



aft HEALTH CARE

A BIENNIAL JOURNAL ON HEALTH AND COMMUNITY WELL-BEING

VOL. 2, NO. 1 | SPRING 2021

aft.org/hc

HELPING
COMMUNITIES
THRIVE BY:

+ ADDRESSING
MORAL INJURY

+ REDUCING
MATERNAL
MORTALITY

+ BUILDING
HEALTH LITERACY

+ APPRECIATING
NURSE PRACTITIONERS

A Moral Imperative

Creating the Conditions for Healthcare
Professionals, and Their Patients, to Thrive



The vaccines are here.
**And soon, this day
will be too.**

IT'S UP TO YOU
COVID-19 VACCINATION



Get the latest information
about COVID-19 vaccines at
[GetVaccineAnswers.org](https://www.getvaccineanswers.org)



Caring for Healthcare Workers

Our Path from Surviving to Healing to Thriving

RANDI WEINGARTEN, AFT PRESIDENT



AFTER A YEAR like no other—filled with so much hardship and trauma—I am overwhelmed with gratitude for the AFT’s healthcare workers. Recently, I spent time with some of those healthcare workers in Alaska, Oregon, and Washington to say thank you and to listen to the nurses, respiratory techs, transporters, doctors, and others who are on the frontlines fighting COVID-19.

The pandemic has taken a terrible toll in the United States: 562,066 deaths as of April 12. At least 3,600 of these lives lost were healthcare workers who contracted the virus on the job. As we all yearn to get this nightmare over, we must honor the memories of those who perished and comfort their loved ones.

But it’s not just the deaths. It’s what healthcare workers have endured—working extra shifts to handle surges of patients, fighting fears that they will bring COVID-19 home to their families, enduring acute shortages of personal protective equipment by reusing masks or using garbage bags as gowns, being the only one often who could hold a patient’s hand, having to tell family after family that their loved one did not pull through. Every time I put on a mask or encourage people to get vaccinated, I think of those healthcare workers.

The term *burnout* does not capture the trauma. Honking for heroes is not enough.

Our nation’s healthcare workers have experienced moral injury—and we must support their healing. That is the course the AFT is embarking on. It starts with fixing our healthcare system: healthcare is a human right and must be treated that way. We need a well-resourced delivery system, with equitable access across communities, and

robust staffing and technology so that providers have the resources to deliver the best care for their patients. If COVID-19 has taught us anything, it has made clear that we need a renewed focus on public health and family well-being.

As Patricia Pittman explains in this issue, “This combination is how many countries—especially wealthy nations—have achieved healthier populations and lower healthcare costs than the United States.”

Making these changes will not be easy, but I have hope. President Biden has jettisoned the chaos and replaced it with a White House that is competent and compassionate.

Biden’s American Rescue Plan is literally a lifeline for working families and our economy—a down payment on ensuring every person in America has the freedom to thrive. Included in the \$1.9 trillion plan, which will cut child poverty in half, are

- \$49 billion for COVID-19 testing, tracing, and research, and \$14 billion to speed vaccine distribution.
- \$24 billion for community health centers, a public health workforce, and rural healthcare providers, plus \$8.5 billion for rural hospitals.
- \$140 million to support healthcare professionals’ mental health and \$200 million for pandemic-related worker protections.
- \$350 billion to state and local governments, which can be used to fund the premium pay healthcare workers deserve.
- Lower premiums for millions who buy insurance through the Affordable Care Act marketplace.
- 100 percent subsidies for continuation of job-based health coverage (COBRA) for those who have lost employer-sponsored healthcare and, through September 6, \$300 per week in enhanced unemployment benefits.
- \$1,400 in direct payments to the vast majority of Americans, enhanced earned-income and child tax credits, and support for childcare for essential workers.

This relief package is already helping families have the vaccines and financial support we need to pull through this pandemic together. It’s helping us open schools and keep them open. But after this down payment, we need a full recovery in which we build back better.

That’s what Biden’s ambitious American Jobs Plan is designed to do.

This \$2 trillion investment will create millions of good-paying jobs and focus our economy on working families. With critical health and wellness provisions—like \$400 billion to expand the home-care workforce, over \$100 billion to remove mold and other hazards from education facilities, \$45 billion to replace all lead pipes, and \$30 billion for pandemic preparedness—this plan jump-starts our economic engine by rebuilding our physical and care infrastructure.

As I reflect on this grueling year, I am full of gratitude for the healthcare workers who sustained us throughout this crisis. And I look forward with hope—determined to ensure that our healthcare heroes get much-needed support and that science and government are harnessed for the common good. +

I am full of gratitude for the healthcare workers who sustained us throughout this crisis.



Moral Injury Among Nurses

Stories of Fractured Hearts and Wounded Souls

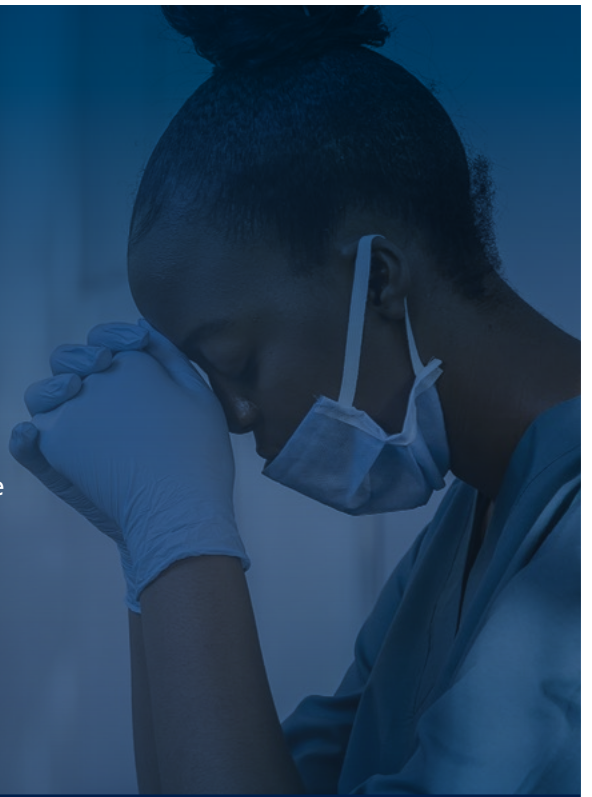
For far too long, the failings of our nation's healthcare system have fallen on nurses' shoulders—and hearts. During National Nurses Week (May 6–12), the AFT is launching a project to better understand, address, and prevent moral injury.

Have you experienced moral distress or moral injury?

The AFT is sponsoring research to gather nurses' experiences so we can identify and advocate for systemic solutions. Together, we can ensure that patients get the care they need and nurses have the fulfilling careers they deserve.

If you are experiencing moral injury, please turn to page 18 for supports.

Visit gwhwi.org/moralinjury.html to share your story today!



AFT Health Care is dedicated to ensuring that everyone has the freedom to thrive. It's about healthcare as a human right, systemic changes to put people above profits, and the social, economic, and environmental factors that affect individuals' and communities' health and well-being.

Get Involved!

Apply to Become a Peer Reviewer

To publish the most relevant, trustworthy, and useful articles, we need to draw on your experience and expertise—so we're developing a peer review board. Please visit aft.org/hc/peer-review to learn more about becoming a reviewer and submit your application today.

Submit a Manuscript

We are interested in learning about your experiences during the pandemic and insights to prepare for future health crises. For details on submitting your manuscript on this and other topics, visit aft.org/hc/article-submission-guidelines.

A MORAL IMPERATIVE

To truly honor healthcare professionals for their courage and caring, we must acknowledge the many long-standing, systemic causes of moral injury—from unsafe staffing to embedded racism—and develop systemic solutions.

4 Moral Injury

From Understanding to Action

BY PATRICIA PITTMAN

6 The Enduring Harms of Structural Racism

14 What Causes Moral Injury?

A Q&A with Debbie White, Barbara Rosen, and Alexis Rean-Walker, leaders of the Health Professionals and Allied Employees

18 Self-Care Strategies in Response to Nurses' Moral Injury During the COVID-19 Pandemic

BY FAHMIDA HOSSAIN AND ARIEL CLATTY

20 The Importance of Respectful Maternity Care for Women of Color

BY JAMILA K. TAYLOR

24 Improving Communication and Care

How Clinicians Can Increase Health Literacy and Equity

BY RACHEL ROBERTS

30 The Invisible Work of Nurse Practitioners

BY LATONYA J. TROTTER

35 Union Highlights

36 What We're Reading



Download this issue for free at aft.org/hc.



Our Mission

The **American Federation of Teachers** is a union of professionals that champions fairness; democracy; economic opportunity; and high-quality public education, healthcare and public services for our students, their families and our communities. We are committed to advancing these principles through community engagement, organizing, collective bargaining and political activism, and especially through the work our members do.

RANDI WEINGARTEN
President
FEDRICK C. INGRAM
Secretary-Treasurer
EVELYN DEJESUS
Executive Vice President

LISA HANSEL
Chief Publications Editor
SHARONE CARMONA
Managing Editor
LUKE STEELE
Editorial Coordinator
SEAN LISHANSKY
Copyeditor

JENNIFER CHANG
Art Director
JENNIFER BERNEY
Graphic Designer
RACHEL ANDERSON
Production Assistant

AFT HEALTH CARE is published semiannually by the American Federation of Teachers, 555 New Jersey Ave. NW, Washington, DC 20001-2079. 202-879-4400, aft.org
Letters to the editor may be sent to the address above or to hc@aft.org.

AFT HEALTH CARE cannot assume responsibility for unsolicited manuscripts.

Please allow a minimum of four weeks for copyright permission requests.

Signed articles do not necessarily represent the viewpoints or policies of the AFT.

AFT HEALTH CARE is mailed to AFT nurses and health professionals, and members in related fields, as a benefit of membership. Subscriptions represent \$2.50 of annual dues. Non-AFT members may subscribe by mailing \$10 per year by check or money order to the address below.

MEMBERS: To change your address or subscription, notify your local union treasurer or visit aft.org/members.

POSTMASTER: Send address changes to AFT Health Care, 555 New Jersey Ave. NW, Washington, DC 20001-2079. Periodicals postage paid at Washington, DC, and additional mailing offices.

© 2021 AMERICAN FEDERATION OF TEACHERS, AFL-CIO

Cover photo:
GO NAKAMURA / GETTY IMAGES

Moral Injury

From Understanding to Action



The COVID-19 pandemic has shined a light on long-festering problems in our health system. It is not a pretty picture: from racial and ethnic health disparities;¹ to the low wages and minimal benefits of the long-term care and home-care workforce (who often have to work more than one job to get by and may have no sick leave or healthcare coverage);² to the maldistribution of our health workforce, especially in rural areas;³ to the hyperdependence of hospitals on elective procedures for their financial sustainability;⁴ to staff burnout;⁵ to racism in our workplaces;⁶ to poor crisis preparedness and the ensuing lack of personal protective equipment in hospitals;⁷ and ultimately to the tragic shortages of critical care staff as hospitalizations surged around the country.⁸

For nurses, and healthcare workers more generally, the lived experience of these factors long predated the pandemic, but COVID-19 (exacerbated by the Trump administration's inadequate response) is forcing us to rethink assumptions about what causes these problems and how best to address them. These problems are systemic and merit bolder changes than generally have been considered up until now.

"Burnout" Hides Systemic Problems

As with so much in our profit-driven healthcare industry, the interrelated problems of nurses' working conditions, high rates of burnout, and turnover have been largely analyzed not in terms of impact on providers, patients, or safety, but in terms of hospital costs. One pre-pandemic study showed that 54 percent of critical care nurses intended to leave their job within the next year.⁹ Other studies found that the turnover rate among hospital bedside nurses had climbed to 17 percent in 2019¹⁰ and that each nurse who left the hospital was estimated to cost up to \$64,000 to replace.¹¹ The human costs—including dreams of long nursing careers abandoned, chronic conditions developed as a result of stress, and patient care compromised—are incalculable. During the pandemic, a combination of the high numbers of nurses needed and the high staff attrition (due to illness, family demands, and unbearable conditions) has driven these human and economic costs up further.¹²

The study of burnout has made important contributions, offering administrators—if they decide to address burnout—clear pathways for improving working conditions. Research has identified workload, work schedules, staffing ratios, and time spent on administrative tasks and charting as causal factors.¹³ Studies have also shown that in addition to causing nurse stress and attrition, burnout negatively affects patient outcomes.¹⁴ Research on the solutions to burnout tends to focus on ways to increase nurse retention. These include, for example, new nurse graduate residency (as transition to practice) programs;¹⁵ the Magnet Recognition Program, which

recognizes hospitals that have positive nurse work environments;¹⁶ staff satisfaction and engagement questionnaires that are used by employers to anticipate problems with motivation, absenteeism, and turnover;¹⁷ and a plethora of psychology-based models of organizational engagement, such as PROPEL, that seek to build interpersonal skills in teams to manage stress and demoralization.¹⁸

All of these approaches have had moderate success in increasing retention, but they have also been shown to be insufficient to stem the bleeding. Fundamentally, they are not cures—they are bandages applied at the individual and organizational levels, and they are hiding the disease being caused by a system that puts profits ahead of patients and providers. Increasingly, the concept of burnout is being challenged, with some going so far as to suggest it is victim blaming, placing responsibility on those experiencing burnout for being insufficiently resourceful or resilient to “withstand the work environment.”¹⁹ But if the real problem does not reside at the individual or organizational level, it cannot be addressed by increasing individual resilience or even by making significant organizational changes such as increased pay and staffing. As scholars at the forefront of challenging burnout starkly framed the issue, “It is absurd to believe that yoga will solve the problems of treating a cancer patient with a declined preauthorization for chemotherapy.”²⁰

Defining Moral Injury

An alternative frame that is gaining traction is *moral injury*. The concept was originally studied in the context of members of the military returning from combat. The Veterans Health Administration (VHA) defines moral injury as “the distressing psychological, behavioral, social, and sometimes spiritual aftermath of exposure” to three types of events: (1) when someone does something that goes against their beliefs (commission of an act); (2) when someone fails to do something in line with their beliefs (omission); and (3) when someone experiences betrayal from leadership, others in positions of power, or peers.²¹ The VHA further affirms that moral injury can occur in response to witnessing behaviors that conflict with an individual's values. The injury itself occurs when the individual perceives that a line has been crossed, and as a result they experience some combination of guilt, shame, disgust, and/or anger. The hallmarks of moral injury have been the inability to forgive oneself, self-destructive behaviors, and demoralization.

Not surprisingly, the concept caught on quickly among healthcare workers. The first definition, published in 1984, referred to situations in which a nurse “knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.”²² Key to this definition were the ideas

Moral injury is being caused by a system that puts profits ahead of patients and providers.

By Patricia Pittman

Patricia Pittman, PhD, FAAN, is a professor in the Department of Health Policy and Management in the Milken Institute School of Public Health at George Washington University, with a secondary appointment in the School of Nursing. She is also the director of the Fitzhugh Mullan Institute for Health Workforce Equity and is the principal investigator for two federally supported health workforce research centers.

Identifying the system-level factors that cause moral injury requires focusing on system-level solutions.

that there is moral certainty of the right course of action and that there is a system-level constraint that prevents the nurse from being able to act accordingly.²³ This definition has expanded over time to include situations that give rise to distress but that are not necessarily cases of certainty and constraint, such as when there is moral uncertainty or conflict about what is moral.²⁴

Regardless of the narrower versus broader definition, experts agree that moral stressors vary in severity, with the least severe, in theory, being more prevalent and the most harmful events less frequent.²⁵ In recognition of this variability, *moral injury* is often used to indicate one type of trauma, while *moral distress* is often used to indicate real but lesser suffering. (Both terms are used throughout this article. As with other stressors, what is distressing to one person may be

injurious to another; also, moral distress that is ignored may become moral injury.)

Applying the Concept of Moral Injury

As the concept of moral injury has gained popularity, it has been used in practice in different ways—both within the field of healthcare and in other fields. Some identify it as one cause of burnout and therefore continue to focus on managing symptoms in order to increase staff retention and build resiliency.²⁶ Others are trying to use the concept of moral injury to shift attention from *individuals' responses to a system to the constraints systems impose on individuals*.²⁷ Identification of the system-level factors that are the causes of moral distress and injury requires focusing on system-level solutions, some of which may not be viewed as modifiable by managers.

The Enduring Harms of Structural Racism

One kind of moral injury is in a class of its own: structural racism. Within healthcare workplaces, racism may emanate from individuals (e.g., remarks or behaviors by patients,¹ families, or colleagues²), the organization (e.g., pay disparities,³ policies biased against natural hairstyles,⁴ or underrepresentation of people of color in leadership positions⁵), or long-standing societal inequities (e.g., nursing⁶ and medical⁷ schools reinforcing race-based myths⁸ or government-driven housing and wealth disparities⁹ forcing Black families to take on more debt to pay for nursing school or to endure more chronic illnesses due to toxins in under-resourced neighborhoods¹⁰). Such experiences can cause trauma, especially over time, not only among the direct victims but also among distressed witnesses.

In the context of COVID-19, these issues take on greater significance and are compounded by the new challenges of the pandemic: already experiencing the traumatic effects of persistent racial harassment and discrimination in the workplace, healthcare workers of color must deal with the same moral struggles as their white colleagues related to inadequate resources and capacity. Far worse,

as they care for COVID-19 patients who disproportionately look like them, and as they disproportionately lose their loved ones, they are relentlessly confronted with the evidence of racism embedded in the healthcare system and their inability to protect themselves or their patients from its harms.¹¹

Yet another avenue for moral injury is the addition of “pandemic racism” on top of the existing “racism pandemic.”¹² The crisis of racism in the United States has come to the fore, visible in the dramatic increase in attacks on Asian and Asian American people* (including healthcare workers)¹³ and in the worldwide protests over the murders of George Floyd and other Black people. Many healthcare workers of color are likely to be grappling with the trauma of racist incidents,¹⁴ along with their own “fear of being targeted or discriminated against within and outside their workplaces.”¹⁵ The potential for moral injury under these circumstances is much higher.

*To learn what the AFT is doing to stop anti-Asian racism, how you can get involved, and more, visit aft.org/StopAsianHate.

While the distress caused is likely particularly severe for Black healthcare providers, our nation's racism harms all of us. As Dr. Oxiris Barbot, former health commissioner for New York City, recently wrote:

When I think of the torture and murder of George Floyd at the knee of a [w]hite police officer, I feel morally wounded. We've been here before, ... [but] Mr. Floyd's death feels different because it represents a cumulative injury on top of the sustained acuity of health inequities playing out in horrifying details through the COVID-19 pandemic.... Data documenting generations of disinvestment and inequitable health outcomes are so clear. We should feel morally injured by actions committed in the name of maintaining false power structures, and by those who choose to linger in descriptions of the wreckage rather than take actions to prevent it.¹⁶

It is long past time to begin to acknowledge and address racism and the trauma—including moral injury—it causes. To jump-start



your efforts or to deepen your ongoing work, here are two perspectives to read on your own and then to share and discuss with your colleagues.

“Who’s Caring for Black Nurses? We Challenge Our Colleagues to Be Allies”

By Patty Wilson, Shaquita Starks, and Frieda Hopkins Outlaw

Black people are disproportionately dying from COVID-19 and violent murders without justice served. It impacts [B]lack nurses professionally and personally when we must continue “business as usual,” often without support from our places of work and with non-[B]lack colleagues who do not acknowledge our lived experience. We ask, “Who’s caring for us?” ... Like being a nurse, being an ally requires compassion and empathy. What’s

more, allyship helps promote health equity and can be an act of resistance to racism within our profession.

