Marcus Düwell Christoph Rehmann-Sutter Dietmar Mieth Editors

International Library of Ethics, Law, and the New Medicine 39

The Contingent Nature of Life

Bioethics and the Limits of Human Existence



Springer

THE CONTINGENT NATURE OF LIFE

INTERNATIONAL LIBRARY OF ETHICS, LAW, AND THE NEW MEDICINE

Founding Editors

DAVID C. THOMASMA[†]
DAVID N. WEISSTUB, *Université de Montréal, Canada*THOMASINE KIMBROUGH KUSHNER, *University of California, Berkeley, U.S.A.*

Editor

DAVID N. WEISSTUB, Université de Montréal, Canada

Editorial Board

TERRY CARNEY, University of Sydney, Australia
MARCUS DÜWELL, Utrecht University, Utrecht, the Netherlands
SØREN HOLM, University of Cardiff, Wales, United Kingdom
GERRIT K. KIMSMA, Vrije Universiteit, Amsterdam, the Netherlands
DAVID NOVAK, University of Toronto, Canada
EDMUND D. PELLEGRINO, Georgetown University, Washington D.C., U.S.A.
DOM RENZO PEGORARO, Fondazione Lanza and University of Padua, Italy
DANIEL P. SULMASY, Saint Vincent Catholic Medical Centers, New York, U.S.A.
LAWRENCE TANCREDI, New York University, New York, U.S.A.

VOLUME 39

The titles published in this series are listed at the end of this volume.

The Contingent Nature of Life

Bioethics and Limits of Human Existence

Edited by

MARCUS DÜWELL

Universiteit Utrecht, The Netherlands

CHRISTOPH REHMANN-SUTTER

Universität Basel, Switzerland

and

DIETMAR MIETH

Universität Tübingen, Germany



Marcus Düwell Universiteit Utrecht The Netherlands

Dietmar Mieth Universität Tübingen Germany Christoph Rehmann-Sutter Universität Basel Switzerland

ISBN: 978-1-4020-6762-4 e-ISBN: 978-1-4020-6764-8

Library of Congress Control Number: 2007938399

© 2008 Springer Science+Business Media B.V.

No part of this work may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, microfilming, recording or otherwise, without written permission from the Publisher, with the exception of any material supplied specifically for the purpose of being entered and executed on a computer system, for exclusive use by the purchaser of the work.

Printed on acid-free paper

9 8 7 6 5 4 3 2 1

springer.com

Contents

Introduction]
Part I Contingency of Life and the Ethical	
The Value of Natural ContingencyLudwig Siep	7
Between Natural Necessity and Ethical Contingency	17
Of Poststructuralist Ethics and Nomadic Subjects	25
Genetics, a Practical Anthropology	37
Science, Religion, and Contingency	53
Part II Ethical Theories and the Limits of Life Sciences	
Bioethics and the Normative Concept of Human Selfhood	7]
Human Cognitive Vulnerability and the Moral Status of the Human Embryo and Foetus	33
Needs and the Metaphysics of Rights	39

vi Contents

The Authority of Desire in Medicine
Procreative Needs and Rights
Needs, Capacities and Morality
Moral Judgement and Moral Reasoning
Philosophical Reflection on Bioethics and Limits
Part III Cases of Limits
Finite Lives and Unlimited Medical Aspirations
Reproductive Choice: Whose Rights? Whose Freedom? *
Assisted Reproduction and the Changing of the Human Body
On the Limits of Liberal Bioethics
The Human Embryo as Clinical Tool
The Naked Emperor
Part IV Abilities and Disabilities
Disability: Suffering, Social Oppression, or Complex Predicament? 235 Tom Shakespeare
Disability and Moral Philosophy: Why Difference Should Count 247 Sigrid Graumann

Contents

Neuro-Prosthetics, the Extended Mind, and Respect for Persons with Disability
Part V Others' Views: Intercultural Perspectives
Normative Relations: East Asian Perspectives on Biomedicine and Bioethics
Limits of Human Existence According to China's Bioethics
There is the World, and there is the Map of the World
Reflections on Human Dignity and the Israeli Cloning Debate
Conceiving of Human Life
Globalization and the Dynamic Role of Human Rights in Relation to a Common Perspective for Life Sciences

