NUMBER 4

OCTOBER 2020



Cambridge Quarterly of Healthcare Ethics

A Quarterly Journal Devoted to Engaging a World Community of Bioethicists

CAMBRIDGE UNIVERSITY PRESS **ANNUAL**

CLINICAL NEUROETHICS ADVISORY BOARD

Cambridge Quarterly of Healthcare Ethics A Quarterly

Journal Devoted to Engaging a World Community of Bioethicists

Thomasine Kushner, University of California, Berkeley kushnertk@gmail.com

ASSOCIATE EDITOR

EDITOR

James Giordano, Georgetown University Medical Center

EDITORIAL BOARD

Yves Agid, Institut du Cerveau et de la Moelle Épinière, France Jennifer Chandler, University of Ottawa, Canada Markus Christen, University of Zurich, Switzerland Joseph J. Fins, Weill Medical College of Cornell University, New York Paul J. Ford, Department of Bioethics, Cleveland Clinic Grant Gillett, University of Otago Medical School, New Zealand John Harris, University of Manchester, England Stephen Hauser, University of California, San Francisco Judy Illes, The University of British Columbia, Canada Philipp Kellmeyer, University of Freiburg Medical Center, Germany Catherine Madison, California Pacific Medical Center, San Francisco Christine Mitchell, Harvard Medical School Erik Parens, The Hastings Center, Garrison, New York John R. Shook, University at Buffalo Alan Yee, California Pacific Medical Center

The Cambridge Bioethics Education Working Groups: Connecting Bioethics Educators Around the World

The purpose of the Cambridge Bioethics Education Working Groups is to encourage people and institutions to work together on developing bioethics education in their countries. These focus groups invite others to share their information and develop mutual projects to further how bioethics is taught in universities, hospitals, and for the general public.

https://www.cambridge.org/core/journals/cambridge-quarterly-of-healthcare-ethics/cambridge-bioethics-education-working-groups

EDITORS

Thomasine Kushner, PhD, University of California, Berkeley Steve Heilig, MPH, San Francisco Medical Society

ASSOCIATE EDITORS

Matti Häyry, Aalto University, Helsinki, Finland Tuija Takala, University of Helsinki, Finland

David C. Thomasma, PhD, Co-Editor, 1992-2002

EDITORIAL BOARD

Akira Akabayashi, Kyoto University, Japan William Andereck, Medicine and Human Values, California Pacific Medical Center, San Francisco Daniel Callahan, The Hastings Center, Garrison, New York Arthur Caplan, Division of Medical Ethics, NYU Langone Medical Center, New York Andrew Dobson, Keele University, England Denise Dudzinki, Department of Bioethics and Humanities, University of Washington School of Medicine Joseph J. Fins, Division of Medical Ethics, Weill Medical College of Cornell University, New York Leonard M. Fleck, Center for Ethics and Humanities, Michigan State University Paul J. Ford, Department of Bioethics, Cleveland Clinic James Giordano, Georgetown University Medical Center John Harris, University of Manchester, England Gerrit K. Kimsma, Vrije Universiteit Amsterdam Eric M. Meslin, Indiana University Center for Bioethics, Indianapolis Christine Mitchell, Center for Bioethics, Harvard Medical School Jonathan D. Moreno, Center for Bioethics, University of Pennsylvania School of Medicine, Philadelphia Rosamond Rhodes, Mount Sinai School of Medicine, New York Pablo Rodriguez del Pozo, Weill Medical College of Cornell University in Qatar Doris Schroeder, Centre for Professional Ethics, University of Central Lancashire, England Robyn Shapiro, Center for the Study of Bioethics, Medical College of Wisconsin Pavel Tichtchenko, Institute of Philosophy, Academy of Science, Moscow, Russia Griffin Trotter, Center for Health Care Ethics, Saint Louis University Mark R. Wicclair, University of Pittsburgh & West Virginia University

Neuroethics Network/Cambridge Consortium for Bioethics Education/International Bioethics Retreat http://www.icmbioethics.com/cambridge-home.html

Cambridge Quarterly of Healthcare Ethics

Volume 29, Number 4, October 2020

CONTENTS

Contributors	495
Guest Editorial	
Guest Editorial: The Metaphor of Paris Yves Agid	498
Articles	
Memory During the Presumed Vegetative State: Implications for Patient Quality of Life NICOLA TAYLOR, MACKENZIE GRAHAM, MARK DELARGY, AND LORINA NACI	501
Precedent Autonomy and Surrogate Decisionmaking After Severe Brain Injury Маскеnzie Graнам	511
On the Nontechnical Limits of Brain Imaging Јина Räiккä	527
The Impact of Incidental Findings Detected During Brain Imaging on Research Participants of the Rotterdam Study: An Interview Study Charlotte H.C. Bomhof, Lisa Van Bodegom, Meike W. Vernooij, Wim Pinxten, Inez D. De Beaufort, and Eline M. Bunnik	542
Pediatric Deep Brain Stimulation for Dystonia: Current State and Ethical Considerations Katrina A. Muñoz, Jennifer Blumenthal-Barby, Eric A. Storch, Laura Torgerson, and Gabriel Lázaro-Muñoz	557
Psychiatric Interventions in Virtual Reality: Why We Need an Ethical Framework Maria Marloth, Jennifer Chandler, and Kai Vogeley	574
Harm, Consent, and Virtual Selves in Full-Body Ownership Illusions: Real Concerns for Immersive Virtual Reality Therapies MARIA BOTERO AND ELISE WHATLEY	585
Ethical Assessment and Reflection in Research and Development of Non-Conformité Européene Marked Medical Devices Patrik K. Telléus and Winnie Jensen	592