For six concrete strategies that will support non-Black colleagues’ efforts to become allies, continue reading: bit.ly/37jZ2Z8.

“How Should Organizations Respond to Racism Against Health Care Workers?”

By Ann Marie Garran and Brian M. Rasmussen

Dr C, an African American, is in her final year of an internal medicine residency. She reports to the emergency department to examine a middle-aged white woman injured in a car accident. The patient appears in stable condition but likely requires further medical testing. In the midst of the examination, the

patient blurts out, “Isn’t there another doctor who can do this? I’d rather have a white doctor.” Dr C, shocked but not surprised, asks the patient if she wants the examination to continue and the patient acquiesces.... The attending staff physician is an older white male, well respected in the organization. He observes the interaction and stands by quietly, allowing the examination to be completed.

How would you respond to this situation? For ethical guidance, continue reading: bit.ly/3ppaaKf.

—P. P.

Endnotes

1. J. Williams and R. Rohrbaugh, “Confronting Racial Violence: Resident, Unit, and Institutional Responses,” *Academic Medicine* 94, no. 8 (August 2019): 1084–88.
2. K. Ackerman-Barger et al., “Seeking Inclusion Excellence: Understanding Racial Microaggressions

Continued on page 38

For healthcare workers of color, systemic racism and being unable to protect patients from its harms are constant sources of distress.



Health systems may discourage caring relationships by limiting time with patients and focusing on administrative tasks.

In healthcare, the umbrella system-level factor most often identified as a cause of moral injury is its for-profit underpinnings. Health systems may discourage caring relationships by limiting time with patients and focusing health workers' attention on administrative tasks, such as electronic health records and paperwork for insurance companies. In that context, moral injury occurs when nurses, and other healthcare workers who are committed to compassionate care, confront a system that cares primarily about profit.²⁸

This is a particularly powerful notion for nursing since nursing is at its core about human caring: nurses aspire to holistic care provided through authentic relationships with patients.²⁹ The experience of an immoral event, whether distressing or traumatic, presents not just a personal dilemma but a professional one as well. The professional identity of a healthcare provider as a caregiver, socialized during professional education and in the early years of practice, provides the backdrop that gives meaning to specific events. Fortunately, that professional identity, while possibly exacerbating stress and trauma, also serves as a platform for long-term collective action that achieves change. The Code of Ethics by the American Nurses Association (ANA),³⁰ for example, offers a strong road map for responding to immoral situations, even if nurses are not always empowered to act on its principles. ANA itself recognized this and has launched an educational project around moral distress.³¹ Most of

its work focuses on defining the concept of moral distress and generally identifying the prevalence of the problem—it has, thus far, left the system-level causes of distress and injury somewhat opaque.

Giving Voice to Moral Injury

How can we give voice to nurses' own experiences of moral injury in different settings and link these systemic conflicts to specific policy and regulatory changes? In particular, it would be helpful to juxtapose elements of nurses' professional identity (as expressed in ANA's Code of Ethics or other theoretical documents) with the potential system-level barriers to fulfilling that identity. These pain points need clarification and amplification so that frontline nurses can understand the nature of the conflict and position themselves to lead policy change.

Some of these pain points are more visible and, therefore, more discussed than others. Take the problem of a nurse who is a single mom and fears reporting a safety problem because of potential reprisal from an attending physician who has the power to move her to a night shift. The ANA code speaks to this issue in the section on "Protection of Patient Health and Safety by Acting on Questionable Practice,"³² and some hospitals have instituted systems with whistleblower protections to encourage people to speak out. This is a well-known problem, and while it persists, there are well-known system-level solutions for frontline nurses.

There are also many issues causing moral distress that are well known but rarely discussed among nurses, likely because the solution requires challenging some of the most basic tenets of for-profit organizations. These situations are particularly common for nurses in leadership roles. Here are some hypothetical cases:

- A chief nursing officer (CNO) is under pressure from the chief financial officer to reduce nursing costs in a hospital. Aware that many states and the public are starting to track nurse-to-patient ratios, the CNO opts to reduce nursing assistive personnel. She experiences moral distress because her action not only leaves people unemployed but also creates more work for the nurse staff and could endanger patients.
- A CNO in a nursing home with high nurse turnover is desperate to hire more nurses quickly. The pressure to cover vacancies in specialty areas leads him to contract with an international nurse staffing agency, even though the agency is known for underpaying international nurses and using high contract-breach fees to prevent them from quitting. He is distressed because he knows that the international nurses will be assigned less favorable shifts and will receive less pay than their US counterparts.
- A member of the state board on nursing fears speaking out about the low quality of for-profit nursing schools in the state because state legislators, who are lobbied and funded by the for-profit education industry, would likely reduce the power of the board's oversight in retaliation. She experiences moral distress because she fears that her inaction could lead to hundreds of new nurse graduates who will fail their licensure tests, delay entry into the profession, and face difficulty repaying their student loans.
- A nurse working in utilization management for an insurance company is troubled by the protocols that reject payment for certain high-cost drugs, but she knows if she is too lenient with the approval process she could lose her job. She experiences moral distress knowing that patients' health may be harmed by these denials.
- A nurse in an assisted nursing facility is aware that some of the therapeutic services and drugs provided to residents are not necessary. While there are whistleblower protections in his organization, no one has ever used them. He fears that if he reports the overuse, he will face reprisals from his managers—but the longer he stays silent, the more distressed he feels.

These are some of the many common stressors that can cause moral injury, not just for the individuals committing the particular act, or omitting an action, but also for those who are witnessing the practices. Even once the pandemic is over, these stressors will remain until we find the collective will to reimagine our healthcare system. One of our nation's most severe causes of moral injury—structural racism—will also remain until we

reckon with the very foundations of our social, economic, and political structures (for an introduction to healthcare's role in that reckoning, see page 6).

Addressing the Causes of Moral Injury

The challenge is how to increase the conversation about these “untouchable” topics and how to address them. As shown in the figure on page 10, there are many levels of potential strategies, none of which are mutually exclusive. For healthcare unions, all of these levels present opportunities to help alleviate moral injury—especially as union membership grows throughout the healthcare workforce.

The strategies begin at the unit level and involve improving participation and team dynamics. They advance to organization-wide labor-management partnerships that give frontline staff a voice in system redesign within healthcare organizations. Then there is the option to use social media to create affinity groups that encourage the sharing of stories and organizing platforms across organizations. Next, there are subgroups of nurses that can create campaigns within professional associations to advocate for more courageous positions based on professional ethics. Lastly, a macro-level strategy is to build statewide and nationwide social movements that are independent of single professions or political parties and can push for specific policy reforms.

Unit-Based Strategies

The first strategy is to give frontline staff a greater voice in unit-level decisions and to create a culture of participation and respect. Approaches such as the Institute for Healthcare Improvement's advancement of unit-based teams that work on continuous quality improvement lay the groundwork for frontline

Even once the pandemic is over, these stressors will remain until we find the collective will to reimagine our healthcare system.

Join the Fight to Prevent Moral Injury

Systemic change is hard, but together we can build a new approach to healthcare that values the well-being of patients and the many people who care for them. To bring more advocates who deeply understand moral injury to this fight, share this video, which can be found at aft.org/hc/spring2021/pittman, and engage with your local, state, and federal representatives.

—EDITORS



Acknowledge grief, while also offering hope and a path forward.

workers to have greater input into the redesign of care delivery.³³ In the context of COVID-19, the Institute for Healthcare Improvement stresses a number of leadership strategies. By taking these actions, leaders can help prevent and mitigate the effects of moral injury:

1. Meet the needs of the health workforce during the crisis by providing PPE (personal protective equipment) for everyone at risk (e.g., including hospital laundry staff), food in break rooms, childcare resources, transportation support, mental health services, etc. (Long term, this also means, at a minimum, living wages, health insurance, and paid leave. Although these may be organization-level decisions, unit-level leaders have a responsibility to speak up for their teams.)
2. Communicate regularly and honestly, listening to workers' concerns (including through formalized listening sessions) and asking questions such as What went well today? and What can we build on?
3. Normalize and encourage help-seeking behavior as a sign of strength and part of a shared value of prioritizing wellness.
4. Acknowledge grief, while also offering hope and a path forward.³⁴

This first level of actions is critical, but it is limited in that it focuses primarily on areas in which staff (including unit leadership) action can affect change. Many of the causes of moral injury cannot be resolved at the unit level.

Organization-Wide Partnerships

A step up from unit-level approaches are institution-wide partnerships on a broad range of issues, which

may include unit-based quality improvement, staffing ratios, new hires, wages and benefits, and workforce development programs, as well as more general questions of revenue and resource allocation in the general budget. These are areas that have traditionally been considered off limits to frontline workers. But, especially in hospitals with unionized staff, these issues may be effectively addressed through ongoing dialogue that centers workers' experiences and ideas. This approach, which is sometimes formalized as a labor-management partnership (LMP), uses a variety of techniques to engage workers in the diagnosis and resolution of organization-level problems.³⁵

A number of LMPs have noteworthy accomplishments to date. Kaiser Permanente's LMP has a campaign called Free to Speak that includes a set of tools intended to make everyone feel it is safe to speak up. The tools, Kaiser writes, "underscore not just the right to speak up but the responsibility of workers, managers and caregivers to do so."³⁶ Maimonides Medical Center uses Study Action Teams, an interdisciplinary group of six to eight frontline workers, managers, and technical staff who are assigned the task of studying a problem and proposing organizational changes. Their aim is to identify disruptive changes that can contribute to broader transformations.³⁷

The role of unions in facilitating labor-management partnerships is well documented, although not all unions view such arrangements as advantageous.³⁸ Certainly, some union leaders (or some representatives on the LMPs) are less connected to their members' needs; other unions may view LMPs as getting too close to management. Contexts vary, and sometimes partnerships are not feasible, but periodically considering LMPs is worthwhile because much can

Strategies to Reduce Moral Injury and Promote System Change

Unit-Based Strategies

to improve relationships, roles, and work culture

Organization-Wide Partnerships

to include frontline workers in redesign of care delivery

Affiliations Across Organizations Through Social Media

to provide support, learn from each other, and strengthen collective action

Subgroups Within Professional Associations

to advance courageous association positions on policy

A Social Movement for Ethical Healthcare

to advance policy changes in states and nationally

be accomplished for patients and providers when genuine collaboration is possible. For local and national unions, detailed study of the potential advantages and pitfalls of LMPs remains an important area of work in and of itself.³⁹

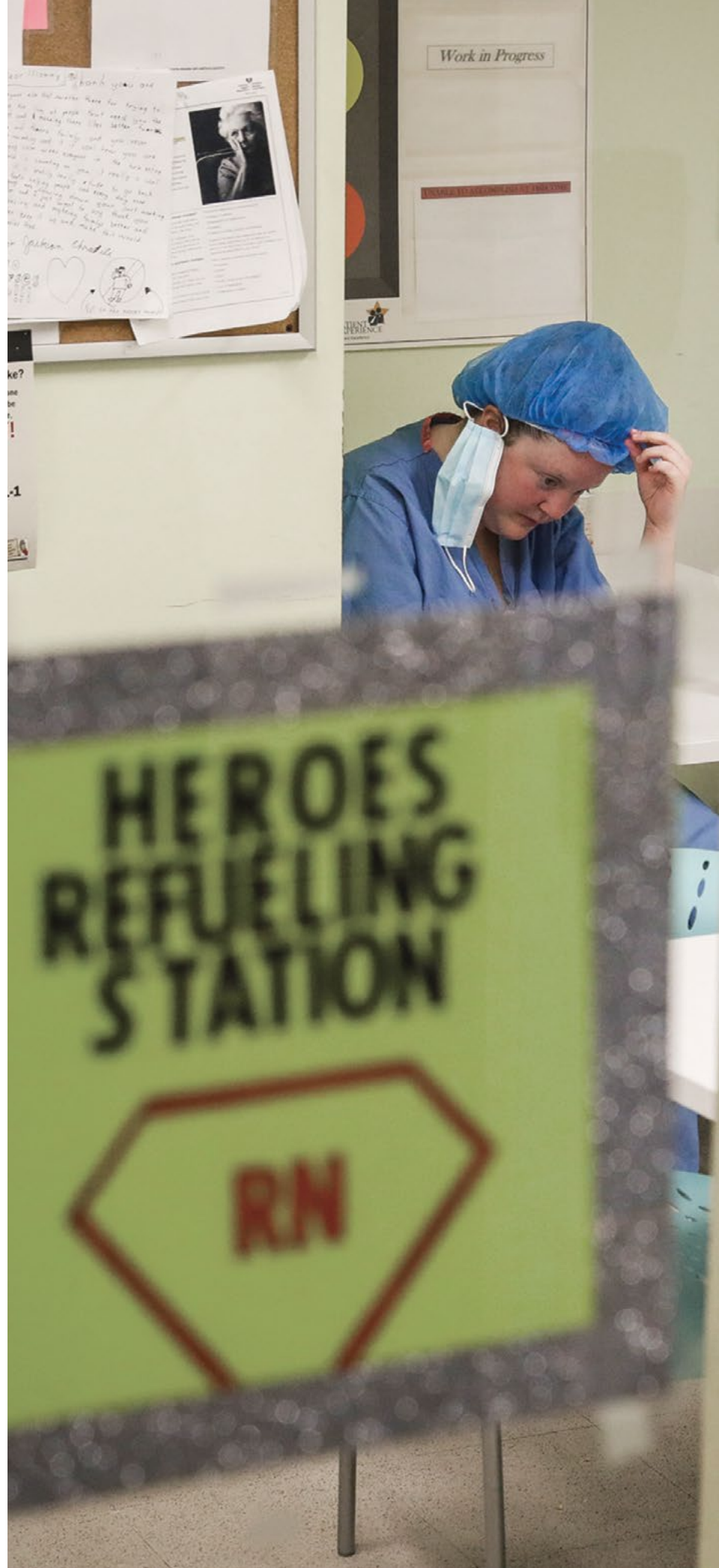
Affiliations Across Organizations Through Social Media

The use of social media provides a third strategy for mobilizing action that can address moral injury. With only 20 percent of healthcare workers unionized, and most of those concentrated in hospitals, many nurses do not know where to turn when experiencing stressors—especially when raising their concerns related to their colleagues' or managers' ethics. Platforms like Twitter have enabled individual nurses to connect with like-minded health professionals across the country, regardless of their institutional affiliations, to discuss problems and solutions. (Many nurses have created profiles that protect their identities and, thus, their jobs, particularly if they work at hospitals with gag orders.) For more in-depth problem solving, closed groups on platforms like Facebook have facilitated dialogue in ways that were not previously possible, both within and across workplaces. That dialogue can lead to substantive discussions, exchanges of strategies being used in different units or facilities, and the development of action plans.

While social media is helpful when there is no labor union, it is also used by labor leaders and members—especially when in-person meetings are not possible. Ideally, union members and leaders will be active on social media to facilitate greater participation within the union, to expand their reach to potential new members, to learn more about their communities' needs, and to share their values and goals with their communities. As the pandemic has shown, union leaders—and all healthcare providers—are also important community leaders who are sharing information about the benefits of masks and social distancing as well as the safety of vaccines.

Subgroups Within Professional Associations

Building on the organizing potential of social media, a fourth strategy is to encourage professional associations to adopt more courageous stances. Professional associations (as distinct from unions of professionals like the AFT) generally regulate and set standards for a profession. Across professions, even outside healthcare, such organizations are notoriously cautious in the positions they assume and the battles they choose to fight. This is a function of attempting to encompass the full profession, representing a wide range of views and interests. However, these associations occupy an important role in educating policymakers, and they often have a seat at the table in policy negotiations. As such, it is important to strengthen their understanding of and commitment to frontline nurses' and other healthcare workers'





experiences. For example, when moral injury results from problems like the relative paucity of people of color in higher-level and leadership roles throughout the healthcare field (from professors to surgeons to CEOs to lobbyists), that is a profession-wide concern that demands profession-wide action.

In the era of social media and Zoom, members of professional associations can now essentially self-convene, and subgroups can set their own agendas. Such was the case after ANA decided in 2019 to limit its political action committee to races in the US Congress, thereby remaining neutral on the presidential election.⁴⁰ Many nurses viewed the Trump administration's lack of leadership in the COVID-19 response as a matter of professional ethics and were outraged when nurse leaders participated in White House photo opportunities—especially because they were not wearing masks.⁴¹ But some saw ANA leadership's actions as attempts to capitalize on opportunities to convey the impact of COVID-19 on nurses and the need for nurses to be involved in developing policies related to reopening businesses and schools.⁴² The resulting surge of protest by nurses across the country via social media calling for ANA to take a position against the Trump administration suggests that it is easier than it used to be to challenge professional leadership.⁴³ No matter whether one agrees with ANA's stance or with the protestors, it is heartening to see that individuals can create their own leadership roles and that grassroots nurses can pressure organizations to change.

A Social Movement for Ethical Healthcare

The fifth and most macro-level strategy involves building a social movement around healthcare ethics. Other nations have universal access to healthcare complemented by strong public health movements that include a broad range of health workers, as well as activists in the general population. This combination is how many countries—especially wealthy nations—have achieved healthier populations and lower healthcare costs than the United States.⁴⁴ Even countries with fewer resources, such as Brazil and Mexico, have built such movements and successfully influenced health reforms in their respective countries.⁴⁵ In the United States, similar movements are growing around the recognition of healthcare as a human right—a position long championed by civil rights activists and receiving increased attention with the passage of the Affordable Care Act in 2010 and the multiple attempts to repeal it in the decade that followed⁴⁶—and the creation of new payment models that prioritize health.* The leaders of these movements around the world see themselves as ideologi-

cally committed to a “health for all” platform but are careful to avoid being profession-specific or partisan in their affiliation. They demand a seat at the table, alongside other more traditional stakeholder groups, and while they are viewed as ideologically driven, they have the added legitimacy of being seen as relatively free from vested interests specific to a single profession or party.

Working toward a broader social movement that focuses on the problems engendered by the commercial orientation and profit-driven nature of our healthcare system is no small undertaking, but it is probably the only way to alter the most significant structural causes of moral injury. Labor unions, nongovernmental groups, academic groups, and professional associations could play an important role in facilitating such a movement.

Managing moral distress, as well as other forms of stress, and creating joy in nursing work are noble goals, and yet they are insufficient. Individual- and organizational-level policies and programs are essential, but they do not necessarily address all the root causes of moral injury. Nurses, along with other healthcare providers, need to elevate the discussion of moral injury to a system-level conversation about solutions. Until the major sources of moral injury are addressed across many different practice settings, a large segment of the nurse workforce will continue seeking to reduce their work hours and even leaving the profession as soon as they can.

The range of strategies that can be used to address moral injury includes partnerships with frontline workers at the unit level and across the healthcare organization, using social media to enhance interaction and organizing among nurses outside of their workplaces, increasing the grassroots pressure on professional organizations to take bolder positions, and building a cross-profession social movement to advance health policy changes nationally. These strategies are mutually supportive and can be used in different ways by different players within the nursing profession as we work together to build a healthcare system in the United States that values health and the essential work of caring for one another. **+**

Let's work together to build a health-care system that values health and the essential work of caring for one another.

