOLOGY RESEARCH. VOLUME 6. Huntington, NY: Nova Science, 2001. 291 p. ISBN 1-59033-014-5. (Gift of the publisher.) [BF76.5.A23 v.6] (17.1; 1.1; 7.1; 9.5.7; 10; 15.6; 18.4; 20.5.1)


Twenty-Sixth Annual Law Review Symposium: The Law of Mental Illness. OHIO NORTHERN UNIVERSITY LAW REVIEW 2003; 29(3): 497-660. (ISSN 0094-534X.) (17.1; 2.2; 4.3; 8.3.2; 8.3.4; 17.5; 17.6; 17.7; LE)


17.2 PSYCHOTHERAPY


Miller, Geri. INCORPORATING SPIRITUALITY IN COUNSELING AND PSYCHOTHERAPY: THEORY AND TECHNIQUE. New York: John Wiley & Sons, 2003. 322 p. ISBN 0-471-41545-6. (17.2; 1.2; 1.3.10; 6; 8.1; 8.3.1; 21.7)


Moskowitz, Eva S. IN THERAPY WE TRUST: AMERICA’S OBSESSION WITH SELF-FULFILLMENT. Baltimore, MD: Johns
17.3 BEHAVIOR MODIFICATION


17.4 PSYCHOPHARMACOLOGY


17.7 INVOLUNTARY CIVIL COMMITMENT


17.8 RIGHT OF THE INSTITUTIONALIZED TO TREATMENT


18.1 HUMAN EXPERIMENTATION (GENERAL)


Goodman, Jordan; McElligott, Anthony; and Marks, Lara, eds. *Useful Bodies: Humans in the Service of Medical Science in the Twentieth Century*. Baltimore, MD: Johns Hopkins University Press, 2003. 217 p. ISBN 0-8018-7342-8. (Gift of the publisher.) [R853 .H8 U846 2003] (18.1; 2.2; 5.3; 7.1; 9.5.1; 16.2; 18.5.5; 18.5.8; 21.3)


Murphy, Timothy F. *Case Studies in Biomedical Research Ethics*. Cambridge, MA: MIT Press, 2004. 340 p. ISBN 0-262-63286-1. (Basic Bioethics series. Gift of the publisher.) [R724 .M876 2004] (18.1; 1.3.7; 2.3; 6; 15.1; 18.2; 18.3; 18.5.2; 18.5.4; 22.2)


Robert, Laura Weiss and Dyer, Allen R. *Concise Guide to Ethics in Mental Health Care*. Washington, DC: American Psychiatric Press [APA], 2004. 354 p. ISBN 0-88048-944-8. (Gift of the publisher.) [RC455.2 .E8 R63 2004] (17.3; 4.3; 8.1; 8.2; 8.3.1; 8.3.3; 8.4; 9.3.2; 9.5.7; 18.4; 18.5.2; 20.4.1)


Numbers in ( ) = NRCBL Classification Numbers
SECTION III 18.2 HUMAN EXPERIMENTATION: POLICY GUIDELINES/IRBS

Twentieth Century held in May 2001 at the Institut für Medizin- und Wissenschaftsgeschichte, Universität zu Lübeck.” Gift of the publisher.) (18.1; 1.2; 1.3.5; 2.2; 4.4; 13.1; 15.1; 15.6; 16.2; 16.3; 18.2; 18.3; 18.4; 18.5.3; 21.1; 21.4; 22.2)

Tomossy, George F. and Weisstub, David N., eds. HUMAN EXPERIMENTATION AND RESEARCH. Avebury, Hants/Burlington, VT: Ashgate, 2003. 612 p. ISBN 0-7546-2226-6. (International Library of Medicine, Ethics and Law series. Gift of the publisher.) [K3611 .H86 H86 2003] (18.1; 1.1; 2.2; 5.3; 6; 8.3.3; 9.4; 9.7; 18.2; 18.3; 18.4; 18.5.1; 18.5.4; 21.1; LE)

