THE JOURNAL OF LAW, MEDICINE & ETHICS

Volume 49:2 • Summer 2021



INDEPENDENT ARTICLES

A Tangled Web: Deception in Everyday Dementia Care Rebecca Dresser

A Just Standard: The Ethical Management of Incidental Findings in Brain Imaging Research Mackenzie Graham, Nina Hallowell, and Julian Savulescu

Principles for Safe Implementation of ICD Codes for Human Trafficking Jordan Greenbaum, Ashley Garrett, Katherine Chon, Matthew Bishop, Jordan Luke, and Hanni Stoklosa

COVID-19 Antibody Testing as a Precondition for Employment: Ethical and Legal Considerations Sara Gerke, Gali Katznelson, Dorit Reiss, and Carmel Shachar A Journal of the American Society of Law, Medicine & Ethics • www.aslme.org

Race and Ethnicity in 21st Century Health Care

GUEST EDITED BY Laura Specker Sullivan and Robert M. Sade

- **165** Introduction Laura Specker Sullivan and Robert M. Sade
- **168** Closing the Gap in Health Care: A Personal Odyssey *Thaddeus John Bell*
- **174** Addressing Racial Inequity in Surgery: Reflections on a Career in Medicine by a Surgeon *Lenworth Jacobs*
- 181 Why a Consideration of Race is Important to Medical School Admissions Nancy L. Zisk
- **190** Affirmative Action in Medical School: A Comparative Exploration *Richard Sander*
- **206 Racial Inequalities in Health Care:** Affirmative Action Programs in Medical Education and Residency Training Programs Jason F. Arnold
- 211 Building Structural Empathy to Marshal Critical Education into Compassionate Practice: Evaluation of a Medical School Critical Race Theory Course Jennifer Tsai
- 222 Engaging Social Justice Methods to Create Palliative Care Programs That Reflect the Cultural Values of African American Patients with Serious Illness and Their Families: A Path Towards Health Equity *Ronit Elk and Shena Gazaway*
- 231 Racial Myths and Regulatory Responsibility Nicolle K. Strand
- **241 Bounded Justice and the Limits of Health Equity** *Melissa S. Creary*

Plus more inside...



ISSN: 1073-1105

THE JOURNAL OF LAW, MEDICINE & ETHICS CONTENTS

VOLUME 49:2 • SUMMER 2021

Symposium Articles

Race and Ethnicity in 21st Century Health Care

Guest Edited by Laura Specker Sullivan and Robert M. Sade

> 159 Letter from the Editor

 $Cover\ image \ \bigcirc Getty\ Images$

165 Introduction: Race and Ethnicity in 21st Century Health Care

Laura Specker Sullivan and Robert M. Sade

168

Closing the Gap in Health Care: A Personal Odyssey *Thaddeus John Bell*

This narrative provides insight into medical education for Black physicians in South Carolina in the 1960s during the civil rights movement. It also discusses the many rewards and challenges of being a physician of color, describes what has been done to develop programs that benefit minority communities, and argues that more such programs are needed.

174

Addressing Racial Inequity in Surgery: Reflections on a Career in Medicine by a Surgeon

Lenworth Jacobs

Racial inequity has influenced both personal and public health in the United States and has impacted enrollment in medical schools and training programs. The effects of racial inequity on training and how it is perceived can differ depending on who is being affected. Recommendations are offered for positive changes through mentoring of individuals, institutional leadership, and structural changes in organizations.

181

Why a Consideration of Race is Important to Medical School Admissions

Nancy L. Zisk

The tremendous toll that COVID-19 has taken on this country's minority population is the most recent reminder of the health disparities between people of color and people who classify themselves as white. There are many reasons for these disparities, but one that gets less attention than it deserves is the lack of physicians of color available to treat patients of color. To ensure that there is a diverse pool of physicians, people of color must be admitted to medical school in sufficient numbers to be meaningful, and the Supreme Court has twice upheld admissions plans that consider race as one factor of many in the admissions process. After a review of the law and the reasons why medical schools and other university programs consider race when making their admissions decisions, this paper concludes that the law must continue to allow for a consideration of race by all undergraduate and graduate schools, including medical schools, as one factor of many in admissions programs and that a consideration of race in admissions programs is imperative to protect the diversity of this country's medical schools and, in turn, the quality of health care physicians in this country will provide.

190

Affirmative Action in Medical School: A Comparative Exploration *Richard Sander*

A significant body of evidence shows that law schools and many elite colleges use large admissions preferences based on race, and other evidence strongly suggests that large preferences can undermine student achievement in law school and undergraduate science majors, thus producing highly counterproductive effects. This article draws on available evidence to examine the use of racial preferences in medical school admissions, and finds strong reasons for concern about the effects and effectiveness of current affirmative action efforts. The author calls for better data and careful investigation of several identified patterns.