Endnotes

1. M. Chowkwanyun and A. Reed, “Racial Disparities and COVID-19—Caution and Context,” *New England Journal of Medicine* 383 (July 16, 2020): 201–203.
2. K. Scales and M. Lepore, “Always Essential: Valuing Direct Care Workers in Long-Term Care,” *Public Policy & Aging Report* 30, no. 4 (2020): 173–77.
3. Fitzhugh Mullan Institute for Health Workforce Equity, “State Hospital Workforce Deficit Estimator,” gwhwi.org/estimator.html; and WWAMI Rural Health Research Center, “Supply and Distribution of the Primary Care Workforce in Rural America,” Policy Brief No. 167, University of Washington, June 2020, depts.washington.edu/fammed/rhrc/wp-content/uploads/sites/4/2020/06/RHRC_PB167_Larson.pdf.

*See, for example, “COVID-19: From Public Health Crisis to Healthcare Evolution” in the inaugural issue of *AFT Health Care*: aft.org/hc/fall2020/kitzhaber.

Continued on page 38



What Causes Moral Injury?

From Dangerous Conditions for Patients to Disregard for Providers, These Union Leaders Have Many Examples to Share

"Patient acuties are up, and staffing is down.... Those with the authority blame the bedside nurses instead of supporting them."

—Barbara

To truly understand moral injury—and the urgency of developing a more supportive healthcare system—we must listen to the professionals who are being harmed, shift after shift. One year into the pandemic, the leaders of the Health Professionals and Allied Employees (HPAE), an AFT affiliate in New Jersey, generously gave us their time to share their members' experiences. For a longer version of this Q&A, visit aft.org/hcl/spring2021/hpae.

—EDITORS

EDITORS: Moral injury has come to the forefront in the last year because of COVID-19, but healthcare providers have long faced systemic barriers to providing the care they know all patients deserve and to being treated respectfully themselves. Will you share some pre-pandemic examples of situations that led, or could lead, to moral injury?

BARBARA ROSEN, HPAE Vice President: In the last decade or more, there's been a rise of for-profit hospitals, and of a profit-driven mentality among many nonprofit hospitals; their mission has turned to caring more about money than

patients. This has put a strain on the staff, leading to moral injury.

Some of our hospitals are better than others, but there's been a widespread decline in working conditions. We've witnessed crumbling infrastructure, obsolete technology, broken equipment, and filthy environments. A nurse in one of our worst hospitals said conditions are so bad that it seems like it's "being run by slumlords." Patient acuties are up, and staffing is down. That in itself is a moral injury because those with the authority blame the bedside nurses instead of supporting them.

Too many of our members have impossible workloads. They're not able to deliver the level of care and compassion that they entered the profession for. Healthcare workers are probably the most compassionate people on the planet. The employers tell them, "Well, you know, we cut [costs, staff] because our motto is to work smarter and not harder," but the staff sees this as "It's work to the death, with less and less and less."

DEBBIE WHITE, HPAE President: As a bedside nurse, I have been a mentor and a preceptor for a long

time. It was only two years ago that I became the president of HPAE, which is a full-time job, and had to leave bedside nursing. When nursing students are learning, they are so idealistic and energetic; they cannot wait to become nurses. Then they graduate and orientation is suddenly cut short because administrators say, "We need you on the floor working as staff right now." They are thrust into an environment where they see even the most experienced nurses unable to keep up with the workload, and they become more and more conflicted. They feel alone as the reality of the workplace begins to manifest.

I have witnessed many a new nurse break down in tears as they realize that they are working in an untenable environment. When these new nurses go to management and say, "I can't keep up," they are told, "It's your time-management skills," or "Maybe this job is not for you," or "Maybe you really just need to work on your stress level," thus effectively blaming the nurse rather than the environment. Many new nurses will eventually leave bedside nursing, saying, "This is not what I signed up for."

ALEXIS REAN-WALKER, HPAE

Secretary-Treasurer: When I think of what moral injury refers to, it is an injury to a person. When I think of morals, I think of your conscience, your values, how you perceive yourself. It is an injury to an individual's moral conscience and values resulting from a transgression of a perceived moral code of conduct.

So, think of me as any particular employee. If I work for your company, you have expectations. You expect me to come to work. You expect me to be there on time. You expect me to do my job well to the best of my ability. I also have expectations. I expect to be provided with the tools to do my work from a moral standpoint. So if I come to work and my employer does not supply me with what I need, I am injured morally. When my employer doesn't supply me with enough colleagues to distribute the workload or PPE for my protection—the gowns, masks, face shields, and gloves I need—that is both insult and injury to me. My employer is not standing by the employment contract; both sides have an expectation, but one side is letting the other side down. This results in psychological harm to one's belief system.

DEBBIE: Consider one nurse I worked with; I'll call him Mike. Every patient review of Mike was exemplary. Mike took the time to listen to his patients, and his patients reported that their concerns were addressed. Mike routinely stayed late to chart because he devoted so much time to his patients' emotional and teaching needs, as well as their physical needs. Mike was famous for picking up those subtle cues that say a patient isn't doing well and should be in a higher level of care.

But routinely, management would say, "You have terrible time management. You're creating incidental overtime. You need to get out on time." Mike would come in day after day and say, "Deb, I just can't keep up with this. I can't take care of the patients and do what management tells me to do." That is moral injury.

Another example centers on the inability to provide patient teaching. For instance, with a newly diagnosed diabetic, teaching a patient to self-inject insulin is critical. Without careful instruction, a patient will have a much more difficult time overcoming the fear inspired from hearing the doctor say, "From now on, you must give yourself a needle a couple of times a day." Helping a patient overcome that fear is time-consuming but key prior to discharge.

As an experienced nurse, I would try to make teaching a priority, but the rest of my assignment might suffer as a result. It is just one of the many ways that short staffing affects patients. Patients suffer, and so do the nurses trying their best to provide care.

BARBARA: We represented staff at a hospital that was privatized. There was a long-term care unit in that hospital that would be staffed with one nurse for 60 residents and about four certified nursing assistants. The workload was not safe, but if anything went wrong, the blame would sit squarely on the shoulders of the nurse. Nurses are leaving their shifts feeling they haven't delivered 100 percent, leading to moral injury.

DEBBIE: The heart of the problem is victimization of staff who work under incredibly stressful, difficult conditions because they become a cog in a wheel, a line item in a

budget. Staffing should be an asset, not a budget line that can be cut down to its lowest number in order to save a healthcare corporation money and reap more profit.

EDITORS: Of all the causes of moral injury, the longest standing in the United States is racism. As union leaders, have you been called upon to defend your members' rights to equality and dignity?

ALEXIS: Far too often. The most recent was just a few days ago.* I got a call regarding an incident involving two members; I believe they are in two different unions, but they are on the same level and work in the same department. They are two African American women who go to work striving for excellence. Upon hiring, they both had bachelor's degrees, and while working one also earned two master's degrees. Despite working and repeatedly bidding on jobs or promotions, they have not advanced. The member who earned the master's degrees is now making a formal complaint against the employer.

Now, this particular employer has recently hired a new president who is working on changing the environment, but sometimes it is too little, too late. One potentially important change is that this employer is allowing two members to start a

*This incident occurred shortly before our initial interview in February 2021.



"Staffing should be an asset, not a budget line that can be cut ... to save a healthcare corporation money."

—Debbie



“What about the nurses at the bedside of patients who are dying from COVID-19? It’s like standing in the gap for family members, doing what they can’t do.”

—Alexis

program within the institution that will hopefully help stop the inequities. Having higher qualifications than your counterpart who receives the promotion is heartbreaking, and this needs to change.

Let me add a COVID-19 example. There is a member, also an African American woman, who recently retired from a particular hospital. One of her siblings got COVID-19 and was admitted to the hospital where her sister had worked. She was not doing well, so the hospital was going to put her on a Do Not Resuscitate (DNR) list without contacting the family.

Thank God the retired member had friends—her former coworkers—at the hospital who called her. And she called that hospital and told them, “I’m telling you now, you better put my sister on the CPR list, because you’re going to resuscitate her if anything happens to her.” Her sister came home a couple days later, and she’s safe and sound, recovered from COVID-19. But the fact that they were going to choose her, without alerting the family, without telling anyone why she had been selected, it leaves me wondering what their criteria are for that DNR list.

EDITORS: Let’s talk about COVID-19 more specifically. How did the pandemic—and the handling of the pandemic—compound moral injury?

DEBBIE: There are a couple of incidents of moral injury that stand out in my mind during COVID-19. The most important to share is that of Alfredo Pabatao. Alfredo, a transport worker, was advised by his employer that masking—during COVID-19—would scare patients. He was told, “Remove your mask and carry it in your pocket. If you need to put it on, you can, but don’t wear it too much because we don’t want to scare the patients.” He followed the direction from the employer, and Alfredo Pabatao is now listed on our memorial page. He contracted COVID-19, and he was the first of our members to die from this awful disease. His employer left him exposed and at risk of contracting a deadly virus. That is extreme moral injury. For Alfredo and his family, it is unspeakable. But even for his colleagues, the moral injury is severe.

Another recent example occurred in mid-November through early February of this year. Our members found counterfeit masks within the facilities of New Jersey’s largest employer. Nurses noted the masks didn’t fit well, didn’t provide a seal around the face, and didn’t have the typical markings of a 3M respirator. Our members, frontline healthcare workers, are caring for a very high number of COVID-19 patients, and they knew that a respirator that didn’t provide a seal around the face was not safe PPE.

The employees were frantic because they couldn’t get their employer to respond and provide genuine respirators. The employer’s response was that they “would look into the matter.” Meanwhile, these counterfeits remained on units for months.

Alexis mentioned this bigger picture with moral injury, in which the employer does not live up to its end of the deal. In this instance, the employer didn’t provide a safe and healthy work environment. Our members flooded the Department of Health with calls, and a formal complaint was also filed. The department investigated, and the employer was cited. We also filed an Occupational Safety and Health Administration (OSHA)

complaint, and we’re awaiting the final outcome.*

In the meantime, the employer transferred these counterfeit respirators to their other facilities, and eventually we began to hear about outbreaks at those same facilities—100 employees infected in one facility, and 50 employees infected at another.

EDITORS: How does something like this affect morale and trust? What does it feel like to work under these circumstances?

DEBBIE: Terrifying, absolutely terrifying. And disheartening. The word *disposable* came up throughout the pandemic. Healthcare workers said *they felt disposable*: “It feels like my employer doesn’t care about me as a person. I am a cog in a wheel.”

After the terror came outrage. Our members were angry: “How dare you treat me this way?” Unfortunately, we are also seeing many nurses, especially those close to retirement, just leave the profession.

BARBARA: We have one hospital that had 420 RNs before the pandemic. Now there are only 300. Nurses have been leaving in droves because they either have been sickened with COVID-19 or are just sick of the working conditions.

DEBBIE: Let’s talk about the mental health of healthcare workers as a result of the pandemic. Driving into the parking lot of a hospital and seeing refrigerator trucks that were used to contain the bodies of those who died during the first surge was absolutely horrifying for our healthcare workers. There was an enormous death toll. This wasn’t necessarily a failure on the part of the employer, it was just an awful truth of the pandemic itself. But adding in all the stressors that currently exist in the workplace to those created by COVID-19—the increased workload; the incredible numbers of very sick, unstable, and dying patients; and the constant, nagging fear of exposure—and you

*The outcome was still pending as of March 12, 2021, when this interview was finalized to go to press.

have a recipe for PTSD. Some members are now starting to experience the anxiety and depression that comes with PTSD—which, of course, is a hallmark of moral injury.

ALEXIS: And what about the nurses at the bedside of patients who are dying from COVID-19? It's like standing in the gap for family members, doing what they can't do. Holding patients' hands when they take their last breath. That is a major, major stressor to go through in your everyday work environment.

EDITORS: Let's turn from digging into the challenges, which are many, and talk about interventions. How can we alleviate current suffering and prevent moral injury in the future?

BARBARA: There are two ways of looking at that. You can work on the symptoms that you're experiencing, and you can get down and work on the root cause of it. We like to look at the etiology: that's where the union's work comes in.

On the federal level, a lot of the issues arose from the Trump administration's mishandling of COVID-19, such as the Centers for Disease Control and Prevention having wishy-washy guidance, OSHA refusing to implement an emergency temporary standard for COVID-19, and the former president's hesitancy to use the Defense Production Act to produce PPE that would have saved lives.

On the state level, we have been working to promote hospital transparency in an attempt to keep money at the bedside instead of in the pockets of profiteers. We succeeded in getting a law passed, CHAPA (the Community Health Care Assets Protection Act), which deals with the conversion to for-profit hospitals. We've been working on a staffing law for at least 15 years; just imagine how much better prepared for COVID-19 we would have been if it had passed. It has been noteworthy that with the lack of any cohesive pandemic plans, we need a seat at the table going forward. New Jersey does not track healthcare worker or hospital outbreaks, unlike nursing

home outbreaks. This information is imperative for analysis and remediation of problem areas. This year, we were successful in getting a law passed that requires the reporting of worker and hospital outbreaks. These legislative fights are not easy because we're up against the hospital association and these big hospital systems, both of which are big political donors.

On the local level, we work for contract language to protect the work environment, create safety committees, and get a seat at the table on a host of patient safety and workforce issues.

Working on all three levels is necessary to deal with the underlying causes—what's causing moral injury in healthcare workplaces.

ALEXIS: For our members who are suffering, I suggest a self-care, self-love approach. Taking time out for yourself—by meditating, walking, exercising, reading a book, or possibly doing therapy. But really, the issue is systemic; the employer has to live up to its end of the agreement—including the spirit of the agreement. I think the increase in staffing would make the biggest difference.

BARBARA: Advocating for quality healthcare is in a whole different arena than what it was when I started nursing 46 years ago.

ALEXIS: When it comes to racism, the key is to remove barriers. If we tried harder to remove structural, institutional, and systematic racism, that would help. Not judging a person by their appearance or discriminating against people based on their names or geographical area. These are changes organizations could make quickly to help relieve stresses. Having stress from your work environment added on top of your personal stress of your day-to-day life—trying to live and survive in a racist society—makes a difference. Attacking things at multiple levels would make a difference.

DEBBIE: One thing we did immediately with COVID-19 was to try to educate as many members as possible. We created an information hub and conducted town halls, sending as much out to our mem-

bers as we could. Because when it came down to it, members would have to advocate for themselves in the moment. We wanted to give them the tools, resources, and knowledge to do that.

We have also remained present in the media. We were one of the loudest voices in the state in terms of worker safety. Many of our workers spoke to the press as well. We advocated for all of our healthcare workers in the state, and even the nonunionized heard us.

We also feel like we need to keep up the pressure on OSHA for an emergency temporary standard, and we've supported state legislation that allows that any essential worker who contracts COVID-19 is presumed to have been exposed in the workplace and is entitled to workers' compensation benefits. This takes the burden of proof from the employee and places it on the employer. We've educated our members all over the state regarding that law and what they should do if they contract COVID-19.

Something else HPAE has been able to do at the local level is to negotiate memorandums of agreement for things like pandemic planning committees, hazard pay, and limits on floating to areas outside the expertise of some of our nurses.

We're currently working on the mental health issues created by the pandemic. We are looking into what kind of a mental health program can be facilitated in our state. Police officers who endure stressful situations are directed immediately to occupational health, where they can get treatment for posttraumatic stress disorder. Developing a similar program for our healthcare workers is one of our initiatives.

BARBARA: When your profession gives you lemons, get up and make lemonade. Take care of yourself and work with the union. There is power in numbers to make the changes you want to see. And I think that's everything in a nutshell. +

Photo Credits

Page 14: Patrick T. Fallon / AFP via Getty Images

Page 15: Go Nakamura / Bloomberg via Getty Images

Page 16: Irfan Khan / Los Angeles Times via Getty Images

"Take care of yourself and work with the union. There is power in numbers to make the changes you want to see."

—Barbara

HPAE WHITE PAPER • JULY 2020

EXPOSED & AT-RISK

New Jersey healthcare workers reveal how our safety systems failed them during the COVID-19 pandemic



A new HPAE survey details systemic failures in New Jersey public health infrastructure and recommendations on preparedness plans and urgent measures to mitigate surges in COVID-19 and future outbreaks.

HPAE
Putting care first

For more on the challenges faced by HPAE's members during the pandemic, read *Exposed & At-Risk*, which HPAE published in July 2020 based on its survey of more than 1,100 healthcare workers in New Jersey: bit.ly/3koQ81B.

Self-Care Strategies in Response to Nurses' Moral Injury During the COVID-19 Pandemic

By Fahmida Hossain and Ariel Clatty

Fahmida Hossain is a PhD candidate and adjunct professor in the Center for Global Health Ethics at Duquesne University. Her goal is to normalize diversity within healthcare; her research applies ethics and narrative as drivers for individual development and organizational change.

Ariel Clatty, PhD, HEC-C, is a medical ethicist at the UPMC Presbyterian and Shadyside hospitals; she recently created a nurse champion program that helps nurses embed ethics in their everyday practice to build a stronger ethics culture.

"Self-Care Strategies in Response to Nurses' Moral Injury During COVID-19 Pandemic," by Fahmida Hossain and Ariel Clatty, is used under CC BY 4.0 (<https://bit.ly/3rle7Rh>); cut for length and lightly edited.

DOI: <https://bit.ly/3cgAnYe>

First published in *Nursing Ethics*, a SAGE journal, on October 30, 2020 (<https://bit.ly/2NRUYIY>).

As Patricia Pittman explains (see page 4), moral injury is a systemic problem. Individual resilience, increased staffing, and other personal or organizational changes can reduce moral distress, but addressing the root causes—such as the questionable incentives of the fee-for-service payment model—requires a wholesale rethinking of our healthcare industry. (Former Oregon governor John Kitzhaber started the conversation about system transformation in the inaugural issue of AFT Health Care, which you can read here: aft.org/hc/fall2020/kitzhaber.) Still, many nurses and other frontline healthcare workers are experiencing moral injury now. While we work toward systemic changes, we hope the self-care strategies and organizational supports suggested here offer some relief.

—EDITORS

In the midst of the pandemic, nurses are working long, arduous shifts for extended periods; as a result, many are experiencing severe emotional trauma. Many nurses feel overwhelmed by the massive number of patients needing care while being immersed in settings full of contagion and facing high-stakes decision-making challenges that affect both their professional and personal lives.¹

Given the severity of the crisis, a significant shift occurred from patient-centered ethics to public health ethics. Whereas patient-centered ethics focuses on duty to care for a particular patient, public health ethics focuses on

equity, common good, and the risk and benefit to society as a whole.² Within a few short weeks, the nursing profession was directed to apply public health as the guiding dictate when caring for patients. This transition is tough and rubs against many basics of nurse training.

Being forced to make clinical decisions in the face of limited resources is a heavy burden for nurses to carry. As a result, many nurses are taken by a sense of helplessness, question their abilities, and are forlorn and frustrated at the bedside of a patient who is cut off from family and friends, dying alone.³ "That's a tough thing to watch every single day, to watch somebody die without their family there," said registered nurse Jennifer Mueller. Her statement clearly and succinctly reveals the trauma she and many nurses are going through.⁴

Moral Distress and Moral Injury

Nurses are critical to the administration of excellent care. They are even more focal during this crisis because they play expanded and multiple roles simultaneously: conducting screening processes, attending to the critically ill, deciding triage protocols, contacting and updating families, and informing the family of the death of a loved one. In many ways, moral distress in this situation might be better seen as moral injury. These moral injuries may be long-lasting due to the intensity of the crisis. Posttraumatic

responses are highly likely as a result. During this crisis, many nurses struggle to share with others the effect of seeing someone die, knowing that the reality of the situation did not permit them to provide the care that was needed or necessary. Here is where the seeds of moral injury are sown.⁵

Self-Care Strategies

When moral distress is not addressed, it can lead to burnout, feelings of frustration, and chronic exhaustion. Unattended stressors can lead to secondary traumatic effects, which are identified as negative feelings, vicariously acquired due to indirect exposure of trauma-related events.⁶ If nurses do not have proper education, training, and tools to mitigate this trauma, they will be ill-prepared to respond to the psychological effects of the pandemic.⁷

Moral Resilience

Moral resilience is the courage and confidence to confront distressful and uncertain situations by following and trusting values and beliefs. Being morally resilient allows one to maintain perspective, keep a situation in context, and understand that some conditions are out of one's control.⁸ Moral resilience can be built and developed—for instance, by practicing mindfulness. Being mindful helps nurses reduce the cases of distress, anxiety, fear, and helplessness that occur through the trauma of COVID-19 clinical settings. Nurses can also strengthen their parasympathetic nervous systems to combat stress through breathing exercises and mindfulness.