Author Biographies

Ahmet Hadi Adanali currently teaches at the Divinity School of Ankara University. He holds an MA in analytical philosophy from the Middle East Technical University at Ankara and a Ph.D. in Islamic Philosophy from the University of Chicago. He has taught at various universities including Gregorian University in Rome and has published in scholarly journals. In the years 2005–2006, he was involved as the Turkish coordinator in the UN Project of the Alliance of Civilizations. His research focuses on questions that relates to borderline topics between philosophy and theology, and science and religion.

Brenda Almond is Emeritus Professor of Moral and Social Philosophy at the University of Hull and is a Member of the Human Genetics Commission in the UK. She is the author of a number of books including The Fragmenting Family (Oxford University Press, 2006) and Ethiek: Reis naar het land van goed en kwaad (Wereldbibliotheek, Amsterdam, 2001).

Joel Anderson was educated at Princeton, Northwestern, and Frankfurt Universities and taught at Washington University in St. Louis for 9 years before joining the Philosophy Department of Utrecht University. His research focuses on philosophical anthropology (esp. links between autonomy, agency, and normativity), ethics (esp. discourse ethics and neuro-ethics), and social theory (esp. "recognition theory" and the conditions for developing autonomy skills). He edited Free Will as Part of Nature: Habermas and His Critics (special issue of Philosophical Explorations, March 2007) and Autonomy and the Challenges to Liberalism (with John Christman, Cambridge UP, 2005). His current book project is entitled "Scaffolded Autonomy: The Construction, Impairment, and Enhancement of Human Agency".

Bernard Baertschi is Maître d'enseignement et de recherche (MER) at the Institute of Biomedical Ethics in the University of Geneva (Switzerland). He graduated from the University of Fribourg and obtained his doctoral degree in Philosophy at the University of Geneva in 1979 (with a study on a French philosopher of the early nineteenth century: Maine de Biran). After having published several papers and books on this period, his philosophical interests shifted to ethics and bioethics. On those topics, his two main books are La valeur de la vie humaine et l'intégrité de la personne (Paris, Vrin, 1995) and Enquête philosophique sur la dignité. Anthropologie et éthique des biotechnologies (Genève, Labor and Fides, 2005).

x Author Biographies

Gerhold K. Becker, currently Visiting Professor at the Graduate School of Philosophy, Assumption University, Bangkok, retired in 2004 as Chair Professor of Philosophy and Religion and Founding Director of the Centre for Applied Ethics after more than 18 years of teaching and research at Hong Kong Baptist University. From 1996–2004, he was a member of the Hong Kong Government's Council on Human Reproductive Technology and from 2000–2004 he served as chairman of the Council's Ethics Committee. He is a Research Fellow of the Centre for Business Ethics of the Shanghai Academy of Social Sciences, associate editor of Rodopi's Value Inquiry Book Series (Amsterdam: New York), and the editor of its special series Studies in Applied Ethics.

Deryck Beyleveld is Professor of Law and Bioethics at Durham before which he was Professor of Jurisprudence at the University of Sheffield (where he founded and directed the Sheffield Institute of Biotechnological Law and Ethics (SIBLE)). In 2006 he held the Belle van Zuylen Visiting Chair (in Human Rights and Bioethics) at the University of Utrecht. His publications cover many areas of law, legal philosophy, moral philosophy, and applied ethics (especially bioethics), and include The Dialectical Necessity of Morality (1991) and (with Roger Brownsword) Law as a Moral Judgment (1986), Mice, Morality and Patents (1993), Human Dignity in Bioethics and Biolaw (2001), and Consent in the Law (2007).