18.2 HUMAN EXPERIMENTATION: POLICY GUIDELINES/IRBS


Hamilton, Ann Folsom. INSTITUTIONAL REVIEW BOARDS: POLITICS, POWER, PURPOSE AND PROCESS IN A REGULATORY ORGANIZATION. Ann Arbor, MI: University Microfilms International [UMI], 2002. 367 p. (Publication Order No. AAT-3053165. Dissertation, (Ph.D.)—University of Oklahoma, 2002.) (18.2; 1.1; 1.3.5; 2.2; LE)


18.3 HUMAN EXPERIMENTATION: INFORMED CONSENT

Doyal, Len and Tobias, Jeffrey S., eds. INFORMED CONSENT IN MEDICAL RESEARCH. London: BMJ Books, 2001. 334 p. ISBN 0-7279-1486-3. (Publisher’s address: BMA House, Tavistock Square, postal code WC1H 9JR.) [R727.3 .I54 2001] (18.3; 1.3.7; 7.2; 8.1; 8.2; 9.5.6; 14.1; 15.1; 17.1; 18.5.1; 18.5.2; 21.1; LE)

18.4 BEHAVIORAL RESEARCH


Thomas, Jay C. and Hersen, Michel, eds. UNDERSTANDING IN CLINICAL AND COUNSELING PSYCHOLOGY. Mahwah, NJ: Lawrence Erlbaum Associates, 2003. 482 p. ISBN 0-8058-3671-3. [RC467 .U53 2003] (18.4; 7.1; 17.1; 18.2; 18.3; 18.5.2; 18.5.7)

18.5.2 RESEARCH ON NEWBORNS AND MINORS


See inside front cover for NRCBL Classification Scheme
18.5.3 RESEARCH ON WOMEN


18.5.4 RESEARCH ON EMBRYOS AND FETUSES

Fassi, Carolyn Rose. UNITED STATES HUMAN STEM CELL POLICY MAKING. Ann Arbor, MI: ProQuest Information & Learning/UMI, 2002. 229 p. (Publication No. AAT-3073774. Dissertation. (Ph.D.)—University of Southern California, 2002. Publisher’s address: 300 North Zeeb Road, PO Box 1346, zip 48106-1346.) (18.5.4; 1.3.5; 2.2; 14.5; 15.1)

Ford, Norman M. and Herbert, Michael. STEM CELLS: SCIENCE, MEDICINE, LAW AND ETHICS. Strathfield, NSW, Australia: St Pats Publications, 2003. 111 p. ISBN 1-876295-74-0. (Windows Into. . .Series. Publisher’s address: 60-70 Broughton Road, PO Box 906, postal code 2135.) (18.5.4; 1.2; 4.4; 14.5; 18.5.1; 21.1; Reference; LE)


Humber, James M. and Almeder, Robert F., eds. STEM CELL RESEARCH. Totowa, NJ: Humana Press, 2004. 183 p. ISBN 1-58829-401-3. (Biomedical Ethics Reviews series; 2004. Gift of the publisher.) [QH587 .S7336 2004] (18.5.4; 1.2; 13.5; 4.4; 9.5.5; 15.1; 18.2; 18.5.5; 19.1; 21.2)


Snow, Nancy E., ed. STEM CELL RESEARCH: NEW FRONTIERS IN SCIENCE AND ETHICS. Notre Dame, IN: University of Notre Dame Press, 2003. 219 p. ISBN 0-268-01778-6. (Gift of the publisher.) [QH588 .S83 S74 2003] (18.5.4; 1.2; 4.4; 5.3; 14.4; 15.1; LE)