Mindful breathing is also helpful before entering into a patient's room as a means to calm oneself from the previous encounter.⁹ There are self-care and breathing apps, such as Calm or Headspace, to help a nurse stay attuned and develop moral resilience.¹⁰ Building on moral conscientiousness, moral resilience includes the ability to make important ethical distinctions, to remain open-minded and curious, and to resist the presumption that there is only one way to consider one's moral obligations or to preserve integrity in any particular situation.¹¹ Moral resilience can help nurses find meaning and respond



PHOTO BY CINDY ORD / GETTY IMAGES

Additional Resources

"Recognizing Moral Distress in the COVID-19 Pandemic: Lessons from Global Disaster Response" by Bethany-Rose Daubman, Lynn Black, and Annekathryn Goodman in the *Journal of Hospital Medicine*
bit.ly/37FmEHJ

"Managing Stress & Self-Care During COVID-19: Information for Nurses" by the American Psychiatric Nurses Association
bit.ly/3bA84Cp

Moral Stress Amongst Healthcare Workers During COVID-19: A Guide to Moral Injury by the Phoenix Australia—Centre for Posttraumatic Mental Health and the Canadian Centre of Excellence—PTSD
bit.ly/3qVIQoG

—EDITORS

to ethical issues in a constructive, positive, and healthy way.

Self-Stewardship

Self-stewardship is the skill of tending to and nurturing one's well-being. Without self-stewardship, it becomes challenging to stay healthy and to serve others well. Self-stewardship—allowing oneself to be seen—helps nurses to contextualize the ethical dilemmas they face between patient-centered care and public health ethics. This helps an individual understand and appreciate that she does nothing "wrong" by providing public health-guided care.¹² Psychological interventions and support provide structured forums in which care professionals can talk through and contextualize the ethical and personal challenges and uncertainties they face.¹³

Structural Support

Discounting or ignoring the mental health of nurses will have some adverse short- and long-term consequences for the healthcare delivery system. Coworkers and institutional leaders must recognize the prevalence and magnitude of moral distress and stand together to view nurses as individuals in need. It is important not to look at nursing in the abstract or as statistics.¹⁴ Nurses are typically uncomfortable sharing their feelings with others, but now is the time to make it comfortable for them to open up.

During the crisis, it is important to acknowledge the successes achieved by nurses. Such acknowledgments help bring light into the darkness that seems to cloak the chaos of the crisis. Beyond acknowledgment, hope and a sense of accomplishment must be cultivated by the organization. Instilling hope—and a belief that the crisis will improve and the future will be better—into the fabric of the organizational culture can bring a remarkable change in mood, safety, mental health, and performance.¹⁵

Organizations must fully acknowledge the stress and burdens faced by providers. Offering hope is a means to keep the community together, and to keep nurses focused and intent on collectively overcoming the challenges they face. Perfectionism must be cast aside. It is unattainable and only leads to unrealistic expectations. The COVID-19 crisis is a challenge that requires nurses to accept ambiguity and uncertainty while honoring themselves by embracing their humanness.

Nurses also need support and education as they try to work to regain "normalcy." Cognitive processing therapy is a form of cognitive behavioral treatment to help victims of trauma. There are four main steps, which include education, information, developing skills, and changing beliefs.¹⁶ Through this, trauma therapists

can help nurses to identify possible symptoms of posttraumatic stress disorder and lead them to understand how receiving treatment can help. The therapist, in turn, can help staff recognize how their thoughts and feelings are related directly to the stress and anxiety they are experiencing. Nurses should be given training and skill-building opportunities that offer coping mechanisms, provided by the institution. This will help nurses question or challenge their beliefs and routines that do not serve them well during the distressing and morally complicated situations they face.¹⁷

Another type of therapy that has shown positive results is emotional freedom techniques. This type of therapy combines cognitive behavioral therapy and exposure therapy, and may also involve a type of acupuncture.¹⁸

Healthcare institutions are obligated to meet the needs of patients, but also the needs of staff. Healthcare staff will continue to put the needs of their patients before their own and may not recognize that they too need to be cared for. It is the duty of the institution to provide the tools that serve to keep staff safe and protected, including the mental and emotional components of their health.



Endnotes on page 39

It is the institution's duty to keep staff safe and protected, including mentally and emotionally.

The Importance of Respectful Maternity Care for Women of Color



By **Jamila K. Taylor**

Jamila K. Taylor, PhD, the director of healthcare reform and a senior fellow at The Century Foundation, leads research and policy efforts to achieve universal coverage and high-quality care. Taylor's specialties are maternal health, reproductive justice, structural barriers to healthcare, racial and gender disparities in health outcomes, and the intersections of health and economic justice. Taylor also chairs the board of directors of Mamatoto Village.

As the United States contends with a pivotal moment of reckoning on racial justice, inequitable treatment in healthcare has risen in the public consciousness¹—largely due to the disproportionately high rates of COVID-19 among Black Americans and other communities of color.² Behind the statistics are personal stories of people of color, across geography, socioeconomic status, and health profile, who have been denied access to lifesaving care, even as their expressions of pain, discomfort, and illness have been ignored. For those of us working in health equity and who have studied the history of mistreatment of marginalized communities by the medical establishment, hearing and seeing these stories play out in the context of COVID-19 is not surprising. As devastating as these stories are, the commonalities are always Black and brown skin, mistreatment, and, far too often, premature death.³

Similarities can be seen in trends related to America's maternal health crisis. Black and Native women are dying at alarmingly high rates due to preventable pregnancy-related causes. According to the Centers for Disease Control and Prevention, non-Hispanic Black

women are approximately three times more likely to experience maternal death than white women.⁴ Native American and Alaska Native women are approximately two times more likely to die than white women. (This is in stark contrast to Hispanic, Latina, Asian, and Pacific Islander women, whose rates are quite similar to white women's.) Most of these deaths are preventable and occur not just during delivery but up to a year after giving birth. Black women also have a 70 percent greater risk of experiencing severe maternal morbidity than white women.⁵

COVID-19 has made maternal health matters even worse. Based on preliminary data, pregnant women who fall ill due to COVID-19 are more likely to be admitted to the intensive care unit and receive invasive ventilation, and they are at increased risk of death compared with nonpregnant women. Black and Hispanic pregnant women are disproportionately likely to experience grave illness and complications due to COVID-19.⁶

Racial health disparities like these do not exist in a vacuum. Research has long shown that social determinants—such as the degree to which people can access affordable, safe housing and nutritious foods and whether they experience residential segregation,

economic disadvantage, or exposure to environmental toxins—are important factors that practically dictate a person’s health and well-being.⁷ Access to quality, respectful healthcare that is free of discrimination and bias is also critically important. Unfortunately, discrimination and bias based on race and gender have pervaded the healthcare experiences of women of color in the United States for centuries.

Medical Mistreatment of Black and Native Women

The medical mistreatment of Black and Native women is not a new phenomenon; it has been widespread since before our nation’s founding. For Black women, it can be traced as far back as the institution of slavery, when Black women’s bodies were used without consent for experimentation in the study of obstetrics and gynecology.⁸ Slave owners actively sought the assistance of physicians in the management of Black women’s fertility. Particularly after the ban on importing enslaved people in 1808, slave owners had financial incentives to force enslaved women to have as many children as possible. Enslavers became familiar with new training practices and surgical procedures for reproductive organs developed by medical doctors by the mid-19th century. Coerced “breeding” of and medical experimentation on enslaved people were commonplace.⁹

Enslaved Black women were subjected to painful and injurious experimental surgeries on their reproductive organs. They were cut open and prodded with all types of surgical instruments without consent. It was during this period that falsehoods about Black people having “thicker skin” and a higher threshold for pain were first spread.¹⁰ While anesthesia was not used in most cases, morphine was sometimes used to drug enslaved Black women in order to make them docile and to reduce the screams that came with undergoing invasive vaginal surgeries.¹¹ Some became morphine dependent as a result.

A doctor named Nathan Bozeman gained renown as a gynecologic surgeon due to his operations on enslaved Black women in Alabama. One 18-year-old enslaved girl became disabled and was rendered sterile as the result of one of his experimental surgeries,¹² but his disregard for enslaved women’s humanity seems to have had no impact on his reputation.¹³ One need not look far to also learn of J. Marion Sims, known as the *father of modern gynecology*, a medical pioneer who employed harsh practices to restrain enslaved Black women during the repeated invasive gynecologic surgeries he conducted on them.¹⁴

It should be noted that the experimental procedures and drugs developed during this time period served to advance the study of gynecology in ways that would ultimately heal white women of most of their reproductive injuries and illnesses. But for women of color, these advances have too often been used

to harm, not heal, as scientific advances have led to further exploitation. Decades after Bozeman and Sims partnered with enslavers, the end of slavery shifted the focus from expanding the enslaved Black population to minimizing the free Black population. Under the guise of the pseudoscience of eugenics—the pursuit of perfection of the (white) human race through controlling the reproduction of people perceived to be physically, intellectually, or morally “unfit”¹⁵—compulsory sterilization began to be used as a form of reproductive control over women of color and low-income women.¹⁶ Black and Native American women have been the main targets of this horrific practice.

In the 1970s, extremely large numbers of Native American women suffered sterilizations* against their will.¹⁸ Many of the forced sterilization procedures were performed by physicians associated with the Indian Health Service (IHS). For example, Native American girls as young as 15 years old entered an IHS hospital in Montana for appendectomies and instead received tubal ligations without their knowledge or consent. Their parents were also not informed of the procedures. The IHS would eventually be accused of sterilizing at least 25 percent of Native American women of reproductive age during the 1970s.¹⁹

Meanwhile, Black women were also being forcibly sterilized in the southern and northern regions of the United States. In 1972, the *Boston Globe* reported that Boston City Hospital was conducting hysterectomies on Black patients at high rates.²⁰ Other incidents were reported at a New York municipal hospital where low-income Black, Puerto Rican, and Native American women were targeted and given hysterectomies against their will. The procedure was so common in the South that it was referred to by the name “Mississippi appendectomy”—a term coined by civil rights leader Fannie Lou Hamer, who had undergone a forced sterilization herself.²¹ At the time, hospitals had no policies requiring informed consent.

Forced sterilizations of women of color are still occurring in the United States. As recently as September 2020, multiple people came forward with allegations that women in the custody of a US Immigration and Customs Enforcement facility in Georgia were being sterilized without their consent.²²

Medical mistreatment by way of nonconsensual experimental surgeries and forced sterilizations added to the centuries-long history of exploitation of Black and Native women. These experiences have caused

For women of color, scientific advances have too often been used to harm, not heal.



*This is just one example in the long history of denial and abuse of reproductive freedom for Native women in the United States, which has seen the same kinds of seemingly contradictory pendulum swings as the history of assaults on Black women’s reproductive freedoms. For instance, as the US government shifted from genocidal practices against Native peoples to forced assimilation, the Bureau of Indian Affairs pressured Native Americans to adopt Euro-American reproductive and birthing practices—including coercing Native women to carry every pregnancy to term, despite some Native peoples’ traditional use of abortion for family planning.¹⁷

some people of color to mistrust the medical establishment, which can make patients less likely to seek care when they need it. Even when people of color do seek care, they may not engage in dialogue about treatment plans or other healthcare issues in clinical settings. The lack of respectful care has persisted, leading to inferior treatment, misperceptions about the pain thresholds of women of color,* and poor health outcomes.²⁴ And while the medical experiences of the majority of women of color are safe and under the care of qualified physicians, nurses, and other healthcare professionals, discrimination and bias persist in ways that continue to have detrimental impacts.²⁵ These detrimental impacts have consequences for the maternity care women of color receive and the likelihood of Black and Native women experiencing pregnancy-related complications and death.

Respectful Maternity Care

Acknowledging the basic human rights of pregnant women and other pregnant and birthing people,

*Beginning in the 18th century, in keeping with their myths about Black women, white doctors promoted the myth that Indigenous women experience less pain than white women during childbirth because of their proximity to nature.²³

such as transgender, nonbinary, and intersex people (who face compounded barriers to accessing quality healthcare and birthing and parenting with dignity), is an imperative to realizing respectful maternity care for all. These basic rights envelop bodily autonomy, dignity, feelings, choices, and personal preferences in the provision of care.²⁶ Too often, healthcare providers focus solely on bodily safety and disease prevention. These are important, but respectful maternity care denotes the importance of thinking more broadly to intentionally center the most marginalized among us in order to address the higher rates of maternal mortality and morbidity among certain populations. Centering the most marginalized people also creates space for empathy and consideration of lived experience in how pregnant and birthing people are treated in medical settings.

Women across racial and ethnic groups feel discriminated against in healthcare settings.²⁷ However, the intersection of race and gender for women of color means that multiple oppressions pervade their healthcare experiences (past and present) in ways that are quite different from the experiences of white women. The result often leads to feelings of invisibility and not being listened to by healthcare providers when expressions of pain and discomfort are made before, during, or after birth, as well



Medical Mistreatment Today: Three Stories

Dr. Shalon Irving was an epidemiologist for the Centers for Disease Control and Prevention. She had dedicated her career to eradicating structural inequality and addressing health disparities. After years of building a successful career in public health, she decided it was time to become a mother. Unfortunately, the new mother, in her mid-30s and highly educated with two master's degrees and a PhD, would not be able to fully experience motherhood. Irving died of complications associated with high blood pressure on January 28, 2017, just three weeks after giving birth. In the weeks leading up to her passing, her blood pressure fluctuated, she experienced headaches and swelling in her limbs, and the incision at the site of her cesarean section became infected. Irving kept telling her nurses and doctors that something was seriously wrong. Her healthcare providers continued to pass off her complications as not serious enough for admittance to the hospital.¹

Kira Johnson also died of preventable pregnancy-related causes. She gave birth to a healthy baby boy on April 12, 2016, at Cedars-Sinai Medical Center in Los Angeles. When her husband noticed blood in her catheter during recovery from a cesarean section, he did what any concerned

husband would do—he notified Johnson's medical team right away. His calls for help were ignored. It would be seven hours before Johnson would receive medical attention. Once she was finally examined, doctors cut open her abdomen and found three liters of blood. She died of postpartum hemorrhage.²

Amber Isaac died on April 21, 2020, just days after tweeting about "dealing with incompetent doctors at Montefiore."³ Like Irving and Johnson, Isaac had undergone a cesarean section. She felt mistreated at an original branch of Montefiore facilities in New York City, so she switched to another location. Isaac's platelet levels started to fall due to the pregnancy-related condition known as HELLP syndrome.* Having to give birth during the early onset of COVID-19 in the United States, as well as experiencing lingering feelings of mistreatment by the medical system, Isaac sought options for a home birth with the assistance of a doula and midwife. When she was found

to have low platelet levels, her pregnancy was deemed high risk. She fought to get further information from her doctors and nurses about her condition and the potential impact on her pregnancy, but her calls were initially ignored. Once admitted to the hospital, Isaac was not allowed to have her partner or other support persons join her due to coronavirus-related protocols limiting nonpatients in medical facilities at the time. Isaac was induced a month before her due date. Her heart stopped during the emergency cesarean section just as her infant was delivered.⁴

Irving, Johnson, and Isaac were all Black women. They all expressed pain, discomfort, and the feeling that *something was not quite right* to their medical teams. Their deaths, as well as the deaths of other people due to preventable pregnancy-related causes, should not be in vain. Healthcare providers can and should do more to implement and support models of care that center women of color, acknowledge their unique lived experiences, and incorporate diverse care teams that respect pregnant and parenting people.

—J. K. T.

*HELLP syndrome is a life-threatening pregnancy complication usually considered a variant of preeclampsia. More information about the condition may be found here: preeclampsia.org/hellp-syndrome.

Endnotes on page 39

as in the postpartum period. At times, it leads to poor maternal health outcomes and even death.

Ignoring Black women's pain in particular, which is grounded in racist stereotypes about how Black people feel and experience pain, has been highlighted as a factor in countless maternal health stories. Some of these include the stories of celebrities such as Serena Williams, who experienced complications after giving birth by cesarean section. Despite being a top athlete who is clearly in tune with her body and knowledgeable about her medical issues, she had challenges obtaining responsive postpartum care once she informed her healthcare team that she was experiencing shortness of breath. Williams also told them that she was worried about her health due to a history of experiencing blood clots.²⁸ Other stories are those of everyday Black women who succumbed to their complications after multiple requests for help, such as Dr. Shalon Irving, Kira Johnson, Amber Isaac, and a host of others (see "Medical Mistreatment Today: Three Stories" on page 22).

Access to timely, quality healthcare can help identify, manage, and treat health conditions that complicate pregnancy, can reduce the risk of poor health outcomes, and can reduce rates of maternal mortality and morbidity. While issues such as continuous perinatal support and health insurance coverage are important, so too is the ability to obtain respectful care. Recently developed evidence-based maternity care models offer guidance for healthcare providers who are ready to examine their practices.

The JJ Way, created by Black British-trained midwife Jennie Joseph, is a maternity care model that centers the agency and choices of pregnant people by including them as partners in their own care team. To increase access to care, no one is turned away from its clinics based on lack of insurance coverage or the inability to pay. The JJ Way provides assistance in navigating the healthcare system along with personalized care plans that are practical and based on each individual's lived experiences. These are all fundamental aspects of centering pregnant and birthing people in healthcare. A recent evaluation in Florida demonstrated that women who received maternity care through the JJ Way had lower preterm birth rates and better low-birth-weight outcomes than the general state population. Furthermore, among at-risk populations, low birth weights were greatly reduced and preterm birth disparities were eliminated.²⁹

Mamatoto Village, a Black woman-led nongovernmental organization based in Washington, DC, also implements a model of care that centers the patients and their lived experiences. Patients served by Mamatoto Village receive comprehensive, culturally responsive services, including classes on childbirth, breastfeeding, and family wellness; access to community birth workers (whom Mamatoto also trains); and connections to family support resources. In

2017, a review of women served by Mamatoto Village found that 74 percent had vaginal births (more than 10 points higher than the citywide percentage), 89 percent succeeded in breastfeeding (6 points higher than citywide), and 92 percent attended their six-week postpartum appointment. Best of all, there were no maternal or infant losses among those who received care under Mamatoto's model.³⁰

These models center pregnant and birthing people and their families by offering enhanced support from pregnancy through the postpartum period. Continuity of care is promoted by centralizing referrals for needed healthcare services, and concerted efforts are made to facilitate navigation of the health system and social services.³¹ Patients under the care of these models also have the support of a team that includes physicians and nurses as well as doulas, postpartum care navigators, community health workers, and midwives. Ensuring racial and economic diversity within the care team is key because research demonstrates that it leads to better health outcomes for women and infants of color.³² The team works collaboratively among themselves and with each patient to ensure optimal care and support that is grounded in cultural humility[†] and centers the lived experiences of the individuals and families being served.³³

Where We Go from Here

The provision of respectful maternity care must be implemented broadly in order to ensure quality healthcare experiences and positive maternal health outcomes for all pregnant and birthing people. Black and Native women stand to gain the most under maternity care models that center the unique lived experiences of people of color and are intentional about ensuring a diverse care team that reflects their communities—those most heavily impacted by maternal mortality and morbidity. Care teams should consist of physicians, nurses, doulas, midwives, and community health workers. They must be adequately trained in cultural humility and antiracism so that they can approach each patient with a genuine interest in listening and learning. They must also be held accountable for providing pregnant and birthing people with quality care that is equitable and free from bias and discrimination.