206

Racial Inequalities in Health Care: Affirmative Action Programs in Medical Education and Residency Training Programs

Jason F. Arnold

This article argues that because racial inequalities are embedded in American society, as well as in medicine, more evidence-based investigation of the effects and implications of affirmative action is needed. Future research should focus on the impact of clinical care when race conscious policies are used in medical education and postgraduate training programs. Philosophical justification underlying the use of affirmative action programs is also needed.

LAW, MEDICINE & ETHICS

CONTENTS

VOLUME 49:2 • SUMMER 2021

211

Building Structural Empathy to Marshal Critical Education into Compassionate Practice: Evaluation of a Medical School Critical Race Theory Course

Jennifer Tsai

Ideas of racial genetic determinism, though unsupported by scientific evidence and atavistic, are common and readilv apparent in American medical education. These theories of biologic essentialism have documented negative effects in learners, including increased measures of racial prejudice. They also increase the likelihood that learners believe health inequities are attributable to genetic racial differences, despite overwhelming evidence of social injustices and the fact that race is not a meaningful biological variable. Thus, problematic treatment of race in medical curricula teaches inaccurate conceptions of race and undermines equity. In contrast, principles of Critical Race Theory are uniquely equipped to develop nuanced comprehension of race and racial inequity in learners. Mixed-methods analysis of a student-led elective -- "Health Systems of Oppression" - at the Warren Alpert Medical School of Brown University demonstrates that the incorporation of Critical Race Theory into medical education enhances students' knowledge capacity, perceived skill, and personal commitment to health justice. This in turn increases learners' Structural Empathy - a concept I introduce as not only the compassionate understanding that disease, risk, safety and inequity are constructed within larger socio-medico-historical contexts of power, but the further mobilization of this knowledge in clinical interactions to humanize patient experiences and promote health justice. Structural Empathy is an important bridge between theory and praxis, and a method of marshalling critical medical education into compassionate medical practice. Of note, medical students who did not receive any Critical Race Theory teaching on race and racial inequity perceived diminished ability and personal commitment to addressing health inequities after their first year of medical training. Critical Race Theory-based pedagogy, therefore, may represent a necessary curricular intervention for the advancement of health equity.

222

Engaging Social Justice Methods to Create Palliative Care Programs That Reflect the Cultural Values of African American Patients with Serious Illness and Their Families: A Path Towards Health Equity

Ronit Elk and Shena Gazaway

Cultural values influence how people understand illness and dying, and impact their responses to diagnosis and treatment, yet end of life care is rooted in white, middle class values. Faith, hope, and belief in God's healing power are central to most African Americans, yet life-preserving care is considered "aggressive" by the healthcare system, and families are pressured to cease it. African Americans let loved ones know of their preferences for end-of-life care orally, yet even when they have their preferences recorded in their medical charts, they are less likely than whites to have their preferences followed. As a result, loved ones receive care that is not concordant with their beliefs or goals; goal-concordant care is considered high quality care.

231 Racial My

Racial Myths and Regulatory Responsibility Nicolle K. Strand

Calls to abolish race as a proxy for biology or genetics in clinical care have reached a fever pitch in the latter half of 2020, including articles in the *New England Journal of Medicine*, and urgent letters from prominent Senators. Often, these clinical algorithms that "correct" for the race of the patient begin with scientific research that makes faulty assumptions and conflates social variables with biological ones. This article argues for the abolishment of race-based research. It examines IRBs' regulatory authority to halt protocols that make the race-biology conflation, provides a conceptual model for IRBs to review protocols, and proposes other additional solutions.

241

Bounded Justice and the Limits of Health Equity

Melissa S. Creary

Programs, policies, and technologies - particularly those concerned with health equity — are often designed with justice envisioned as the end goal. These policies or interventions, however, frequently fail to recognize how the beneficiaries have historically embodied the cumulative effects of marginalization, which undermines the effectiveness of the intended justice. These well-meaning attempts at justice are bounded by greater socio-historical constraints. Bounded justice suggests that it is impossible to attend to fairness, entitlement, and equity when the basic social and physical infrastructures underlying them have been eroded by racism and other historically entrenched isms. Using the case of Brazil's National Health Policy for the Black Population, this paper proposes that bounded justice can contribute to justice discourses by serving as a concept, a proffering to a multi-disciplinary conceptual framework, and a potential analytic for those interested in the design of policy, technology, and programmatic interventions towards health equity.

Independent Articles

257 A Tangled Web: Deception in Everyday Dementia Care

Rebecca Dresser

Care workers and families often engage in deception in everyday interactions with people affected by dementia. They do things like tell people that a deceased relative is away at work, hidden car keys have been lost, and the nursing home is a hotel or college dormitory. Many caregivers defend these practices, describing how "therapeutic lies" and "benevolent deception" can help people coping with the confusion that accompanies dementia. Yet they also acknowledge that deception can be harmful, damaging trust and causing even more confusion for people dealing with dementia. While benevolent deception can be justified, there are often more respectful and less potentially damaging ways to help people with dementia seeking to make sense of their lives.