Contents continued

Contents continued

Responsibility-Enhancing Assistive Technologies and People with Autism FIACHRA O'BROLCHAIN AND BERT GORDIJN	607
"Who Will I Be?": Relational Identity, Living with Amyotrophic Lateral Sclerosis, and Future-Oriented Decisionmaking ERIKA VERSALOVIC AND ERAN KLEIN	617
	017
Neuroethics for Fantasyland or for the Clinic? The Limitations of Speculative Ethics	(2)
Sven Ove Hansson	630
Departments and Columns	
The Case I Can't Forget	
Two Patients: Professional Formation before "Narrative Medicine"	
Joseph J. Fins	642
Symptoms of Consciousness	
Where Science Meets Story: Notes from an	
Extended Field Trip Robert A. Burton	651
	001
Responses and Dialogue	
In Defense of Narrative Authenticity A Response to "Deep Brain Stimulation, Authenticity and Value" by Jonathan Pugh, Hannah Maslen, and Julian Savulescu and "Deep Brain Stimulation, Authenticity and Value: Further Reflections" by Sven Nyholm and Elizabeth O'Neill (CQ 26 (4))	
Muriel Leuenberger	656
Perspectives	
The Hybridization of the Human with Brain	
Implants: The Neuralink Project	(())
Éric Fourneret	668

EDITORIAL OFFICE: Editorial correspondence, including manuscript submission, should be addressed to Thomasine Kushner, PhD. To facilitate review, please submit manuscripts as electronic copy, preferably in MS Word, to kushnertk@ gmail.com. Books for review should be sent to Greg Loeben, 2532 N. 4th Street, #442 Flagstaff, AZ 86004. Books for review on neuroethics should be sent to Thomasine Kushner, 1001 Bridgeway #A1, Sausalito, CA 94965.

SUBSCRIPTION INFORMATION: *Cambridge Quarterly of Healthcare Ethics* (ISSN 0963-1801) is published quarterly in January, April, July, and October by Cambridge University Press, One Liberty Plaza, Floor 20, New York, NY 10006/ Cambridge University Press, Journals Fulfillment Department, UPH, Shaftesbury Road, Cambridge CB2 8BS, UK. Annual subscription rates for volume 29 (2020) USA, Canada, and Mexico/Elsewhere: Institutional rates, print and online: \$704/£438; online only: \$559/£348; print only: \$699/£436. Individual rates, print only: \$146/£89. Single part: \$201/£125. Students and retirees: \$121/£76. American Society for Bioethics and Humanities members: \$101/£60. Prices include postage. Subscription offices: One Liberty Plaza, Floor 20, New York, NY 10006, USA; outside the USA, Canada, and Mexico: Cambridge University Press, Journals Fulfillment Department, UPH, Shaftesbury Road, Cambridge CB2 8BS, UK. Claims for missing issues should be made immediately after receipt of the next issue. *Cambridge Quarterly of Healthcare Ethics* and other Cambridge journals can be found at http://journals.cambridge.org.

Cambridge Quarterly of Healthcare Ethics is a partner journal of the American Society for Bioethics and Humanities.

Periodicals postage paid at New York, NY and additional mailing offices. POSTMASTER: Send address changes in the USA, Canada, and Mexico to *Cambridge Quarterly of Healthcare Ethics*, Cambridge University Press, One Liberty Plaza, Floor 20, New York, NY 10006, USA. Send address changes elsewhere to *Cambridge Quarterly of Healthcare Ethics*, Cambridge University Press, Journals Fulfillment Department, UPH, Shaftesbury Road, Cambridge CB2 8BS, UK.

© **Cambridge University Press 2020.** All rights reserved. No part of this publication may be reproduced, in any form or by any means, elec tronic, photocopying, or otherwise, without permission in writing from Cambridge University Press. Policies, request forms, and contacts are available at: http://www.cambridge.org/rights/permissions/permission.htm

Cambridge Quarterly of Healthcare Ethics is indexed in Index Medicus and in the ASSIA, ISI, MEDLINE, Philosopher's Index, and Proquest databases.

Permission to copy (for users in the USA) is available from Copyright Clearance Center, http://www.copyright.com, email: info@copyright.com.