In addressing America's maternal health crisis, the unique and profound history of medical mistreatment toward Black and Native women must not go unacknowledged. It is no coincidence that these women are among the most subjugated in this country. The blatant

Models that center pregnant and birthing people and their families improve outcomes.



Continued on page 39

[†]Cultural humility is the ability to have an interpersonal viewpoint that is open to those with different cultural backgrounds. It focuses on a lifelong commitment to self-evaluation and self-critique by acknowledging that learning and commitment to embracing cultural differences are continual.

Improving Communication and Care

How Clinicians Can Increase Health Literacy and Equity



By **Rachel Roberts**

Rachel Roberts, MPH, is the community health engagement and strategy manager at the Institute for Healthcare Advancement. In addition, she is a part-time instructor in the public health and kinesiology departments at California State University, Fullerton. Roberts has enjoyed a career in public health for over 30 years.

I've been a health educator for more than 30 years. Since I started this work in the 1980s, I've observed a transformation in how the health professions think about communicating information as we've embraced the concept of health literacy. Introduced in the 1980s, health literacy is now central to our strategies for written and verbal communication, as we work to help patients grasp otherwise confusing medical information. An essential part of these efforts is a focus on health equity. Health educators consider differences in language, culture, and level of health literacy, striving to develop health communication that is equitable and effective for all.

Simple, straightforward information tailored to meet the needs of our diverse patient populations is essential to helping people struggling with illnesses like cancer and diabetes or caring for a sick loved one. We've made a lot of progress over the last 30 years, but we still have a lot of work to do. As we deal with the COVID-19 pandemic and the strain it has put on every aspect of our daily lives and those of

our patients, providing clear health information that meets patients where they are is more important than ever.

To illustrate the importance of clear communication, I often begin health literacy presentations by sharing a true story from only three years ago.

I took my 15-year-old son to the hospital one day because he woke up lethargic and confused, with a 105-degree fever. Due to a virulent flu strain, the emergency department (ED) was overwhelmed, resulting in a four-and-a-half-hour wait. While we waited, I viewed my surroundings and the overcrowded ED from a public health perspective, listening to different languages and noticing other demographic differences, including age and race. I also observed parents asking older children to help read and complete hospital forms, and others needing professional translators. Although we were a diverse group, we shared the anxiety of not knowing how best to care for our sick loved ones.

At 1:30 a.m., nine hours after we arrived at the ED, the doctor discharged my son with these exact words:

Doctor: Your son has influenza A. I'm prescribing Tamiflu. Give him one pill BID. I'm also prescribing Zofran for the nausea. He needs to take one pill sublingually as needed. Do you have any questions?

Me: No.

My son didn't talk much on the drive home, but he asked a question that I will never forget: "Mom, do you know how to take care of me?" When I asked why, he said he was worried about his diagnosis because the doctor said he had *type A*. And he was confused about how to take his medicine since he heard the doctor say to take it *BID*. After considering the information, I translated it into simple terms, to my son's visible relief. After a long pause he asked, "Mom, why didn't the doctor just say that?"

I had understood terms such as *BID* because I spent many years as a patient educator working in medical clinics where these terms are commonly used—but the doctor didn't know that. How many other parents received the same discharge instructions that night and were too intimidated or ashamed of their lack of knowledge to ask for clarification? How many left the hospital confused and apprehensive about their ability to care for their children? When providers communicate in terms that are easy to understand, they help to create an environment where patients, no matter their education level, language, or age, are better able to comprehend health information, ask questions, and make decisions that improve their health. Striving to empower all patients to take charge of their health through clear communication is where health literacy and health equity meet.¹

Health Literacy Is a Shared Responsibility

Every decade, health professionals across the United States convene to establish 10-year goals and objectives aimed at improving the health of our nation. With Healthy People 2030, health literacy has taken a central role for the first time; health literacy was made a focus during the development process,² and one of the primary goals for 2030 is to “Eliminate health disparities, achieve health equity, and attain health literacy to improve the health and well-being of all.”³

Although numerous definitions of health literacy exist, earlier iterations aligned more with personal health literacy or *one's* ability to *do* something. Healthy People 2030 expanded the concept by adding *organizational health literacy*, which places the responsibility on both parties—the person receiving the information and the organization disseminating it:

- *Personal health literacy* is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.
- *Organizational health literacy* is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.⁴

As the growing research on the impact of health literacy shows, when clinicians and patients both engage to build patients' knowledge of their conditions, treatment options, and potentially beneficial lifestyle changes, outcomes tend to improve.⁵ Studies from the last decade have found, for example, fewer visits to emergency care or hospitalizations, shorter hospital stays, more preventive screenings and care, greater ability to understand and follow care instructions,

and, particularly for elderly people, better overall health and longer lives.⁶ Still, there is much research to be done to better understand how to improve patients' knowledge and impact their behavior.⁷

The Role of Health Literacy in Improving Health Equity

Health equity, in the simplest terms, means everyone has opportunities to achieve and maintain their optimal health—no matter their age, racial or ethnic background, gender, sexual orientation, zip code, education, employment, or other (currently influential) factors.⁸ The fight for health equity involves addressing the conditions that lead to health disparities, including improving access to quality medical care, healthful food options,⁹ and other services and resources that support health.* These are significant challenges

- in predominantly Black and Latinx neighborhoods, the products of centuries of systemic housing and environmental discrimination;[†]
- on Native American lands, where people often have to travel hours to obtain fresh food, safe water, and healthcare;¹⁰ and
- in rural communities, where health facilities are closing at an astonishing rate.¹¹

While advancing health equity requires sustained, collaborative work on numerous fronts, focusing on improving health literacy is one key way health professionals can work to address health disparities every day.¹²

During the pandemic, health inequities have become even more apparent, as people in lower-income neighborhoods and Black, Native American, and Hispanic people suffer disproportionately from higher rates of COVID-19 exposure, severe illness, and mortality.¹³ Clear communication is vital in communities where infection and positive testing rates are high. Efforts to reduce risk of exposure to COVID-19, promote proper use of face coverings, and obtain and distribute vaccines require effective communication, beginning with language that is easier to read and understand.

The Development of Health Literacy: From Jargon to Communication

As a health educator in the 1980s, my role was to inform patients about their new diagnoses and walk them through treatment options. Patient education protocols called for verbal instructions supplemented with printed handouts. However, the verbal explana-

Improving health literacy is one way health professionals can work to address disparities.



*If you would like to start a conversation about advancing health equity with your colleagues, the American Public Health Association's three-page guide “Creating the Healthiest Nation: Advancing Health Equity” is a great place to start: bit.ly/3rfaGvJ.
†For more on environmental racism, see Harriet A. Washington's “Healing a Poisoned World” in the Fall 2020 issue of *AFT Health Care*: aft.org/hc/fall2020/washington.

tions and the provided printed materials often relied heavily on confusing medical terminology and acronyms. I frequently witnessed clinicians referring to some patients as “noncompliant” for failing to follow directions. Here is an example to illustrate the point.

Mr. Howard, a 59-year-old patient, saw his doctor to recheck his blood pressure and learn the results of a recent blood test.

Doctor: Mr. Howard, the results of your fasting lipid panel show that your LDL levels are elevated. You also have hypertension. I recommend that you reduce your intake of saturated fats, decrease your sodium intake to reduce your risk of cardiovascular disease, and exercise. Do you have any questions?

Patient: No.

I frequently witnessed clinicians referring to patients as “noncompliant” for failing to follow directions.

Three months later, Mr. Howard’s cholesterol levels and blood pressure were unchanged. He told the nurse who measured his blood pressure that he’d just returned from lunch with colleagues and enjoyed his favorite meal: a steak and french fries.

Mr. Howard was an educated man—the clinician and I both knew he had a college degree in aeronautical engineering. He was clearly capable of understanding complex subjects, but when it came to his diagnosis, he had appeared uncertain and apprehensive. And yet he hadn’t asked any questions and didn’t seem to have followed the recommendations regarding his diet. Was he “noncompliant,” as the provider suggested to me after seeing his follow-up bloodwork, or was there something else going on?

It wasn’t until health literacy was introduced in the now-foundational book *Teaching Patients with Low Literacy Skills*, first published in 1985,¹⁴ that many of us in the health professions began to realize the problem wasn’t solely (or perhaps even primarily) with the patients.* If we wanted to help our patients improve their health, our method of communicating needed to change. Of course, some patients are unwilling to follow treatment instructions, much less broader health advice, and others have financial, logistical, or physical challenges that prevent them from attaining their health goals. However, as health professionals absorbed the concept of health literacy and effective communication techniques, we realized we were often using terms our patients simply did not understand.

Two major studies of adult literacy illuminated an important contributor to the problem. According to the National Adult Literacy Survey, first released in 1993, up to half of the US adult population had

reading levels (in English) considered marginal or low.¹⁵ Then, the 2003 National Assessment of Adult Literacy, released in 2005, confirmed fairly widespread difficulties with comprehending more complex text, showing about one-third of adults having difficulty with prose and document literacy and about one-half having difficulty with quantitative literacy.¹⁶ Importantly, this study also had a health literacy component, which found that while 65 percent of adults had “intermediate” or “proficient” health literacy, 22 percent performed at the “basic” level, and 14 percent at “below basic.”¹⁷ Prior to these studies, we had thought low literacy was a problem for a small segment of the population, not nearly as widespread as the research indicated. As such, many patient education handouts in the 1980s were written at reading levels that up to half of the US population could not fully comprehend.¹⁸ This issue persists: in 2019, 43 million adults in the United States were considered to have low reading levels,¹⁹ and research indicates that far more needs to be done to develop patient education resources that are written at appropriate levels.²⁰

Building on the 1993 literacy survey and follow-up work by a special committee²¹ focused on helping clinicians grasp patients’ comprehension challenges, the American Medical Association Foundation released *Health Literacy and Patient Safety: Help Patients Understand*. This instructional video (which also had a companion guide) introduced health literacy, offered frank explanations by patients of what they did not understand and the embarrassment that prevented them from asking for clarifications, and showed clinicians teaching patients. In one example, a clinician asked a patient to repeat what was explained to her. This patient, among others in the film, struggled to recite the information because she was unfamiliar with the medical jargon and acronyms.²²

Today, we continue to be guided by the 2003 National Assessment of Adult Literacy, which showed that adults are more at risk for low health literacy if they

- are age 65 or older;
- live below the poverty level;
- speak another language alone or in addition to English;
- belong to certain racial/ethnic groups, including Black, Hispanic, American Indian/Alaska Native, or multiracial;
- never attended or did not complete high school; or
- have only a high school or high school-equivalent (GED) education.²³

Clearly, people in these demographic groups are more apt to experience problems with health literacy. However, it’s a misconception to think that only these groups struggle. People of all walks of life—including

**Teaching Patients with Low Literacy Skills* discusses patient teaching using illustrations, graphics, and simple terms rather than medical jargon. According to the authors, it became “the major resource book available to health providers who knew that their patients weren’t getting the message” (2nd ed., p. v).

Mr. Howard—experience health literacy problems, regardless of education, age, or socioeconomic status. While improved health literacy—including paying particular attention to the needs of members of these groups—is essential to advancing health equity, everyone benefits from clear health communication.

Unfortunately, some describe health literacy, especially the use of simpler language that is easier for people without a medical education to understand, as a “dumbing down” of health information.²⁴ That’s simply not true, as you’ll notice in the example below.

A 43-year-old female patient, accompanied by her sister, visited her doctor to learn the results of a recent biopsy. The patient has a master’s degree in public health, while her sister is an oncology nurse specializing in uterine, prostate, and cervical cancers. Here’s how the consultation played out:

Doctor: The biopsy results show you have a carcinoid tumor on the ampulla of Vater. It is benign, but you need to follow up with an oncologist as soon as possible. Based on the initial findings, it has not metastasized, but I will schedule an ERCP to perform another biopsy and possibly a tumorectomy. Do you have any questions?

Patient: [speechless]

Unless you have a background in gastroenterology, which involves the intestines and stomach, it’s very likely that you’d be confused, especially when facing the shock of this unusual diagnosis. Noticing that the patient was unable to process the information, her sister intervened.

Patient’s sister: Doctor, I’m an oncology nurse, but I’m not familiar with the ampulla of Vater. Would you please

1. Show us a picture of the ampulla of Vater with the surrounding organs and describe its function?
2. Explain the reason you’re using the terms *benign*, which means noncancerous, and *metastasize*, which refers to the spread of cancer. And the reason for seeing an oncologist?
3. Define *carcinoid tumor*?

I’m sure we’ll have other questions, but let’s start there.

The doctor proceeded to explain using illustrations and simpler terms until both the patient and her sister were satisfied. By the end, they understood the complex language that the doctor had used initially, which increased their medical knowledge and their ability to pursue treatment.

A critical point for healthcare providers is to see that in this case study, the communication was not oversimplified to the point of “dumbing down,” but the information was fully explained. Unfortunately, not all patients feel comfortable advocating for clear communication, especially if they are at risk for low

literacy. However, if health professionals incorporate health literacy strategies into patient teaching as a general protocol, this will ensure all patients have an equal opportunity to understand and retain health information.

Three Recommendations for Communicating with Patients

1. Use Plain Language

The COVID-19 pandemic has meant the rapid introduction of new vocabulary into our everyday language, causing chaos, fear, and confusion for many people. *Social distancing*, *quarantine*, *isolation*, and *contact tracing* are only a few of these terms. The terms *quarantine* and *isolation* may be clear to many of us, but what do they mean in the context of a pandemic? These terms give us cause to investigate further. And yet, many people (especially those with low health literacy) may not realize if their understandings of these terms differ from healthcare professionals’ intended meanings and might perpetuate confusion throughout their communities.

Plain language is critical to successful communication about COVID-19 risk and prevention, vaccines, and other topics related to this or other diseases and conditions. It involves identifying complex jargon and terminology and then choosing common language substitutes that the general public is better able to understand. When people comprehend health information, they have a much greater opportunity to follow instructions, make informed decisions, and properly care for themselves or their loved ones.²⁵ Here are a few examples of plain language we often see in communication about COVID-19:

- Mitigate: Slow the spread of the virus.
- Social distance: Stay at least six feet from others.
- COVID-19 vaccination: A shot to help protect you from getting COVID-19.
- Isolate: Separate yourself from others if you have COVID-19.

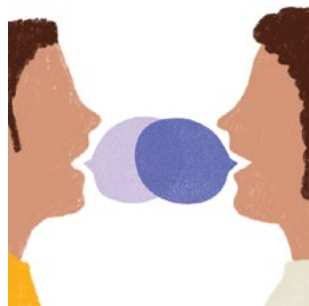
Think about the terms and acronyms you and your colleagues use daily that others outside of your workplace may not understand. Then boil them down to simple, accurate substitutes. For example, instead of saying *hypertension*, say *high blood pressure*. Then describe what it means. Rather than *ambulate*, say *walk around* or *move*. The Plain Language Medical Dictionary ([visit apps.lib.umich.edu/medical-dictionary](http://visit.apps.lib.umich.edu/medical-dictionary)) is a helpful resource that offers substitute words for complex medical terms.

2. Vet Written Materials

Many healthcare professionals lack the time or resources to write and create their own printed and web-based media. Instead, they identify quality



Think about the terms you use daily that others outside your workplace may not understand.



Teach-back gives you an opportunity to evaluate how well you explained the information.

patient education resources written by others and put them to use in their own clinical settings. When I am reviewing materials, I try to keep a variety of patients in mind—from those who may have low literacy to those who are simply too shy to ask questions. It's important to ensure that everyone has access to the same easy-to-understand written information and relatable illustrations, giving consideration to language and culture.

The *Federal Plain Language Guidelines* manual offers comprehensive instructions on writing and designing consumer-friendly information. It also serves as a useful tool to vet the quality of off-the-shelf materials.²⁶ The following is a short checklist of plain language tips developed from the federal guidelines:

- **Plain language:** Content is written in layperson terms or defines medical terminology as needed.
- **Chunking:** Messages are grouped into logical sections.
- **White space:** The page is not filled with text; paragraphs or sections vary in length but are generally short and visually manageable; there are sections with no text or images (commonly referred to as white space) to provide eye rest and make the page seem less difficult to navigate.
- **Type size:** Type size is 12 or 14 point. Use a larger type size, 14 or 16 point, for older adults to accommodate vision problems.
- **Images:** Culturally appropriate images are used to illustrate important points.

For years, I taught type 2 diabetes self-management classes where patients learned meal planning, self-blood glucose monitoring, and other subjects related to living well with a chronic disease. When I was hired to teach this class in the 1990s, my supervisor provided me with copies of patient education handouts as a foundation for my training. The problem was that the handouts resembled a passage from a medical dictionary. I purchased a book called *Diabetes for Dummies* instead. My colleagues across the country had similar experiences. As we collectively realized that patients were often overwhelmed with the amount of new information and apprehensive about their ability to succeed, health communication slowly evolved to have a greater focus on meeting patients' communication needs and supporting their understanding as an important part of meeting their physical and mental health needs.

Take a look at the two diabetes definitions that follow and note the differences. I've chosen two extremes: one that is concise and complex from a dictionary, and one that is written in plain language from a center that emphasizes communicating with the public. The differences are striking and show the value of plain language writers, who are trained to extract health information from complex definitions to create effective health communication.

Merriam-Webster

Definition of *diabetes mellitus*

A variable disorder of carbohydrate metabolism caused by a combination of hereditary and environmental factors and usually characterized by inadequate secretion or utilization of insulin, by excessive urine production, by excessive amounts of sugar in the blood and urine, and by thirst, hunger, and loss of weight.²⁷

Centers for Disease Control and Prevention

What Is Diabetes?

Diabetes is a chronic (long-lasting) health condition that affects how your body turns food into energy.

Most of the food you eat is broken down into sugar (also called glucose) and released into your bloodstream. When your blood sugar goes up, it signals your pancreas to release insulin. Insulin acts like a key to let the blood sugar into your body's cells for use as energy.

If you have diabetes, your body either doesn't make enough insulin or can't use the insulin it makes as well as it should.²⁸

You'll notice the dictionary groups many subjects together, including pathophysiology, signs, symptoms, and risk factors. But the second example incorporates plain language guidelines, including "chunks" of information, a title, and simpler terms. Still, even the plain language version requires a substantial amount of background knowledge for full comprehension. Written materials should serve as supports and reminders—not the sole or primary explanations. There is no substitute for a thorough explanation, given verbally, with text and image enhancements and with genuine checks for understanding.

3. Take Time for Teach-Back

For providing explanations and instructions, one essential method is teach-back. This is a technique that evaluates how effectively *we* convey information rather than how well the *patient* understands. (There are several steps to teach-back that are beyond the scope of this article; see teachbacktraining.org for more details.)