Rosi Braidotti is Distinguished Professor in the Humanities at Utrecht University in the Netherlands. She has published extensively in feminist philosophy, epistemology, poststructuralism and psychoanalysis. Her books include Patterns of Dissonance. Cambridge, Polity Press, 1991; Nomadic Subjects: Embodiment and Sexual Difference in Contemporary Feminist Theory. New York: Columbia University Press, 1994; Metamorphoses: Towards a Materialist Theory of Becoming Polity Press, 2002. She has co-edited the following: Women, the Environment, and Sustainable Development. Towards a Theoretical Synthesis (with E. Charkiewicz, S. Hausler and S. Wieringa) Zed Books, 1994; Between Monsters, Goddesses and Cyborgs (with Nina Lykke). London: Zed Books, 1996; Thinking Differently. A European Women's Studies Reader (with Gabriele Griffin) Zed Books, 2002; and numerous essays and chapters in various texts. Her latest book is: Transpositions. On Nomadic Ethics, Polity Press, 2006.

Daniel Callahan was a cofounder of The Hastings Center in 1969 and served as its President from 1969–1996. He is a Senior Fellow at the Harvard Medical School and a Senior Fellow at Yale and also an Honorary Faculty Member of the Charles University Medical School in Prague, the Czech Republic. He won the 1996 Freedom and Scientific Responsibility Award of the American Association for the Advancement of Science. His research interests have ranged from the beginning to the end of life, health policy and research policy. His project on medicine and the market is examining the impact of market theory, thinking, and practice on health care systems. A related interest is that of globalization and it impact on health status in different parts of the world. He is the author or editor of 39 books.

Norbert Campagna, born 1963, Dr. Phil., Associate Assistant-Professor at the Philosophy Departement of the Université du Luxembourg. He has published 16

Author Biographies xi

books in the domains of political philosophy, philosophy of law and sexual ethics. Last publications: Le droit, la nature et la volonté (Paris 2006), Strafrecht und unbestrafte Straftaten (Stuttgart 2007). Email-Address: norbertcampagna@hotmail.com

Ole Döring holds an MA Phil from Göttingen University and a Ph.D. from Bochum University. He studied Philosophy and Sinology as majors, in Tübingen and Göttingen. Since 1996, he has conducted several research projects on the state of East Asia-related sciences, and on bioethics in China and East Asia. He has been a senior research fellow with the Faculty for East Asian Studies at Bochum University since 2001, with a research project on Culture-Transcending Bioethics (KBE). He has been teaching at the universities of Bochum, Bremen, Hamburg and Lüneburg, and in various universities in the PR China and Taiwan. In 2004, he accepted a position of a Visiting Professor at Hunan Normal University, Changsha (PR China). He has organised several international bioethics conferences, and has conducted extended field research and training courses in China. Since 2006, he has been a core group member of the European-Chinese research consortium BIONET under the EC FP6, at the GIGA-Institute of Asian Studies (Hamburg, Germany). His recent book is entitled Chinas Bioethik verstehen (Understanding China's Bioethics), Hamburg 2004.

Marcus Düwell (born in 1962) holds a chair for philosophical ethics at the Department for Philosophy at Utrecht University. He is research director of the Ethics Institute of Utrecht University, director of the Netherlands Research School for Practical Philosophy and director of the Leiden-Utrecht Research Institute ZENO. From 1993–2001 he was academic coordinator of the Interdepartmental Center for Ethics in the Sciences and Humanities at the University of Tübingen. His research interests include bioethics (especially ethics of genetics, environmental ethics) and basic questions of moral philosophy (foundations of individual rights, human dignity) and the relation between ethics and aesthetics. He is editor-in-Chief of the book series "Ethics and Applied Philosophy" (Springer publisher).

Sigrid Graumann has studied Biology and Philosophy at the University of Tuebingen. She was scholar of the Postgraduate College, "Ethics in the Sciences and Humanities" at the University of Tuebingen. She has got her Ph.D. with the thesis: "Somatic Gene Therapy for Monogenetic Diseases – Conceptual and Ethical Questions". Since April 2002 she is Senior Researcher at the Institute Man, Ethics and Science, Berlin. She was member of the Enquete-Commission "Ethics and Law of Modern Medicine" of the German Bundestag 2000–2002 and 2003–2005, and she is member of the Central Ethics Commission of the German Medical Association and board-member of the Academy of Ethics in Medicine (Germany). Her research interests are ethical questions of biomedical research, feminist and disability ethics.