THE JOURNAL OF

LAW, MEDICINE & ETHICS

CONTENTS

VOLUME 49:2 • SUMMER 2021

263

COMMENTARY **Deception in Dementia:** Adding Caregivers to the Equation *Jalayne J. Arias*

266

COMMENTARY Creating the Truth with Persons Living with Advanced Dementia Jason Karlawish

269

A Just Standard: The Ethical Management of Incidental Findings in Brain Imaging Research

Mackenzie Graham, Nina Hallowell, and Julian Savulescu

Neuroimaging research regularly yields "incidental findings": observations of potential clinical significance in healthy volunteers or patients, but which are unrelated to the purpose or variables of the study. Management of these findings has been the subject of continued debate in the bioethics literature, with two questions dominating discussion: 1) should neuroimaging researchers look for incidental findings, and 2) what should be disclosed to participants when an incidental finding has been discovered? We argue that the standard approaches to these questions are inadequate. We adopt a novel approach, focussing on what participants are owed as a matter of distributive justice. We argue that researchers must carry out their research in a way that is consistent with the state's obligation to ensure a basic standard of care. We then argue that disclosure of incidental findings is not something which participants are owed as matter of basic care. Accordingly, researchers are not obligated to disclose such findings, and in fact, there are reasons of distributive justice which weigh against such disclosure. Our approach thus provides an ethical foundation for the management of incidental findings in brain imaging.

$\mathbf{282}$

COMMENTARY Grey Matter – The Problems of Incidental Findings in Neuroimaging Research Nicholas Murphy and Charles Weijer

285

Principles for Safe Implementation of ICD Codes for Human Trafficking Jordan Greenbaum, Ashley Garrett, Katherine Chon, Matthew Bishop, Jordan Luke, and Hanni Stoklosa

Human trafficking is associated with a variety of adverse health and mental health consequences, which should be accurately addressed and documented in electronic health records. Use of new human trafficking diagnostic codes from the International Classification of Diseases facilitates continuity of patient care, and allows researchers to study risk and resilience factors, health impacts and treatment effects. As with other conditions associated with stigma, violence, and/ or legal implications, use of relevant diagnostic codes and other methods of documentation present multiple challenges when applied to cases of trafficking and exploitation. These problems are related to patient concerns, barriers within clinical practice, and issues related to organizational adoption. To meet these challenges, several principles for safe documentation in electronic health records are described. Based on these principles, strategies for appropriate documentation and use of diagnostic codes on human trafficking are discussed. Strategies stem from prior efforts by experts working with other vulnerable populations (e.g. intimate partner violence, human immunodeficiency virus infection and child maltreatment), and multidisciplinary expertise shared at a convening hosted at the Department of Health and Human Services in Washington, DC in Dec. 2019.

290

COMMENTARY

ICD Codes – An Important Component for Improving Care and Research for Patients Impacted by Human Trafficking Adam Landman and Holly Gibbs

293

COVID-19 Antibody Testing as a Precondition for Employment: Ethical and Legal Considerations

Sara Gerke, Gali Katznelson, Dorit Reiss, and Carmel Shachar

Employers and governments are interested in the use of serological (antibody) testing to allow people to return to work before there is a vaccine for SARS-CoV-2. We articulate the preconditions needed for the implementation of antibody testing, including the role of the U.S. Food & Drug Administration.

303

COMMENTARY Provide Vaccines, Not Require Immunity or Vaccination Passports ... For Now Julian Savulescu

LAW, MEDICINE & ETHICS

CONTENTS

VOLUME 49:2 • SUMMER 2021

Symposium ar-

Columns

ticles are solicited by the guest editor for the purposes of creating a comprehensive and definitive collection of articles on a topic relevant to the study of law, medicine and ethics. Each article is peer reviewed.

Independent

articles are essays unrelated to the symposium topic, and can cover a wide variety of subjects within the larger medical and legal ethics fields. These articles are peer reviewed.

Columns are

written or edited by leaders in their fields and appear in each issue of JLME.

Next Issue:

Malingering and Health Policy

A Symposium Guest Edited by Daniel Goldberg **307** CURRENTS IN CONTEMPORARY BIOETHICS **Interpersonal Racism in the Healthcare Workplace:** Examining Insidious Collegial Interactions Reinforcing Structural Racism

315

Abbas Rattani

PUBLIC HEALTH AND THE LAW Nationalizing Public Health Emergency Legal Responses James G. Hodge, Jr.

321

HEALTH POLICY PORTAL **Over-the-Counter Monograph Safety, Innovation, and Reform Act** *Jason Gardiner and Aaron S. Kesselheim*

328

GLOBAL HEALTH LAW Strengthening Human Rights in Global Health Law: Lessons from the COVID-19 Response

Judith Bueno de Mesquita, Anuj Kapilashrami, and Benjamin Mason Meier

332

Letter to the Editor