Soler, D.; Beyeleveld, D.; Friele, M.B.; Holowka, J.; Lilie, H.; Lovell-Badge, R.; Mandla, C.; Martin, U.; and Parodi Avellaneda, R. EMBRYO RESEARCH IN PLURALISTIC EUROPE. Berlin/New York: Springer-Verlag, 2003. 429 p. ISBN 3-540-20379-6. (Wissenschaftsethik und Technikfolgenbeurteilung series; Bd. 21. Gift of the Europäische Akademie.) (18.5.4; 1.1; 3.5; 5.3; 7.1; 14.1; 14.5; 15.1; 19.5.1; 21.1; 22.2; LE)

18.5.8 RESEARCH ON MILITARY AND GOVERNMENT PERSONNEL

18.5.9 RESEARCH ON FOREIGN NATIONALS

Macklin, Ruth. DOUBLE STANDARDS IN MEDICAL RESEARCH IN DEVELOPING COUNTRIES. Cambridge, UK/New York: Cambridge University Press, 2004. 280 p. ISBN 0-521-54170-0. (Cambridge Law, Medicine and Ethics series; No. 2. Gift of the publisher.) (18.5.9; 1.1; 9.2; 9.3.1; 9.7; 18.2; 21.1)

19.1 ARTIFICIAL AND TRANSPLANTED ORGANS OR TISSUES (GENERAL)

Ach, Johann S.; Anderheiden, Michael; and Quante, Michael. ETHIK DER ORGANTRANSPLANTATION. Erfangen: Harald Fischer Verlag, 2000. 239 p. ISBN 3-89131-402-7. (19.1; 1.1; 8.3.1; 17.1; 18.5.4; 19.5; 19.6; 20.2.1; 20.5.2; 22.2)

Hakim, Nadey S. and Papalois, Vassilios E., eds. HISTORY OF ORGAN AND CELL TRANSPLANTATION. London: Imperial College Press, 2003. 444 p. ISBN 1-86094-209-1. (Publisher’s address: 57 Shelton Street, Covent Garden, postal code WC2H 9HE.) [RD120.7 .HS7 2003] (19.1; 2.2; 9.5.7; 9.7; 19.2; 19.3; 19.5; 20.2.1; 22.2)

Picoult, Jodi. MY SISTER’S KEEPER: A NOVEL. New York: Atria Books/Simon & Schuster, 2004. 423 p. ISBN 0-7434-5452-9. (“The product of preimplantation genetic diagnosis, Anna was conceived to provide a bone marrow match for her leukemia-stricken teenage sister, Kate. Anna begins to question her moral obligations in light of countless medical procedures and decides to fight for the right to make decisions about her own body.”) (19.1; 4.4; 8.3.4; 9.5.1; 9.5.7; 15.2; Fiction)

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20.3.1 ATTITUDES TOWARD DEATH: FAMILY


20.4.1 CARE OF THE DYING PATIENT (GENERAL)

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20.4.2 CARE OF THE DYING CHILD

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20.5.4 LIVING WILLS/ADVANCE DIRECTIVES

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Symposium: Precommitment Theory in Bioethics and Constitutional Law. TEXAS LAW REVIEW 2003 June; 81(7): 1729-2081. (ISSN 0040-4411.) (20.5.4; 8.3.3; 18.3; 21.1; LE)

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20.7 SUICIDE/ASSISTED SUICIDE


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Kellerman, Jonathan. DR. DEATH: A NOVEL. New York: Ballantine Books, c2000, 2001. 436 p. ISBN 0-345-448804. (“To some, Eldon Mate was evil personified. Others saw the former physician as a saint. When Mate is found mutilated in a rented van, harnessed to his...
21.1 INTERNATIONAL/POLITICAL DIMENSIONS OF BIOLOGY/MEDICINE (GENERAL)  SECTION III

own killing machine, [psychologist-detective Alex] Delaware is asked to aid his old friend, homicide cop Milo Sturgis, in the hunt for the death doctor’s executioner.”) (20.7; 8.1; 20.5.1; Fiction)