Hille Haker is Professor of Theological Ethics at Goethe-University, Frankfurt, and since 2005 a member of the European Group on Ethics in Sciences and New Technologies (EGE). From 2003–2005, she was Associate Professor of Christian Ethics at Harvard University. From 1989–2003 she taught at the University of Tuebingen and directed EU-projects in bioethics at the Center for Ethics. Her books include Ethik der genetischen Frühdiagnostik (2002) Moralische Identität (1999),

xii Author Biographies

and the co-edited volumes: Ethik-Geschlecht-Wissenschaften (2006) and The Ethics of Genetics in Human Procreation (2000). She is director of a international critical Catholic journal "Concilium", and in this function co-edited several issues, the latest on Women's voices and HIV-AIDS.

Prof. Dr. Dr.h.c. Ludger Honnefelder is Professor em. of Philosophy at the University of Bonn. Since 2005 Guardini Professor at the Humboldt-University of Berlin. He is a member of the Northrhine-Westphalian Academy of Sciences, the Standing Committee "Science & Ethics" of All European Academies (ALLEA), and the Steering Committee for Bioethics (CDBI) of the Council of Europe. Professor Honnefelder was director of the Institute for Science and Ethics at the University of Bonn and the German Reference Centre for Ethics in the Life Sciences (Bonn) and a member of the Enquete Commission "Law and Ethics of Modern Medicine" of the German Bundestag (from 2000–2002). His main scientific interests are Ethics, Applied Ethics/Bioethics, Metaphysics, History of Medieval Philosophy.

Matthias Kettner is dean of the faculty of humanities and liberal arts at Witten/Herdecke university (www.uni-wh.de) in Germany. He was assistant professor from 1994–2000 at the Institute for Advanced Studies in the Humanities at Essen (www.kwi-nrw.de) where his research focused on clinical ethics committees in Germany, communicative ethics, and the relationship of applied ethics, biopolitics and democracy. Prior to that, he collaborated with Karl-Otto Apel and Jürgen Habermas in research on discourse ethics at Frankfurt University where he had earned a Ph.D. in philosophy and a diploma in psychology. Recently edited books: "Biomedizin und Menschenwürde" (2004) "Angewandte Ethik als Politikum" (2001), both by Suhrkamp Verlag, Frankfurt. contact: kettner@uni-wh.de

Michiel Korthals is Professor of Applied Philosophy at Wageningen University. He studied Philosophy, Sociology, German and Anthropology at the University of Amsterdam and the Karl Ruprecht Universität in Heidelberg. His academic interests include bioethics and ethical problems concerning food production and environmental issues, deliberative theories, and American Pragmatism. Main publications: Filosofie en intersubjectiviteit, Alphen a/d Rijn, 1983; Duurzaamheid en democratie (Sustainability and democracy, Boom, 1995); Philosophy of Development (Kluwer, 1996 with Wouter van Haaften and Thomas Wren), Tussen voeding en medicijn (Between Food and Medicine), Utrecht 2001, Pragmatist Ethics for a Technological Culture (with Keulartz et al.; Kluwer 2002), Ethics for Life Sciences (Springer, 2005), Before Dinner. Philosophy and Ethics of Food (Springer 2004), and in 2006, Pépé Grégoire, Een filosofische duiding van zijn beelden/A Philosophical Interpretation of his Sculptures, Zwolle: Waanders.

Professor Sheila A.M. McLean LL.B., M.Litt., Ph.D., LL.D. (Edin), LL.D. (Abertay, Dundee), F.R.S.E., F.R.C.G.P., F.Med.Sci., F.R.C.P.E. (Edin), F.R.S.A. Professor McLean is the first holder of the International Bar Association Chair of Law and Ethics in Medicine at Glasgow University and is Director of the Institute of Law and Ethics in Medicine at Glasgow University. She has acted as a consultant to the World Health Organisation, the Council of Europe, and a number of individual states. She has acted as an expert reviewer for many of the major grant awarding bodies and similar organisations outwith the United Kingdom. She has published

Author Biographies xiii

extensively in the area of medical law, is on the Editorial Board of a number of national and international Journals and is regularly consulted by the media on matters of medical law and ethics. In 2005 she was awarded the first ever Lifetime Achievement Award by the Scottish Legal Awards.

