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THE JOURNAL OF
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C O N T E N T S

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Symposium Articles

**A Bold
Agenda for
the Next Steps
in Health
Reform**

Guest Edited by
Brietta R. Clark,
Erin C. Fuse Brown,
and Lindsay F. Wiley

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the Editor*

Cover image ©Getty Images

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**Introduction: A Bold Agenda for the
Next Steps in Health Reform**
*Brietta R. Clark, Erin C. Fuse Brown,
and Lindsay F. Wiley*

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**Equity, Participation, and Power:
Achieving Health Justice Through
Deep Democracy**
Ben Palmquist

This article explores how health governance has evolved into an enormously complicated—and inequitable and exclusionary—system of privatized, fragmented bureaucracy, and argues for addressing these deficiencies and promoting health justice by radically deepening democratic participation to rebalance decision-making power. It presents a framework for promoting four primary outcomes from health governance: universality, equity, democratic control, and accountability, which together define health justice through deep democracy. It highlights five mechanisms that hold potential to bring this empowered participatory mode of governance into health policy: participatory needs assessments, participatory human rights budgeting, participatory monitoring, public health care advocates, and citizen juries.

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**Social Solidarity in Health Care,
American Style**
*Erin C. Fuse Brown, Matthew B.
Lawrence, Elizabeth Y. McCuskey, and
Lindsay F. Wiley*

The ACA shifted U.S. health policy from centering on principles of actuarial fairness toward social solidarity. Yet four legal fixtures of the health care system have prevented the achievement of social solidarity: federalism, fiscal pluralism, privatization, and individualism. Future reforms must confront these fixtures to realize social solidarity in health care, American-style.

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Struggle for the Soul of Medicaid
*Nicole Huberfeld, Sidney Watson,
and Alison Barkoff*

Medicaid is uniquely equipped to serve low-income populations. We identify four features that form the “soul” of Medicaid, explain how the administration is testing them, and explore challenges in accountability contributing to this struggle. We highlight the work of watchdogs acting to protect Medicaid and conclude with considerations for future health reform.

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**Following the Money: The ACA’s Fiscal-
Political Economy and Lessons for
Future Health Care Reform**
*William M. Sage and Timothy M.
Westmoreland*

It is no exaggeration to say that American health policy is frequently subordinated to budgetary policies and procedures. The Affordable Care Act (ACA) was undeniably ambitious, reaching health care services and underlying health as well as health insurance. Yet fiscal politics determined the ACA’s design and guided its implementation, as well as sometimes assisting and sometimes constraining efforts to repeal or replace it. In particular, the ACA’s vulnerability to litigation has been the price its drafters paid in exchange for fiscal-political acceptability. Future health care reformers should consider whether the nation is well served by perpetuating such an artificial relationship between financial commitments and health returns.

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Health Policy by Litigation

Katie Keith and Joel McElvain

Since its enactment, the Affordable Care Act (ACA) has faced numerous legal challenges. Many of these lawsuits have focused on implementation of the law and the limits of executive power. Opponents challenged the ACA under the Obama Administration while supporters have turned to the courts to prevent the Trump Administration from undermining the law. In the meantime, Congress remains gridlocked over the ACA and many other critical health policy issues, leaving the executive branch to adopt its preferred policy approach and ultimately leading to lawsuits. This article briefly discusses the history of litigation over the ACA and some reasons why this litigation has been so enduring. The article then identifies other areas of health policy that are or could be future targets for litigation. Finally, the article comments on the potential impact of the courts on future health reform efforts.

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ERISA Preemption Reform as Health Reform

Elizabeth Y. McCuskey

If federal health reforms continue to rely on employer-sponsored health care coverage, ERISA preemption reform should be part of the next steps. State-level reform has acquired greater urgency, while the justifications for preempting that source of reform has eroded. This article recommends a statutory waiver for ERISA preemption as a feasible way to adapt to these circumstances. It offers proposed statutory text for reformers inclined to pursue ERISA reform as health reform.