Begin by conveying the message to the patient using simple terms, written communication, and illustrations as needed. Then, ask the patient to explain the information back to you in their own words. This critical step allows the patient to think about what they heard, process the information, and demonstrate their understanding by restating the information. It also gives you an opportunity to evaluate how well you explained the information and correct any misinformation by rewording the instructions. These steps are repeated until the patient clearly understands.²⁹

Let's revisit the example I introduced earlier when my son was discharged from the hospital. But this time, let's focus on the doctor's instructions.

Doctor: Your son has influenza A. I'm prescribing Tamiflu. Give him one pill BID. I'm also prescribing Zofran for the nausea. He needs to take one pill sublingually as needed. Do you have any questions?

Me: No.

Here's how those same instructions might be conveyed using the teach-back method to communicate with and ensure the understanding of a mother who is not a healthcare professional:

Doctor: Your son has influenza A. I'm prescribing Tamiflu. Give him one pill BID. I'm also prescribing Zofran for the nausea. He needs to take one pill sublingually as needed. Mrs. Smith, I know it's late and you've been here for more than nine hours, but I just want to be sure I explained everything correctly. Would you please explain to me what I just told you?

Mother: Well, I'm not sure, but I think influenza is the flu. What does A mean?

Doctor: Yes, you're right that influenza is the flu. A and B are just common types of the flu, but they don't indicate anything serious.

Mother: So my son needs to take the medicine you're giving him. I know he needs one pill, but you said something about B and D. Then you're giving him something else for the nausea. Is he supposed to drink that, too?

Doctor: Let me explain the medicines again. I didn't explain it well the first time. The flu medicine is called Tamiflu. Give your son one pill two times every day. He should take one in the morning and one at night. Zofran is for the upset stomach. If your son feels nauseous, like he might throw up, he needs to put one pill under his tongue. The pill will slowly melt and make his stomach feel better. Since I was not clear the first time, let's check again. Will you explain how to give him his medicine?

Mother: My son needs to take two Tamiflu pills every day. If he feels like he's going to throw up, he needs to put one Zofran pill under his tongue.

Doctor: Yes, that is correct. What other questions do you have?

Mother: Nothing for now.

You'll notice this exchange is longer than the original and includes some back-and-forth in which the doctor stops to reteach as the mother makes clear what she doesn't understand. The doctor is thoughtful about taking responsibility for being unclear (which helps prevent the mother from feeling embarrassed about

not understanding), and the exchange ends with the open-ended question, "What other questions do you have?" The open-ended phrasing invites an individual to share freely, whereas a close-ended question like "Do you have any questions?" forces a simple *yes* or *no* response. A patient who speaks another language or has less education might respond *no* in the original scenario because they may be too embarrassed to admit they don't understand the term *BID*. Using the teach-back method would have alerted the doctor about the uncommon term and allowed for immediate correction.

Conclusion

Reducing health disparities through effective communication using plain language, vetted written materials, and teach-back involves coordinated effort and training at personnel, organizational, and policy levels. While organizational and policy changes will require sustained efforts, the techniques described here can provide a strong foundation for patient education and improving health equity now. Although health educators have worked to enhance health communication over the years, our work isn't done. It's important for all of us working in health professions to slow down and consider the ways we communicate and the implications of miscommunication. As we work toward health equity, we must think about the information necessary to empower patients to improve their health and the health of their communities. +

Endnotes

1. National Institute for Children's Health Quality, "The Intersection of Health Equity and Health Literacy," [Insights, nichq.org/insight/intersection-health-equity-and-health-literacy](https://insight/nichq.org/insight/intersection-health-equity-and-health-literacy).
2. US Department of Health and Human Services, Office of Disease Prevention and Health Promotion, "Healthy People 2030," health.gov/our-work/healthy-people/healthy-people-2030.
3. US Department of Health and Human Services, Office of Disease Prevention and Health Promotion, "Healthy People 2030 Framework," health.gov/healthypeople/about/healthy-people-2030-framework.
4. US Department of Health and Human Services, Office of Disease Prevention and Health Promotion, "Health Literacy in Healthy People 2030," health.gov/our-work/healthy-people/healthy-people-2030/health-literacy-healthy-people-2030.
5. M. McDonald and L. Shenkman, "Health Literacy and Health Outcomes of Adults in the United States: Implications for Providers," *Internet Journal of Allied Health Sciences and Practices* 16, no. 4 (2018): Article 2.
6. N. Berkman et al., "Low Health Literacy and Health Outcomes: An Updated Systematic Review," *Annals of Internal Medicine* 155, no. 2 (2011): 97–107; S. Kripalani et al., "Health Literacy and the Quality of Physician-Patient Communication During Hospitalization," *Journal of Hospital Medicine* 5, no. 5 (2010): 269–75; J. Wright et al., "Association of Health Literacy with Postoperative Outcomes in Patients Undergoing Major Abdominal Surgery," *JAMA Surgery* 153, no. 2 (2018): 137–42; and M. Fabbri et al., "Health Literacy and Outcomes Among Patients with Heart Failure: A Systematic Review and Meta-Analysis," *JACC: Heart Failure* 8, no. 6 (2020): 451–60.
7. R. Walters et al., "Establishing the Efficacy of Interventions to Improve Health Literacy and Health Behaviours: A Systematic Review," *BMC Public Health* 20, no. 1040 (2020); J. Zibellini et al., "Effect of Health Literacy Interventions on Pregnancy Outcomes: A Systematic Review," *Women and Birth* 34, no. 2 (2021): 180–86; and P. Dahal and H. Hosseinzadeh, "Association of Health Literacy and Diabetes Self-Management: A Systematic Review," *Australian Journal of Primary Health* 25, no. 6 (2019): 526–33.
8. American Public Health Association, "Health Equity," apha.org/topics-and-issues/health-equity.

When people comprehend health information, they can better care for themselves and their loved ones.



Continued on page 40

The Invisible Work of Nurse Practitioners



On March 11, 2020, the World Health Organization categorized the COVID-19 outbreak as a global pandemic.¹ Less than a month later, nurse practitioners (NPs) in five US states were given emergency authority to do what NPs in 22 other states could already do: practice independently.²

Tennessee was one of those five: on March 19, 2020, Tennessee Governor Bill Lee signed an executive order that released NPs from the formal requirements of physician oversight.³ The executive order was of great relief to NPs like Renee Collins. Collins is a co-owner of a practice that provides home-based primary care to older adults in rural Tennessee. All of the providers she employs are NPs. But she has more than their salaries to worry about in her budget. She also has to hire a physician—not to see patients, but to meet the state requirement for physician oversight. What oversight means might be a surprise to many. In most cases, the physician never examines or speaks with any of the NPs' patients. In states like Tennessee, the physician is required to visit an NP's site of practice once a month and to retrospectively audit 20 percent of an NP's charts.⁴ The physician collects a fee for this service, costing the practice not only in money but also in the time it takes to find, schedule, and manage an outside provider. Collins, and NPs across the state, hoped that the executive order would become permanent. But she was not optimistic. "We're needed when there's a crisis," she told a reporter. "But when the crisis is over, we're not needed anymore."⁵

On the Frontlines of a Healthcare Crisis

Nurse practitioners are no strangers to crisis. In a sense, they were produced by it. Created in the 1960s, the NP was a solution to the shortage of primary care physicians. The post-World War II baby boom produced a sharp rise in demand for maternal and pediatric care. At the same time, physicians were discovering the

rewards of specialization, with fewer medical students choosing to go into less lucrative specialties like family medicine, pediatrics, or internal medicine. Moreover, the trend toward specialization fed into the rising cost of care, as a greater proportion of "generalist" problems were recast as specialist problems. The twin crises of physician scarcity and rising costs required new solutions—and NPs offered one.⁶

And they have proven to be a solution with staying power. Because, unlike the pandemic, the healthcare crises they were created to address show no signs of abating. Demand for healthcare continues to soar, with a graying population helping to keep the need for services high. In 1950, just 8 percent of the US population was 65 or older. By 2019, it was 16.5 percent. And by 2050, it is projected to be 22 percent.⁷ While medical advances have made old age healthier, it remains a part of the life course that requires increased medical and supportive care. Likewise, the other crisis, the allure of physician specialization, has only gotten more serious. Between 1985 and 2011, the proportion of US medical students who chose primary care residencies declined by 24 percent; and in an especially dramatic drop, between 1999 and 2003, the proportion of internal medicine residents who went on to work in primary care plummeted from 54 to 20 percent.⁸ The result? In 1961, half of US physicians were in primary care, but by 2015, only a third were.⁹

In the wake of physician abdication of primary care, nursing's footprint has grown.¹⁰ By 2017, the population of practicing NPs had swelled to about 190,000,¹¹ with over 80 percent of recent NP graduates reporting they were going into primary care.¹² There are still more physicians than NPs providing primary care in the United States,¹³ but with each passing year, more NPs than physicians are entering the primary care workforce.

Today, the NP as physician substitute is a fairly well-known story, at least within healthcare policy circles. What is less often considered is whether or not

By **LaTonya J. Trotter**

LaTonya J. Trotter is a sociologist at Vanderbilt University who writes about how changes in the organization of medical work impact social inequality. In her book *More Than Medicine: Nurse Practitioners and the Problems They Solve for Patients, Health Care Organizations, and the State*, she considers how nurse practitioners are creating new possibilities for what the medical encounter could be, while demonstrating the depth of the crisis we face. Portions of this article were first published in *More Than Medicine*, © Cornell University Press 2020; adapted with permission.



the problem they are addressing is only or even primarily about physician scarcity. Not everyone struggles to find a doctor; those with the least profitable conditions and the fewest resources are far more likely to have difficulty. As a consequence, NPs are more likely to treat populations whose care is often socially as well as medically complicated: people who are poor, are uninsured, receive Medicaid, and/or qualify for Medicare due to a disability.¹⁴ Far from being a simple substitute, NPs systematically care for different patients than physicians.

While some may believe NPs are best suited to provide “routine” care, the reality is that by becoming the provider to the socially marginal and medically vulnerable, NPs are often managing the most complicated patients. And the available evidence suggests they are up to the challenge. Fifty years of research on the safety and effectiveness of NP-led care supports the conclusion that their patients do at least as well as those who see physicians.¹⁵ This evidence suggests a possibility that few health policy experts have considered. Perhaps the utility of NPs is found not in their similarity to physicians, but in their difference from them. And maybe, just maybe, the problems NPs are a solution to have less to do with physician scarcity than with deeper questions of social inequality and how we choose to care for our most vulnerable citizens. These are the questions I brought with me as I spent two and a half years following a group of providers at a place I call Forest Grove Elder Services (a pseudonym).¹⁶

Forest Grove is best understood as a nursing home diversion program. All of its patients were eligible for nursing home care due to various physical or cognitive needs. In order to avoid institutional care, the Grove provides a comprehensive set of services that includes, but goes well beyond, medical care. In addition to primary care, the Grove provides physical and occupational therapy, recreational activities, and social work services. It also coordinates and manages the

care its patients receive outside its walls, from specialist appointments to rehabilitation services. A dedicated fleet of accessible vans ferry patients to and from the Grove, as well as to these outside services.

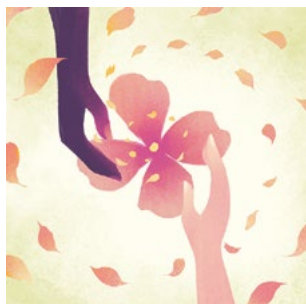
From a funding perspective, what is unique about the Grove is the way it tries to manage costs. The state authorized the use of Medicare and Medicaid dollars to pay for these enhanced services as an experiment to test if providing comprehensive, community-based care could save money through averted hospitalizations and nursing home placement. But in the time I spent at the Grove, I found that what was truly unique about the organization is the way its NPs make this model work. Like many healthcare organizations, the Grove employs both physicians and NPs to provide medical care. However, what makes the Grove different from other collaborative environments is that its NPs are the formal leaders of the healthcare team. What it meant for NPs to lead was not just about decision making, but about fundamentally reshaping how care happens.

More Than Medicine

When I first met Michelle, she had been an NP for almost 20 years. But she had been a nurse for longer still. Like most NPs, she started her career as a registered nurse (RN); her first job was at the hospital bedside. She had already amassed over two decades of experience before she went back to school to become an NP. Maybe that is why when I spent time with Michelle, it became impossible to think of her as a substitute physician. To watch Michelle was to watch a *nurse* at work.

“Ms. Payne. Can you think of anyone else who could come by a few times a day?” Ms. Payne was 86 years old. Like most of the Grove’s patients, she lived with a litany of complaints: diabetes, rheumatoid arthritis, congestive heart failure. Yet none of these were why she was sitting in Michelle’s office on that day. In two weeks, Ms. Payne was scheduled to have cataract surgery to

By becoming providers to the socially marginal, NPs often manage the most complicated patients.



**At the Grove, NPs
are fundamentally
reshaping how
care happens.**

improve her increasingly cloudy vision. Michelle's aim was to make sure Ms. Payne was prepared for the operation. Cataract removal is a low-risk outpatient procedure. The surgery was not the problem. The problem was what would happen afterward.

I sat in the corner, trying to be unobtrusive in a room that seemed full with three people. I listened as Michelle reviewed the surgeon's postoperative instructions. Ms. Payne would need to apply a series of prescription eye drops—four times a day for four weeks—to control inflammation, prevent infection, and minimize complications. There is nothing remarkable about their application. One would simply stretch an arm upward, tilt one's head skyward, arch the arm over a selected eye, grip the bottle with a personal selection of fingers, and then squeeze with the right amount of pressure. These coordinated steps, however, require a set of abilities that not everyone possesses. Ms. Payne had rheumatoid arthritis, a condition that not only inflames the joints but also often deforms them. This condition had left her hands curled in on themselves like talons. As Michelle described how often the drops would need to be applied, all three of us looked at these hands, our eyes filling with doubt.

In everyday life, when we cannot administer our own medication, parents, children, or even a good friend might be enlisted to assist. This practice is both common and legal as long as it is done for free, which explains why Michelle asked Ms. Payne whether she could think of anyone who might help. Anyone would have sufficed. However, when payment enters the equation, the universe of anyone shrinks considerably. In most states, only physicians and nurses can administer medication outside of an institution. This includes prescription eye drops. Justifying the expense of paying for an RN to visit Ms. Payne four times a day, every day, for four weeks, might not have been impossible, but it certainly would not have been easy. Yet, sending her home after surgery with no plan for applying the eye drops bordered on medical malpractice.

Over the next two weeks, I watched as Michelle “knit together” a range of resources on Ms. Payne's behalf. She called the surgeon to see if a simpler regimen might work on weekends. She asked an RN colleague to meet separately with Ms. Payne to go ask if she were sure that no one could assist her, even once a day. A cousin? A neighbor? Someone from her church? The nurse reminded Ms. Payne, gently but firmly, that not wanting to ask is not the same thing as being unable to ask.

With the RN's help, Michelle eventually crafted a plan that is one part neighbor, one part modified regime, and one part approval for some nursing visits on weekends. Arriving at this complex calculus took more than a little time and a great deal of work. The surgeon performed the technical miracle of curing the patient; Michelle performed a miracle of her own in helping to ensure the

best possible outcome. With Ms. Payne's eyesight improved, the odds are good that she will be able to stay in her own home for some time to come.

Among elder care professionals, there is a saying: “The best long-term care insurance is a daughter.” Even with Medicare and Medicaid paying for services, navigating bureaucracies, coordinating care, and knitting together complex information is someone's full-time job. Yet, for many, these idealized daughters are in short supply. Few families have access to a physically healthy adult whose time is not taken up by work in the paid labor market or by unpaid responsibilities such as caring for dependent children. Moreover, this work is not unskilled; an adult's availability does not necessarily signal possession of the knowledge or expertise to do what needs to be done. To categorize this as the work of daughters reveals it as the kind of invisible work that money cannot always buy, and for which insurers rarely reimburse.¹⁷ But if this work happens within the reimbursed medical visit, there is a greater chance that it might occur. The NPs I spent time with did this kind of work as part of the medical exam, making it not just an adjunct to medical work, but a transformation of it. And when they did it well, there was a good chance that their patients would experience fewer complications—and that the state would incur fewer costs.

The Hard Work of Being an NP

“The NPs do all the hard work.” That was Joanne's assessment. Joanne was one of the RNs who supported the work of the NPs within the clinic. In spending time with Joanne, I learned that she was currently taking classes for a master's degree in business. She did not want to do the work of an RN for the rest of her life. “Why business?” I asked. “Why not become an NP of some kind?” She answered from the perspective of someone who had spent several years making her own observations of what the NPs spent their time doing. Because, she explained, it was hard work. And after being a nurse for almost a decade, she was ready for something a little less hard.

When I asked what made the work hard, she responded, “Let's say you're Mr. Smith. And you're in the hospital right now. And the hospital calls one of our doctors [to get his medical history]. Chances are, they don't know Mr. Smith like an NP knows Mr. Smith: his family situation, including his financial situation; what's going on; what hospital work we've done in the past; what has worked for him in the past.” Joanne marshaled her own data to back up this claim. “You pull a physician note [from the medical record], and it's empty. Not empty, but there's nothing in there but, you know, a few words.... But you have the NP notes going much deeper into what is found. You find the situation and the conditions of daily living because they're coming in from their nursing background when you access all those things that you're adding to the problem.”

From Joanne's perspective, the hard work that the NPs performed gave them a better relationship with their patients, which in turn gave them a better understanding of their clinical care. I pondered Joanne's words for some time. To speak of relationship is usually to invoke the intangible world of emotions. Yet when Joanne illustrated this term, she did not describe an affective tie between NP and patient, but one born of deep, layered knowledge. Moreover, she was explicit in calling out the action required to cultivate that knowledge. For Joanne, this was not the result of an emotional attachment; it was the result of hard work. As I spent more time in the clinic, I began to understand how the NPs' work might improve patient care.

One afternoon, I sat with Michelle as she met with Mr. George. His weight had gone up by seven pounds in less than two weeks. This was of particular concern to Michelle because Mr. George had congestive heart failure. Rapid weight gain from fluid retention is one of the classic signs that something is amiss. It could be a worsening of his heart; it could be a change in his diet; it could be a problem with his medication. What Michelle knew for sure was that if Mr. George retained too much fluid, he might find himself struggling to breathe.

This was the kind of slow-moving emergency that Michelle faced on a daily basis. Because it was not just age that defined her patients; it was medical frailty. All of Michelle's patients had multiple chronic conditions like diabetes, arthritis, and hypertension—as well as an array of physical and cognitive impairments that interfered with daily life. Her job as their primary care provider was not just to provide medical care, but to manage the full range of services upon which her patients depended. Mr. George saw a regular cardiologist for his heart failure. But if the problem could be treated without that level of care—and cost—it was Michelle's job to make it happen.

As Michelle met with Mr. George, I recognized a technique that I had often seen her employ. When she wanted to understand a problem, either from a patient, family member, or colleague, she asked questions that did not reveal her own suppositions. Instead, she let the person to whom she was speaking give their own rendering of the facts. I watched as Michelle spent half an hour listening to Mr. George describe how he took his medications and when. She was meticulous in her questioning. Because Mr. George was not conversant with the names of the medications he took, she showed him pictures of each of his pills as she asked him when he took them. When Michelle got to one of his last medications, he said, "This one I take halfways." She stopped and asked, "What do you mean by halfways?" In the conversation that followed, Michelle learned that Mr. George was only taking half of this pill; he was concerned about side effects and believed he felt better when he took less of it. He did not know that the pill he was taking less of was one of the medications that helped him manage his heart failure.