Dietmar Mieth (*1940) has a Chair for Theological Ethics at the Catholic Faculty of Theology at the University of Tübingen. From 1990–2001 he was founding director of the Inter-Departemental Center for Ethics in the Sciences and Humanities at the same university. He was Member of the ethical advisory groups of the European Commission (European Group on Ethics in the Sciences and New Technologies), the German Federal Ministry of Health and the Enquete-Committee of the German Parliament "Ethics and Law in Modern Medicine". His research interests include social ethics, bioethics, narrative ethics, religious experience and medieval mysticism.

Maurizio Mori is professor of bioethics at the University of Turin, Italy. Since 1985 he is coordinator of the bioethics branch of the Center "Politeia" in Milan; and since 2006 he is President of the Consulta di Bioetica, a national Association founded in 1989 to promote bioethics in a pluralistic attitude. He is editor in chief of Bioetica. Rivista interdisciplinare, the only bioethical journal open to ethical pluralism in Italy. He has written 5 books and over 250 papers published in Italian and in international journals. His major interests are in reproductive issues and end of life; stem cells; history and nature of bioethics, truth telling, Ethics Committees, resource allocation. He contributed also to ethical issues on environment and non-human animals, as well as to business ethics.

Albert W. Musschenga (1950) is Director of the Blaise Pascal Institute and Professor of Ethics at the Vrije Universiteit, Amsterdam. He published books on Quality of Life (1987), Integrity (2004), (co-)edited a number of volumes about a wide range of subjects. He also published a great number of articles on practical and theoretical ethics. His current research focuses on the relation between empirical sciences and ethical theory.

Christoph Rehmann-Sutter, born 1959, is currently directing the Unit for Ethics in the Biosciences at the University of Basel, Switzerland. He studied first molecular and subsequently philosophy and sociology. Ph.D. in philosophy of biology and bioethics in 1995 at Technical University of Darmstadt. 2000 venia docendi in Philosophy at University of Basel. 1997–1998 he was research fellow at the University of California Berkeley. Since 2001 President of the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE), which gives recommendations for the Swiss government and parliament. Since 2008 also Visiting Professor at the London School of Economics and Political Science (LSE). Research and writing interests: philosophical foundations of bioethics, sociological methods in bioethics and medical ethics, ethical issues of gene therapy, genetic testing, embryo research, and technical risks, genome theories, ethics of counselling.

Carlos M. Romeo-Casabona is Professor of Criminal Law at The University of the Basque Country and Director of the Inter-University Chair BBVA Foundation-Provincial Government of Biscay in Law and the Human Genome, at the UD and of xiv Author Biographies

UPV/EHU. He has a Doctorate in Law and in Medicine. He is author, co-author and editor of several books and numerous articles, published in seven languages. He is a member of the Spanish National Commission on Assisted Human Reproduction, of the steering Bioethics Committee of the Council of Europe, of the Ethics Committee of HUGO, Chairman of the Ethics Committee on Clinical Research of the Autonomous Community of the Basque Country. He is an Adviser of the Spanish Minister of Health and of the Ministry of Justice. He has been awarded five Honorary Degrees "Doctor Honoris Causa" from several Latin-American and Spanish Universities.

Tom Shakespeare was trained in sociology at the University of Cambridge, and has researched and taught at the Universities of Sunderland, Leeds and Newcastle, where he is currently research fellow at the Policy, Ethics and Life Sciences Institute. His books include The Sexual Politics of Disability and most recently Disability Rights and Wrongs.