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What States Can Do to Address Out-of-Network Air Ambulance Bills

Erin C. Fuse Brown, Alex McDonald, and Ngan T. Nguyen

Out-of-network air ambulance bills are a pernicious and financially devastating type of surprise medical bill. Courts have broadly interpreted the Airline Deregulation Act to preempt most state attempts to regulate air ambulance billing abuses, so a federal solution is ultimately needed. However, in the absence of a federal fix, states have experimented with a variety of approaches that may survive preemption and provide some protections for their citizens

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Payment Theory and the Last Mile Problem

John V. Jacobi

Health reform debate understandably focuses on large system design. We should not omit attention to the "last mile" problem of physician payment theory. Achieving fundamental goals of integrative, patient-centered primary care depends on thoughtful financial support. This commentary describes the nature and importance of innovative primary care payment programs.

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Parity is Not Enough! Mental Health, Managed Care, and Medicaid

Matthew B. Lawrence

This commentary describes limitations of mental health parity requirements in ensuring access to insurance coverage for mental health treatment and surveys regulatory options employed by states in Medicaid managed care programs as supplements to parity that can further reduce the risk of inappropriate denials of coverage.

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Filling a Federal Void: Promises and Perils of State Law in Addressing Women's Health Disparities

Valarie K. Blake and Michelle L. McGowan

Federal law often avoids setting minimum standards for women's health and reproductive rights issues, leaving legislative and regulatory gaps for the states to fill as they see fit. This has mixed results. It can lead to state innovation that improves state-level health outcomes, informs federal health reform, and provides data on best practices for other states. On the other hand, some states may use the absence of a federal floor to impose draconian policies that pose risks to women's and maternal health. Health reforms at the federal level must tread carefully to enable state innovation, while imposing foundational safeguards for promoting women's health nationwide.

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Designing Policy Solutions to Build a Healthier Rural America

Sameer Vohra, Carolyn A. Pointer, Amanda Fogleman, Thomas Albers, Anish Patel, and Elizabeth Weeks

Disparities exist in the health, livelihood, and opportunities for the 46-60 million people living in America's rural communities. Rural communities across the United States need a new energy and focus concentrated around health and health care that allows for the designing capturing, and spreading of existing and new innovations. This paper aims to provide a framework for policy solutions to build a healthier rural America describing both the current state of rural health policy and the policies and practices in states that could be used as a national model for positive change.

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**Structural Racism and Maternal Health
Among Black Women**

Jamila K. Taylor

Historical foundations rooted in reproductive oppression have implications for how racism has been integrated into the structures of society, including public policies, institutional practices, and cultural representations that reinforce racial inequality in maternal health. This article examines these connections and sheds light on how they perpetuate both racial disparities in maternal health and high rates of maternal mortality and morbidity among Black women.

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**Structural Racism and Health
Disparities: Reconfiguring the Social
Determinants of Health Framework to
Include the Root Cause**

Ruqaiyah Yearby

The government recognizes that social factors cause racial inequalities in access to resources and opportunities that result in racial health disparities. However, this recognition fails to acknowledge the root cause of these racial inequalities: structural racism. As a result, racial health disparities persist.

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**Emergency-Only Hemodialysis Policies:
Ethical Critique and Avenues for Reform**

*Richa Lavingia, Rajeev Raghavan, and
Stephanie R. Morain*

An estimated 6,500 undocumented immigrants in the United States have been diagnosed with end-stage renal disease (ESRD). These individuals are ineligible for the federal insurance program that covers dialysis and/or transplantation for citizens, and consequently are subject to local or state policies regarding the provision of healthcare. In 76% of states, undocumented immigrants are ineligible to receive scheduled outpatient dialysis treatments, and typically receive dialysis only when presenting to the emergency center with severe life-threatening symptoms. 'Emergency-only hemodialysis' (EOHD) is associated with higher healthcare costs, higher mortality, and longer hospitalizations. In this paper, we present an ethical critique of existing federal policy. We argue that EOHD represents a failure of fiduciary and professional obligations, contributes to moral distress, and undermines physician obligations to be good stewards of medical resources. We then explore potential avenues for reform based upon policies introduced at the state level. We argue that, while reform at the federal level would ultimately be a more sustainable long-term solution, state-based policy reforms can help mitigate the ethical shortcomings of EOHD.