[Physician Assisted Suicide]. AMERICAN JOURNAL OF HEALTH-SYSTEM PHARMACY 1998 March 15; 55(6): 543-553, 578-593. (ISSN 1079-2082. Special Issue.) (20.7; 8.1; 9.7; 20.5.1)

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21.1 INTERNATIONAL/POLITICAL DIMENSIONS OF BIOLOGY/MEDICINE (GENERAL)


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Lee, Kelley; Buse, Kent; and Fustukian, Suzanne, eds. HEALTH POLICY IN A GLOBALISING WORLD. Cambridge/New York: Cambridge University Press, 2002. 331 p. ISBN 0-521-00943-X. (21.1; 5.2; 9.1; 9.3.1; 9.5.1; 9.5.2; 9.5.5; 16.3)


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21.3 CHEMICAL AND BIOLOGICAL WEAPONS


21.4 TORTURE AND GENOCIDE


Kramer, Naomi and Headland, Ronald. THE FALLACY OF RACE AND THE SHOAH. Ottawa: University of Ottawa

**Special Issue: Ethics and Reason in Chemical and Biological Weapons Research. MINERVA: A REVIEW OF SCIENCE, LEARNING AND POLICY 2002; 40(1): 3-113. (ISSN 0026-4695.) (21.3; 1.1; 1.3.9; 5.3; 6; 15.1; 21.2)**


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21.6 INTERNATIONAL MIGRATION OF HEALTH PROFESSIONALS


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Guerrini, Anita. EXPERIMENTING WITH HUMANS AND ANIMALS: FROM GALEN TO ANIMAL RIGHTS. Baltimore, MD: Johns Hopkins University Press, 2003. 165 p. ISBN 0-8018-7197-2. (Johns Hopkins Introductory Studies in the History of Science series.) (22.2; 1.2; 2.2; 7.1; 15.4; 18.1)


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22.3 ANIMAL PRODUCTION


INFORMATION SCIENCE


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BMC MEDICAL ETHICS 2000; 1(1). Irregular. ISSN 1472-6939. (Publisher’s address: BioMed Center Ltd., Middlesex House, 34-42 Cleveland Street, London W1T 4LB. Free online at: http://www.biomedcentral.com/bmcmedethics/. (2.1)

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McCarrick, Patricia Milmoe and Darragh, Martina. INCENTIVES FOR PROVIDING ORGANS. Washington, DC: Kennedy Institute of Ethics, Georgetown University, 2003. 12 p. (Scope Note series; 43. Appeared as Scope Note 43 in the Kennedy Institute of Ethics Journal 2003 March; 13(1): 53-64.) (19.5; 9.3.1; 21.1)

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Poland, Susan Cartier and Bishop, Laura Jane. BIOETHICS AND CLONING, PARTS 1 AND 2. Washington, DC: Kennedy Institute of Ethics, Georgetown University, 2003. [51 p.] (Scope Note series; 41 and 42. Available for $15.00 prepaid; $20.00 outside North America. Appeared as Scope Notes 41 and 42 in the Kennedy Institute of Ethics Journal 2002; 12(3): 305-324 [and] 2002 December; 12(4): 391-407. Available from: Kennedy Institute of Ethics, Scope Note Series, Georgetown University, Box 571212, Washington, DC 20057-1212.) (14.5; 1.2; 2.1; 7.1; 18.1; 22.3)

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Abortion, Motherhood, and Mental Health: Medicalizing Reproduction in the United States and Great Britain. Section III: 12.5.1—Lee, Ellie.


Academic Ethics: Problems and Materials on Professional Conduct and Shared Governance. Section III: 1.3.3—Hamilton, Neil W.


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AIDS in Developing Countries. Section III: 9.5.6—Harris, Nancy, ed.

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Where Have We Failed? A Systematic Analysis of U.S. Health Care. Section III: 9.1—Howe, Roger K.

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1.3.10 Social Work
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2.2 Bioethics and Medical Ethics/ History
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