Dr. Carmel Shalev is a human rights lawyer and ethicist, who specializes in reproduction, health and biotechnology. She has served as legal advisor to the Ministry of Health and on numerous public committees in the area of health ethics in Israel. She also served as an expert member of the United Nations Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW), where she specialized in women and health. Between 1998 and 2004 Dr. Shalev established and directed the Unit of Health Rights and Ethics at the Gertner Institute for Health Policy Research, Tel Hashomer. She now teaches at the Tel Aviv University Law Faculty, and other academic institutions in Israel, and works as a local and international consultant in the field of biomedicine and research ethics.

Ludwig Siep teaches philosophy at the university of Münster/Germany. He is chairman of the Central Ethics Committee of Stem-Cell Research (Berlin), head of the Center for bioethics at the University of Münster, member of the Northrhine-Westphalian and corresponding member of the Bavarian Academy of Sciences. His fields of research are ethics, applied ethics and history of philosophy, especially German Idealism. Among his books: Hegels Fichtekritik und die Wissenschaftslehre von 1804 (1970, Japan Transl. 2001); Anerkennung als Prinzip der praktischen Philosophie (1979, Italian Transl. 2007); Praktische Philosophie im Deutschen Idealismus (1992); Der Weg der Phänomenologie des Geistes (2001); Konkrete Ethik (2004, Japan Transl. 2006); (Ed.), Hegels Grundlinien der Philosophie des Rechts (2005).

Theo van Willigenburg (b. 1960, Ph.D. 1991 Utrecht University) was Socrates professor of medical ethics at the Amsterdam Medical School, professor of practical philosophy in the faculty of Philosophy Erasmus University Rotterdam and professor of business ethics at the Rotterdam School of Management. He is currently affiliated to the University of Amsterdam and is director of the Kant Academy Utrecht. His main research interest are in metaethics (sources of normativity and motivation), neurophilosophy and the philosophy of emotions. He has written several textbooks and has published in journals like Philosophical Investigations, Journal of Applied Philosophy, The Journal of Medicine and Philosophy, Utilitas, Philosophical

Author Biographies xv

Explorations, Ethical Theory and Moral Practice, The Journal of Value Inquiry, and The Journal of Medicine and Philosophy.

Boris Yudin, born in 1943 in Moscow, Russia, philosopher, professor of the Lomonosov's Moscow State University, Dr. of Sciences (philosophy), Corresponding Member of the Russian Academy of Sciences (RAS). Main fields of research interests – ethics of science and technology, bioethics (ethics of biomedical research, ethical issues of the beginning and the end of human life, human enhancement). Head of department of Comprehensive Problems of Human Studies, Institute of Philosophy of the RAS. Editor-in-Chief of the scientific and popular journal "Chelovek" (the human being). Vice-Chairman of the Russian Committee of Bioethics. Representative of Russia in the Steering Committee on Bioethics of Council of Europe. In 1998–2007 – Member of Board of Directors, International Association of Bioethics.

Laurie Zoloth is Director of the Center for Bioethics, Science and Society and Professor of Medical Ethics and Humanities at Northwestern University, Feinberg School of Medicine, and Professor of Religion and a member of the Jewish Studies faculty at Northwestern University, Weinberg College of Arts and Science. In 2005, after two terms of service on NASA's National Advisory Council, she received the NASA Public Service Medal. In 2001, she was President of the American Society for Bioethics and Humanities. Professor Zoloth is the chair of the HHMI Bioethics Committee and is a founding board member of the International Society for Stem Cell Research, and of the Society for Neuroethics, on NASA's first Planetary Protection Advisory Committee, and on the boards of several national organizations. In 2007 she was nominated to the Institute of Medicine. She is the author of The Ethics of Encounter: A Jewish Perspective on Health Care Justice, and is co-editor of two books on religion, science, and ethics. In 2000, she was co-PI for an NIH ELSI grant on identity, ethnicity, and citizenship after the Human Genome Project. She has published extensively in the areas of ethics, family, feminist theory, religion and science, Jewish Studies, and social policy. Her current research projects include work on the emerging issues in medical and research genetics and on the ethical issues in stem cell research, and her research interest in distributive justice in health care continues.