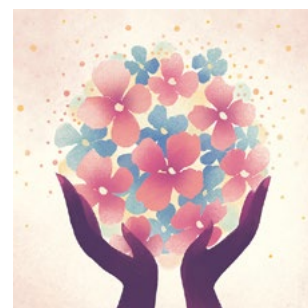
The case of Mr. George could be described as an issue of noncompliance or patient education—the kind of nonmedical problem you had to be neither an NP nor a physician to solve. But the nature of the problem was only apparent in hindsight. Michelle not only had to ask the right questions, she had to listen. If she had simply inquired, "Are you taking your medications?," Mr. George may have reported—honestly, from his perspective—that he was. If she had sent him directly to the cardiologist, Mr. George might have had his medications changed or increased without addressing his underlying concern of side effects—the concern that had motivated him to modify his medications without understanding the risks. It was listening, conversation, *and* medical knowledge that led Michelle to the right conclusion and the best plan of action. What Joanne had described as "the hard work" of being an NP did not just make Mr. George feel listened to or cared for, it was a crucial part of keeping him medically stable and independent. When Michelle did this work well, she not only helped Mr. George but also saved his insurer from paying for a more expensive trip to the cardiologist.

But their conversation would have benefits beyond any single exam. Michelle's questions were open-ended. Therefore, along with hearing what she might have thought was important, she heard information that was important to Mr. George. He had his own ideas about how each of his medications made him feel. He asked questions of his own about why he was taking certain pills or why the pharmacy had switched him from a brand name to a generic version. And as they talked, Michelle learned just a little bit more about Mr. George. Such as how he reasoned about which pills to take and when. That despite not knowing which pills were for which condition, he was otherwise willing and compliant with taking them. She learned more about his relationship with a neighbor who came over to help him put groceries away and brought him dinner on Sundays. In addition to learning why he was retaining fluid, she learned more about his support network and personal resources. If she needed to help him address a different issue, she would have new information to draw from to make that happen.

The Nursing Model of Care

"The nursing model is much more holistic [than the medical model]. You're looking at the whole person. Yes, disease is part of the person, but so is their environment, so is their mentation, their spirit, so is their social environment. So I think instinctually, we all—nurses—that's how we look at some things." These were the words of Norah, an NP who worked alongside Michelle. These words were in response to a question I had asked about how NPs differed from physicians. For Norah, it was nursing's whole-person orientation that allowed them to "hear things," and to "identify needs" that a physician would not necessarily notice.

The relationships between the Grove NPs and patients are born of deep, layered knowledge.





Nurses shore up a healthcare system that is crumbling under the weight of social inequality.

Norah was quick to make sure I did not misunderstand her. “Look,” she said. “There’s a lot of things that [the physicians] understand *way* better than I do.” However, for Norah, recognizing the physician’s expertise did not take away from her own. “NPs have really taken on that kind of responsibility,” she told me. “It’s the nature of the profession.” When I watched NPs like Michelle and Norah at work, I came to understand how that different responsibility looked in action. And why it mattered for patients.

A Crisis of Care

Nurse practitioners were originally created to address the problem of physician scarcity. When the issue is defined as a numbers problem, leveraging a more quickly trained provider seems both a creative and practical response. However, to watch NPs at work is to discover that the numbers are not the whole story. Because the Grove’s patients were not getting “less skilled physicians.” They were getting differently skilled—and highly skilled—nurses. This distinction is not just about semantics or even much-deserved recognition: it is about making visible the true problems we face in healthcare.

Because we are not simply facing a crisis of cost or personnel; we are facing a crisis of care. For the Grove’s patients, the work of knitting together information, resources, and systems was not a luxury, it was a necessity. Certainly, not all NPs care for patients as ill as those the Grove served. But in becoming the primary care providers for people who are poor, disabled, or otherwise medically marginalized, NPs across the country are often asked to meet a fairly high bar of expertise. Moreover, while the expertise required includes that of medicine, it often goes beyond it. Because what ails patients like Ms. Payne and Mr. George is as much about inequality as illness. A lifetime of poverty and racial discrimination are known causes of poor health.¹⁸ These social conditions not only make it difficult to access quality healthcare, there is good evidence that they literally age the body and directly produce illness. The NPs who listen, advocate, and coordinate will not solve these problems. Nonetheless, they can and do serve as on-the-ground lifelines for patients navigating the interwoven terrain of organizational, medical, and social problems that all too often go unnamed and unaddressed.

This crisis, however, goes beyond the exam room. Because the scarcity at work is less about providers than policy. We should not forget that the creation of the NP is only one of many possible responses to the crises we face. Despite being organized as a private system, healthcare’s largest payer in the United States is the government.¹⁹ Given this reality, what might have happened if we, as a nation, had matched the weight of our financial investment with a cohesive, national healthcare policy? What if, when faced with the growing evidence that health disparities were

caused by social inequality, we had invested in social policies to ameliorate the worst excesses of poverty? Or used the full weight of the law to eradicate entrenched forms of racial discrimination? These are paths we did not take. Instead, we unraveled the national safety net, leaving individual providers to knit together the last threads of what remained.

Many have argued that the pandemic has exposed the cracks in our healthcare system. I hope it also shines light on the workers who are often called upon—and feel a calling within themselves—to span those cracks. In the hours I spent watching NPs like Michelle and Norah at work, I came to the conclusion that it is often nurses who are left with the invisible work of holding healthcare together. Before, during, and after the pandemic, nurses do not only the visible work of patient care but also the invisible work of shoring up a healthcare system that is crumbling under the weight of social inequality. As of the writing of this article in the first months of 2021, most of the executive orders that expanded NP practice autonomy have already been rescinded, even as the pandemic rages on. NPs like Renee Collins are back to paying physicians for oversight. But her patients in rural Tennessee will never know the difference because Collins is clear in her purpose: “Nurses are not wanting to be doctors.... We are simply wanting to fill the gap for access.”²⁰ ✚

Endnotes

1. World Health Organization, “WHO Director-General’s Opening Remarks at the Media Briefing on COVID-19—11 March 2020,” March 11, 2020, [who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020](https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020).
2. M. Bachtel, R. Hayes, and M. Nelson, “The Push to Modernize Nursing Regulations During the Pandemic,” *Nursing Outlook* 68, no. 5 (September–October 2020): 545–47.
3. “Executive Order 15 of March 19, 2020, an Order Suspending Provisions of Certain Statutes and Rules and Taking Other Necessary Measures in Order to Facilitate the Treatment and Containment of COVID-19,” State of Tennessee Executive Order by the Governor, publications.tnsofiles.com/pub/execorders/exec-orders-lee15.pdf; see also “Executive Order 28 of April 17, 2020, an Order Amending Executive Order No. 15 and Taking Other Necessary Measures to Facilitate the Treatment and Containment of COVID-19,” State of Tennessee Executive Order by the Governor, publications.tnsofiles.com/pub/execorders/exec-orders-lee28.pdf.
4. “FAQ: Physician Supervision of PAs and APNs,” Tennessee Board of Medical Examiners, October 2016, tn.gov/content/dam/tn/health/documents/SUPERVISION_FAQs.pdf.
5. K. Horan, “Nurse Practitioners Praise Executive Order amid COVID-19 Outbreak,” NewsChannel 5 Nashville, April 7, 2020, newschannel5.com/news/nurse-practitioners-praise-executive-order-amid-covid-19-outbreak.
6. J. Fairman, *Making Room in the Clinic: Nurse Practitioners and the Evolution of Modern Health Care* (New Brunswick, NJ: Rutgers University Press, 2008); and H. Silver, L. Ford, and S. Steady, “A Program to Increase Health Care for Children: The Pediatric Nurse Practitioner Program,” *Pediatrics* 39, no. 5 (May 1967): 756–60.
7. “Share of Old Age Population (65 Years and Older) in the Total U.S. Population from 1950 to 2050,” Statista Research Department, September 2020, statista.com/statistics/457822/share-of-old-age-population-in-the-total-us-population.
8. M. Schwartz, “Health Care Reform and the Primary Care Workforce Bottleneck,” *Journal of General Internal Medicine* 27, no. 4 (April 2012): 469–72.
9. J. Dalen, K. Ryan, and J. Alpert, “Where Have the Generalists Gone? They Became Specialists, Then Subspecialists,” *American Journal of Medicine* 130, no. 7 (July 1, 2017): 766–68.
10. J. Pohl et al., “Primary Care Workforce Data and the Need for Nurse Practitioner Full Practice Authority,” *Health Affairs* (blog), December 13, 2018, healthaffairs.org/doi/10.1377/hblog20181211.872778/full.

Continued on page 40

Prioritizing Safety for Healthcare Workers and Patients

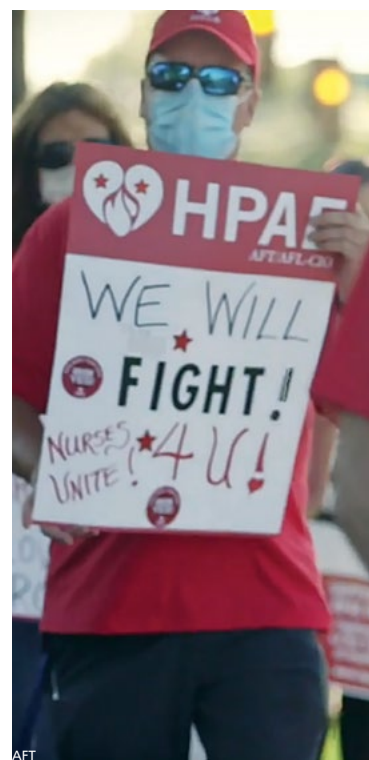
The AFT and our fellow unions have won a significant victory in the fight to protect healthcare workers from COVID-19 and other infectious diseases spread by contact, droplet, or air. One of the biggest obstacles to health professionals feeling safe at work during the pandemic has been the Occupational Safety and Health Administration's (OSHA) lack of a safety and health standard for infectious diseases. The standard that had been in development since 2009 (which was itself the result of a petition by the AFT and other unions) was put on hold under the Trump administration, leaving healthcare workers without legally enforceable protection from COVID-19 through surge after surge. What's more, under Trump, OSHA refused to enforce existing standards or even require compliance with Centers for Disease Control and Prevention guidelines. AFT members filed hundreds of complaints over the past year, and in October 2020 the AFT joined with several healthcare unions in a lawsuit demanding an immediate emergency standard and a permanent standard within two years. In February, the Biden administration informed the federal court it is prioritizing development of an infectious disease standard, and the lawsuit has been suspended. The AFT will continue to hold OSHA accountable for progress, and we invite you to do the same. Learn more here: go.aft.org/OSHA-lawsuit.



Fighting for Fairness at the State Level

From Alaska to New York, AFT locals and state federations are fighting to make working conditions under COVID-19 fairer for all workers.

- Workers' compensation insurers have repeatedly insisted that employees cannot prove they contracted COVID-19 on the job and have delayed or denied claims outright, even with evidence of repeated and persistent exposure. Some states acted quickly to extend workers' compensation presumption—the automatic presumption that employees in high-risk workplaces who contract COVID-19 did so at work—to health professionals and other frontline workers. But in other states, getting fair treatment for frontline workers has involved pitched battle—and AFT affiliates are leading the fight. Among them are the Alaska Nurses Association and the Health Professionals and Allied Employees (HPAE) in New Jersey; both fought for and won passage of workers' compensation presumption bills.
- In New York, the Public Employees Federation is celebrating the recent passage of two related bills: one that will extend the window for accidental death benefits to the families of public employees who contracted COVID-19 on the job, and another that allows up to four hours of paid leave for public employees to receive the COVID-19 vaccination.
- Lack of transparency about COVID-19 on the part of employers endangers frontline workers' lives and makes the job of protecting their health that much more difficult. The Ohio Nurses Association successfully lobbied for a state directive that the Ohio Department of Health include every Ohio hospital facility and all health workers' COVID-19 diagnoses in the state COVID-19 data tool. HPAE in New Jersey also helped ensure the passage of a new transparency law that requires health employers to collect and regularly report data on COVID-19 infections and deaths.



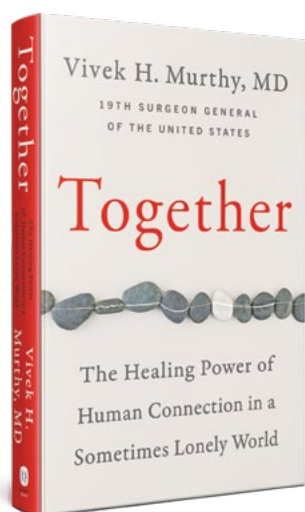
Supporting Asian Americans and Pacific Islanders

As anti-Asian violence has risen across the country since the COVID-19 pandemic, the AFT has increased efforts to support our Asian American and Pacific Islander members and their communities. In July 2020, at the AFT's virtual convention, AFT President Randi Weingarten announced the formation of the Asian American and Pacific Islander (AAPI) Task Force. The task force, which includes AFT leaders from across the country, began meeting in February 2021. Its main goal is to provide national leadership and collaborate on ways to use the strength of our union to address issues faced by AAPI communities; the most urgent issue is the spike in violent attacks against Asian Americans, including against many healthcare workers as well as against elders and women. Visit aft.org/StopAsianHate to read the AFT's statement of solidarity with Asian American and Pacific Islander communities, hear more from AAPI Task Force leaders, find videos and other resources to help protect AAPI workers, and sign up for solidarity actions.



The Value of Social Connection

With strong social relationships, people sleep better, have stronger immune systems, and live longer.



In *Together: The Healing Power of Human Connection in a Sometimes Lonely World* (Harper Wave, 2020), US Surgeon General Vivek Murthy takes on a topic with increasing relevance in the COVID-19 world—loneliness and the challenges of social connection—from a health perspective. From birth, we have a biological need for meaningful connection with others in the same way we need food and water; and like hunger or thirst, Murthy says, the feeling of loneliness is the body's way of telling us we need human connection. If we don't or can't address that need when it arises, the sympathetic nervous system can go into overdrive, leading to cardiovascular stress and increased inflammation over time. People with weak social relationships have a greater risk of heart disease, hypertension, stroke, dementia, depression, and anxiety and are as likely to die prematurely as those who smoke 15 cigarettes a day. But with strong social relationships, people sleep better, have stronger immune systems, and live longer.

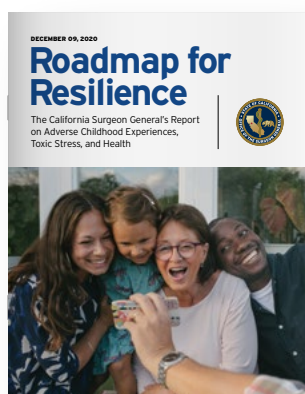
According to Murthy, one of the biggest challenges in addressing loneliness is that people often feel shame about admitting it, especially men, teenagers, and elderly people. Living in a competitive, individual-oriented, and politically divided society like the United States contributes to the problem. Social media can be a double-edged sword, too: it allows us to connect with others and can provide valuable community for people who may be marginalized in other social environments (such as LGBTQ youth), but it can also contribute to social isolation by encouraging harmful comparisons and substituting transactional, surface-level interactions for more meaningful ones.

As Murthy points out, loneliness is a signal, not an accusation of unworthiness. Recognizing the problems it creates offers us an opportunity to begin building a culture of connection based on meaningful intimate and social relationships and on shared purpose in our communities.

We show our innate desire for connections and relationships in the way we rally around friends, family, neighbors, and communities in crisis, even when they're on the other side of the world. We deliver home-cooked food, send money, publicly express support, and march in solidarity. So how do we bring that atmosphere of mutual concern and service with us into the rest of our lives? According to Murthy, it has to start on an individual level because that's where loneliness begins.

It's important to spend time in reflection, so we can gain self-knowledge and work toward self-acceptance, and to engage with others in mutually caring relationships that can reinforce our growing self-compassion. We have a responsibility in our communities, too, to treat those we encounter as complex, multifaceted people deserving of consideration and kindness. Employers can counter loneliness by working to create a culture in which each employee feels known, respected, and cared for, modeled by the leadership and encouraged through the thoughtful development of inclusive policies and practices. And for local, state, and federal governments, it's essential to understand how policies—such as limited access to parks and libraries or immigration laws that make it difficult for families to be together—can increase loneliness and to take action to increase human connection.

Preventing ACEs and Toxic Stress to Advance Equity



The prevalence of adverse childhood experiences (ACEs) is a public health crisis that has only grown with the additional stressors of the COVID-19 pandemic. Without the buffering effects of responsive and loving adult care and community support, a child exposed to repeated or sustained adversity—abuse, neglect, or other challenges such as divorce or a family member's substance misuse or mental illness—may experience toxic stress. Unlike lower levels of stress that are healthy or tolerable, toxic stress can affect neurological, endocrine, immune, and metabolic development. In addition to increasing the likelihood of a toxic stress response, acute stressors

like the pandemic can reduce access to valuable sources of support, like schools, health providers, and community organizations, and increase occurrences of household violence, among other effects. Because of COVID-19, many children have been largely isolated from their peers and their community support systems for more than a year; lost jobs, food insecurity, and the illness or death of loved ones may also have caused household upheaval. All of these factors increase the risk of toxic stress.

ACEs and toxic stress are present in every demographic group but are disproportionately high for members of already vulnerable populations, includ-

ing racially marginalized people; people who are unemployed, unable to work, or have low incomes; people without adequate health insurance; and LGBTQ people. The health effects can ripple down through generations, and so can the social and economic ones. ACEs are associated with 9 of the 10 leading causes of death for adults in the United States; they're also connected to increased likelihood of unemployment, poverty, homelessness, incarceration, and more—and they cost the United States hundreds of billions of dollars per year in healthcare, education, social services, and lost productivity. If we want to build a more equitable world, we have to work to prevent ACEs and toxic stress.

All of these challenges, and a path forward, are laid out in *Roadmap for Resilience: The California Surgeon General's Report on Adverse Childhood Experiences, Toxic Stress, and Health*, which explains the science of ACEs and California's plan to reduce them by half in one generation. It's an ambitious plan, but research shows that even simple interventions can make significant differences. At 400-plus pages, plus supplementary materials, the report offers health professionals, policymakers, public employees, and advocates an invaluable set of resources to understand, recognize, and work to prevent ACEs, and to provide compassionate care and much-needed relief to children and adults.

California's roadmap stresses the importance of primary, secondary, and tertiary prevention, which build on each other and are all essential to reducing ACEs. *Primary prevention* focuses on proactive investment in nurturing relationships and strong, healthy communities at individual, family, local, state, and federal levels. Key strategies are to

- raise awareness about the effects of ACEs and how to help children develop healthy stress responses;
- support positive adult-child relationships;
- build individual, family, and community resilience; and
- address social determinants of health like increasing access to early childcare and education, cleaning up environmental contamination, and reducing structural racism in healthcare, education, and justice systems.

The most critical element is coordinated, cross-sector training in and implementation of ACEs-aware and trauma-informed practices involving first responders, health professionals, social workers, educators, public safety workers, and more.

This training facilitates *secondary prevention* efforts, which focus on early detection and evidence-based interventions for children experiencing adversity. The goal is to prevent the development of toxic stress

physiology and resulting health issues through

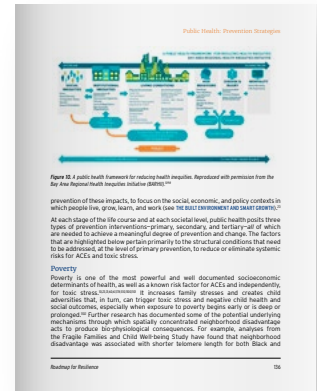
- early screening for ACEs, ACEs-associated health conditions, and protective factors;
- education about toxic stress and strategies to regulate stress responses; and
- team-based care that includes health professionals, social workers, educators, and local agencies as needed.