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**The Complex Cancer Care Coverage
Environment — What is the Role
of Legislation? A Case Study from
Massachusetts**

*Christine Leopold, Rebecca L. Haffajee,
Christine Y. Lu, and Anita K. Wagner*

Over the past decades, anti-cancer treatments have evolved rapidly from cytotoxic chemotherapies to targeted therapies including oral targeted medications and injectable immunoncology and cell therapies. New anti-cancer medications come to markets at increasingly high prices, and health insurance coverage is crucial for patient access to these therapies. State laws are intended to facilitate insurance coverage of anti-cancer therapies.

Using Massachusetts as a case study, we identified five current cancer coverage state laws and interviewed experts on their perceptions of the relevance of the laws and how well they meet the current needs of cancer care given rapid changes in therapies. Interviewees emphasized that cancer therapies, as compared to many other therapeutic areas, are unique because insurance legislation targets their coverage. They identified the oral chemotherapy parity law as contributing to increasing treatment costs in commercial insurance. For commercial insurers, coverage mandates combined with the realities of new cancer medications — including high prices and often limited evidence of efficacy at approval — compound a difficult situation. Respondents recommended policy approaches to address this challenging coverage environment, including the implementation of closed formularies, the use of cost-effectiveness studies to guide coverage decisions, and the application of value-based pricing concepts. Given the evolution of cancer therapeutics, it may be time to evaluate the benefits and challenges of cancer coverage mandates.

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Agency, Autonomy and Euthanasia

George L. Mendz and David W. Kissane

Agency is the human capacity to freely choose one's thoughts, motivations and actions without undue internal or external influences; it is distinguished from decisional capacity. Four well-known conditions that can deeply affect agency are depression, demoralization, existential distress, and family dysfunction. The study reviews how they may diminish agency in persons whose circumstances may lead them to consider or request euthanasia or assisted suicide. Since agency has been a relatively neglected dimension of autonomous choice at the end of life, it is argued that to respect the autonomy of individuals, it is essential to establish their agency.

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Empirical Investigation of Ethical Challenges Related to the Use of Biological Therapies

Tara Bladt, Thomas Vorup-Jensen, Eva Sædder, and Mette Ebbesen

The aim of this study was to investigate the ethical dilemma of prioritising financial resources to expensive biological therapies. For this purpose, the four principles of biomedical ethics formulated by ethicists Tom Beauchamp and James Childress were used as a theoretical framework. Based on arguments of justice, Beauchamp and Childress advocate for a health care system organised in line with the Danish system. Notably, our study was carried out in a Danish setting.

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An International Review of Health Technology Assessment Approaches to Prescription Drugs and Their Ethical Principles

Leah Z. Rand and Aaron S. Kesselheim

In many countries, health technology assessment (HTA) organizations determine the economic value of new drugs and make recommendations regarding appropriate pricing and coverage in national health systems. In the US, recent policy proposals aimed at reducing drug costs would link drug prices to six countries: Australia, Canada, France, Germany, Japan, and the UK. We reviewed these countries' methods of HTA and guidance on price and coverage recommendations, analyzing methods and guidance documents for differences in (1) the methodologies HTA organizations use to conduct their evaluations and (2) considerations they use when making recommendations. We found important differences in the methods, interpretations of HTA findings, and condition-specific carve-outs that HTA organizations use to conduct evaluations and make recommendations. These variations have ethical implications because they influence the recommendations of HTA organizations, which affect access to the drug through national insurance and price negotiations with manufacturers. The differences in HTA approaches result from the distinct political, social, and cultural contexts of each organization and its value judgments. New cost-containment policies in the US should consider the ethical implications of the HTA reviews that they are considering relying on to negotiate drug prices and what values should be included in US pricing policy.

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Symposium articles 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.

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Climate Change and Human Health

A Symposium
Guest Edited
by Jason
Smith