For children and adults who already exhibit evidence of a toxic stress response, *tertiary prevention* aims to improve outcomes (in turn acting as primary prevention for the next generation). Tertiary prevention methods can decrease the likelihood or lessen the severity of ACEs-associated health conditions by helping people

- build healthy, supportive relationships;
- sleep well, eat nutritious foods, engage in regular exercise, and practice mindfulness; and
- access culturally competent mental and behavioral healthcare as needed.

For these tertiary strategies to be effective, it's essential that healthcare, public health, social services, education, justice, and other sectors work to prevent further harm. This effort has to occur at the individual level—for example, by making sure a child with asthma and the child's caregivers understand the condition and have access to medication, regular checkups (with compassionate, trauma-informed providers), and transportation so they don't miss appointments. But it's just as important to prevent harm at the structural level through legislation and policy changes, such as efforts to decriminalize homelessness and mental illness so that people who are housing insecure or have mental illness can receive care and support rather than punishment.

Roadmap for Resilience emphasizes that reducing ACEs is possible with concerted efforts both within and across multiple sectors, as well as in partnership with families and children. After summarizing the research base, the first half of the report offers detailed recommendations for each sector and at each level of prevention, including case studies and special sections on the compounding role of COVID-19; the second half outlines California's specific strategies and the statutory framework, including the ACEs Aware Initiative, as a model other states can learn from. Download the full report and sector-specific briefs, and watch an introductory webinar, at osg.ca.gov/sr-report. To take your learning further, join regular, free webinars hosted by the ACEs Aware Initiative (some qualify for continuing education credits): acesaware.org/heal/educational-events.



Toxic stress
can negatively
impact
development,
but it **can also**
be prevented.



The Enduring Harms of Structural Racism

Continued from page 7

as Experienced by Underrepresented Medical and Nursing Students," *Academic Medicine* 95, no. 5 (May 2020): 758–63; T. Strayhorn, "Exploring the Role of Race in Black Males' Sense of Belonging in Medical School: A Qualitative Pilot Study," *Medical Science Educator* 30 (2020): 1383–87; and A. Osseo-Asare et al., "Minority Resident Physicians' Views on the Role of Race/Ethnicity in Their Training Experiences in the Workplace," *JAMA Network Open* 1, no. 5 (2018): e182723.

3. J. Moore and T. Continelli, "Racial/Ethnic Pay Disparities Among Registered Nurses (RNs) in U.S. Hospitals: An Econometric Regression Decomposition," *Health Services Research* 51, no. 2 (April 2016): 511–29.

4. F. Crittenden, "More Than Just Hair: Combating Hair Discrimination in Medicine," *in-Training*, June 10, 2019, [in-training.org/more-than-just-hair-combating-hair-discrimination-in-medicine-18350/](https://www.in-training.org/more-than-just-hair-combating-hair-discrimination-in-medicine-18350/); the first lawsuit about hair-related discrimination in the workplace was about a hospital: C. Griffin, "How Natural Black Hair at Work Became a Civil Rights Issue," *JSTOR Daily*, July 3, 2019, [daily.jstor.org/how-natural-black-hair-at-work-became-a-civil-rights-issue](https://www.jstor.org/how-natural-black-hair-at-work-became-a-civil-rights-issue).

5. C. Snyder, B. Frogner, and S. Skillman, "Facilitating Racial and Ethnic Diversity in the Health Workforce," *Journal of Allied Health* 47, no. 1 (2018): 58–65.

6. A. Villarruel and M. Broome, "Beyond the Naming: Institutional Racism in Nursing," *Nursing Outlook* 68, no. 4 (2020): 375–76.

7. R. Shim, "Dismantling Structural Racism in Academic Medicine: A Skeptical Optimism," *Academic Medicine* 95, no. 12 (December 2020): 1793–95.

8. I. Swetlitz, "Some Medical Students Still Think Black Patients Feel Less Pain Than Whites," *Stat*, April 4, 2016, [statnews.com/2016/04/04/medical-students-beliefs-race-pain/](https://www.statnews.com/2016/04/04/medical-students-beliefs-race-pain/); and K. Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs About Biological Differences Between Blacks and Whites," *PNAS* 113, no. 16 (April 19, 2016): 4296–301.

9. See R. Rothstein, "Suppressed History: The Intentional Segregation of America's Cities," *American Educator* 45, no. 1 (Spring 2021): 32–37.

10. See H. A. Washington, "Healing a Poisoned World," *AFT Health Care* 1, no. 1 (Fall 2020): 16–21, 44.

11. M. Evans et al., "Diagnosing and Treating Systemic Racism," *New England Journal of Medicine* 383 (2020): 274–76; A. Wingfield, "The Disproportionate Impact of Covid-19 on Black Health Care Workers in the U.S.," *Harvard Business Review*, May 14, 2020, hbr.org/2020/05/the-disproportionate-impact-of-covid-19-on-black-health-care-workers-in-the-us/; and U. Blackstock, "Why Black Doctors Like Me Are Leaving Faculty Positions in Academic Medical Centers," *Stat*, January 16, 2020, [statnews.com/2020/01/16/black-doctors-leaving-faculty-positions-academic-medical-centers](https://www.statnews.com/2020/01/16/black-doctors-leaving-faculty-positions-academic-medical-centers).

12. S. Thorne, "Pandemic Racism—and the Nursing Response," *Nursing Inquiry* 27, no. 3 (July 2020): e12371.

13. I. Natividad, "Racist Harassment of Asian Health Care Workers Won't Cure Coronavirus," *Berkeley News*, April 9, 2020, news.berkeley.edu/2020/04/09/racist-harassment-of-asian-health-care-workers-wont-cure-coronavirus.

14. S. Liu and S. Modir, "The Outbreak That Was Always Here: Racial Trauma in the Context of COVID-19 and Implications for Mental Health Providers," *Psychological Trauma: Theory, Research, Practice, and Policy* 12, no. 5 (2020): 439–42.

15. *Racial Inequities and Moral Distress: A Supplement to Moral Stress Amongst Healthcare Workers During COVID-19; A Guide to Moral Injury* (Centre of Excellence on PTSD and Phoenix Australia, August 2020), 12.

16. O. Barbot, "George Floyd and Our Collective Moral Injury," *American Journal of Public Health* 110 (2020): 1253.

Moral Injury

Continued from page 13

4. J. Garber, "A Silver-Lining to COVID-19: Fewer Low-Value Elective Procedures," *Lown Institute*, April 20, 2020, lowninstitute.org/a-silver-lining-to-covid-19-fewer-low-value-elective-procedures.

5. N. Talaei et al., "Stress and Burnout in Health Care Workers During COVID-19 Pandemic: Validation of a Questionnaire," *Journal of Public Health (Berlin)* (2020), ncbi.nlm.nih.gov/pmc/articles/PMC7275852.

6. A. Garran and B. Rasmussen, "How Should Organizations Respond to Racism Against Health Care Workers?," *AMA Journal of Ethics* 21, no. 6 (2019): E499–E504.

7. T. Rebmann, A. Vassallo, and J. Holdsworth, "Availability of Personal Protective Equipment and Infection Prevention Supplies During the First Month of the COVID-19 Pandemic: A National Study by the APIC COVID-19 Task Force," *American Journal of Infection Control* (2020), [ajicjournal.org/article/S0196-6553\(20\)30814-2/fulltext](https://ajicjournal.org/article/S0196-6553(20)30814-2/fulltext).

8. Fitzhugh Mullan Institute, "State Hospital Workforce"; O. Goldhill, "People Are Going to Die": Hospitals in Half the States Are Facing a Massive Staffing Shortage as Covid-19 Surges," *Stat News*, November 19, 2020, [statnews.com/2020/11/19/covid19-hospitals-in-half-the-states-facing-massive-staffing-shortage](https://www.statnews.com/2020/11/19/covid19-hospitals-in-half-the-states-facing-massive-staffing-shortage).

9. B. Ulrich et al., "Critical Care Nurse Work Environments 2018: Findings and Implications," *Critical Care Nurse* 39, no. 2 (April 1, 2019): 67–84.

10. F. Shaffer and L. Curtin, "Nurse Turnover: Understand It, Reduce It," *American Nurse Journal*, August 10, 2020, myamericannurse.com/nurse-turnover-understand-it-reduce-it.

11. Lewin Group, *Evaluation of the Robert Wood Johnson Wisdom at Work* (Falls Church, VA: Lewin Group, 2009), rwjf.org/en/library/research/2009/01/evaluation-of-the-robert-wood-johnson-wisdom-at-work.html.

12. J. George, "Bidding War for Nurses; Cutting Quarantine Time; 'Out of Control Fire,'" *MedPage Today*, November 25, 2020, [medpagetoday.com/infectiousdisease/covid19/89885](https://www.medpagetoday.com/infectiousdisease/covid19/89885).

13. National Academy of Medicine, *Taking Action Against Clinician Burnout: A Systems Approach to Professional Well-Being* (Washington, DC: National Academies Press, 2019).

14. D. Vahey et al., "Nurse Burnout and Patient Satisfaction," *Medical Care* 42, no. 2 Suppl. (January 31, 2004): I157–I166; and L. Aiken et al., "Effects of Hospital Care Environment on Patient Morality and Nurse Outcomes," *Journal of Nursing Administration* 38, no. 5 (May 2008): 223–29.

15. J. Medas et al., "Outcomes of a Comprehensive Nurse Residency Program," *Nursing Management* 46, no. 11 (November 2015): 40–48.

16. C. Friese et al., "Hospitals in 'Magnet' Program Show Better Patient Outcomes on Mortality Measures Compared to Non-'Magnet' Hospitals," *Health Affairs* 34, no. 6 (2015): 986–92.

17. See, for example, B. Bredimus, "Changing Culture to Drive Nurse Engagement and Superior Patient Experience," *Nurse Leader* 17, no. 5 (October 1, 2019): 395–98.

18. T. Muha and M. Murphy, *PROPEL to Quality Healthcare: Six Steps to Improve Patient Care, Staff Engagement, and the Bottom Line* (Boca Raton, FL: CRC Press, 2018).

19. W. Dean, S. Talbot, and A. Dean, "Reframing Clinician Distress: Moral Injury Not Burnout," *Federal Practitioner* 36, no. 9 (September 2019): 400–402.

20. Dean, Talbot, and Dean, "Reframing Clinician Distress."

21. S. Norman and S. Maguen, "Moral Injury," National Center for PTSD, US Department of Veterans Affairs, www.ptsd.va.gov/professional/treat/cooccurring/moral_injury.asp.

22. A. Jameton, *Nursing Practice: The Ethical Issues* (Englewood Cliffs, NJ: Prentice-Hall, 1984).

23. C. Fourie, "Who Is Experiencing What Kind of Moral Distress? Distinctions for Moving from a Narrow to a Broad Definition of Moral Distress," *AMA Journal of Ethics* 19, no. 6 (2017): 578–84.

24. C. Fourie, "Moral Distress and Moral Conflict in Clinical Ethics," *Bioethics* 29, no. 2 (February 2015): 91–97.

25. *Racial Inequities and Moral Distress: A Supplement to Moral Stress Amongst Healthcare Workers During COVID-19; A Guide to Moral Injury* (Centre of Excellence on PTSD and Phoenix Australia, August 2020), moralinjuryguide.ca/wp-content/uploads/2020/08/racial-inequities-and-moral-distress.pdf.

26. *Are Your Nurses Experiencing Moral Injury? What You Can Do to Support Your Team*, white paper (Morrisville, NC: Relias, 2020).

27. Moral Injury of Healthcare, "Moral Injury of Healthcare," fixmoralinjury.org.

28. Dean, Talbot, and Dean, "Reframing Clinician Distress."

29. A. Lukose, "Developing a Practice Model for Watson's Theory of Caring," *Nursing Science Quarterly* 24, no. 1 (2011): 27–30.

30. American Nurses Association, "View the Code of Ethics for Nurses," nursingworld.org/practice-policy/nursing-excellence/ethics/code-of-ethics-for-nurses.

31. See, for example, J. Batcheller, "A Nurse's Guide to Preventing Compassion Fatigue, Moral Distress, and Burnout," American Nurses Association, nursingworld.org/continuing-education/online-courses/a-nurses-guide-to-preventing-compassion-fatigue-moral-distress-and-burno-12b2af6c.

32. See "3.5 Protection of Patient Health and Safety by Acting on Questionable Practice," in *Code of Ethics for Nurses with Interpretative Statements* (Silver Spring, MD: American Nurses Association, 2015), nursingworld.org/coe-view-only.

33. R. Resar et al., *Frontline Dyad Approach to Maximize Frontline Engagement in Improvement and Minimize Resource Use* (Cambridge, MA: Institute for Healthcare Improvement, March 2012).

34. IHI Multimedia Team, "How Leaders Can Promote Health Care Workforce Well-Being," *Improvement Blog*, Institute for Healthcare Improvement, December 10, 2020, [ihimultimedia.org/communities/blogs/](https://www.ihimultimedia.org/communities/blogs/)

how-leaders-can-promote-health-care-workforce-wellbeing.

35. "Chapter 1: The Evolution and Value of Labor-Management Partnerships," in *From the Ground Up: How Frontline Staff Can Save America's Healthcare*, ed. P. Lazes and M. Rudden (Oakland, CA: Berrett-Koehler, 2020).

36. Labor Management Partnership, Kaiser Permanente, "Free to Speak," impartnership.org/focus-areas/free-to-speak.

37. Lazes and Rudden, *From the Ground Up*.

38. Lazes and Rudden, *From the Ground Up*.

39. P. Pittman and E. Scully-Russ, "Workforce Planning and Development in Times of Delivery System Transformation," *Human Resources for Health* 14 (2016): 56.

40. C. Myers, "ANA Adopts New Presidential Election Policy," *American Journal of Nursing* 119, no. 10 (October 2019): 19–20.

41. T. Vásquez, "Nurses Association's Refusal to Denounce Trump Angers Members," *Prism*, October 12, 2020, prismreports.org/article/2020/10/12/nurses-associations-refusal-to-denounce-trump-angers-members.

42. See, for example, American Nurses Association, "ANA President Visits White House for Nurses Day Proclamation Signing Ceremony," May 6, 2020, nursingworld.org/news/news-releases/2020/ana-president-visits-white-house-for-nurses-day-proclamation-signing-ceremony.

43. See, for example, J. Berklán, "Providers Outraged After 'Insulting' Trump Tweet Downplays COVID-19 Dangers," *McKnight's*, October 6, 2020, mcknights.com/news/providers-outraged-after-insulting-trump-tweet-downplays-covid-19-dangers/; J. Ensign, "Past Presidents of the ANA Endorse Biden-Harris," *Medical Margins: On Humanizing Health Care* (blog), September 25, 2020, josephineensign.com/2020/09/25/past-presidents-of-the-ana-endorse-biden-harris/; and "We Are Nurses, America's Most Trusted Profession. And We Support Biden," *Newsweek*, October 2, 2020, [newsweek.com/we-are-nurses-americas-most-trusted-profession-we-support-biden-opinion-1535962](https://www.newsweek.com/we-are-nurses-americas-most-trusted-profession-we-support-biden-opinion-1535962).

44. R. Tikkanen and M. Abrams, *U.S. Health Care from a Global Perspective, 2019: Higher Spending, Worse Outcomes?* (New York: Commonwealth Fund, January 2020), commonwealthfund.org/publications/issue-briefs/2020/jan/us-health-care-global-perspective-2019/; and L. Tran, F. Zimmerman, and J. Fielding, "Public Health and the Economy Could Be Served by Reallocating Medical Expenditures to Social Programs," *Social Science and Medicine* 3 (December 2017): 185–191.

45. R. Abrantes Pêgo and C. Almeida, "Theory and Practice in Health Systems Reform in Brazil and Mexico," *Cad. Saúde Pública*, Rio de Janeiro 18, no. 4 (July/August 2002): 971–989, scielo.br/pdf/csp/v18n4/10180.pdf.

46. V. Newkirk, "The Fight for Health Care Has Always Been About Civil Rights," *The Atlantic*, June 27, 2017, [theatlantic.com/politics/archive/2017/06/the-fight-for-health-care-is-really-all-about-civil-rights/531855/](https://www.theatlantic.com/politics/archive/2017/06/the-fight-for-health-care-is-really-all-about-civil-rights/531855/); and J. Cohn, "The ACA, Repeal, and the Politics of Backlash," *Health Affairs Blog*, March 6, 2020, [healthaffairs.org/doi/10.1377/hblog20200305.771008/full](https://www.healthaffairs.org/doi/10.1377/hblog20200305.771008/full).

Photo Credits

Page 4: Ashlee Rezin Garcia / Chicago Sun-Times via AP

Page 7: Tayfun Coskun / Anadolu Agency via Getty Images
 Page 8: Ashlee Rezin Garcia / Chicago Sun-Times via AP
 Page 11: Erin Clark / The Boston Globe via Getty Images
 Page 12: Go Nakamura / Getty Images

Self-Care Strategies

Continued from page 19

Endnotes

1. N. Montemurro, "The Emotional Impact of COVID-19: From Medical Staff to Common People," *Brain, Behavior, and Immunity* 87 (July 2020): 23–24; and C. Mannelli, "Whose Life to Save? Scarce Resources Allocation in the COVID-19 Outbreak," *Journal of Medical Ethics* 46, no. 6 (2020): 364–366.
2. N. Berlinger et al., *Ethical Framework for Health Care Institutions Responding to Novel Coronavirus SARS-CoV-2 (COVID-19): Guidelines for Institutional Ethics Services Responding to COVID-19* (Garrison, NY: Hastings Center, 2020).
3. M. Asken, "Now It Is Moral Injury: The COVID-19 Pandemic and Moral Distress," *Medical Economics*, April 29, 2020.
4. A. James, "'Unfriend Me': Nurse Shares Frustrations, Life Experience Months into Pandemic," ABC15 News, July 24, 2020, wpde.com/news/local/unfriend-me-nurse-shares-frustrations-life-experience-months-into-pandemic.
5. N. Greenberg et al., "Managing Mental Health Challenges Faced by Healthcare Workers During COVID-19 Pandemic," *BMJ* 368 (2020): m1211.
6. R. Jarrad and S. Hammad, "Oncology Nurses' Compassion Fatigue, Burn Out, and Compassion Satisfaction," *Annals of General Psychiatry* 19 (2020): 22.
7. J. Moon and J. Kim, "Ethics in the Intensive Care Unit," *Tuberculosis and Respiratory Diseases* 78, no. 3 (July 2015): 175–79.
8. C. Rushton, "Moral Resilience: A Capacity for Navigating Moral Distress in Critical Care," *AACN Advanced Critical Care* 27, no. 1 (February 2016): 111–19.
9. R. Williams, J. Brundage, and E. Williams, "Moral Injury in Times of COVID-19," *Journal of Health Service Psychology* (May 2, 2020): 1–5.
10. M. Abraham and R. Smith, "Beyond Resilience: Addressing Moral Distress During the COVID-19 Pandemic," *Psychotherapy.net*, 2020, psychotherapy.net/article/moral-distress-during-COVID-19-pandemic.
11. Rushton, "Moral Resilience."
12. C. Phillips et al., "Transforming Leaders into Stewards of Teaching Excellence: Building and Sustaining an Academic Culture Through Leadership Immersion," *Contemporary Issues in Education Research* 11, no. 1 (2018): 1–10.
13. Williams, Brundage, and Williams, "Moral Injury."
14. A. Goodman et al., "ETHICS in Disaster Response: The Development of an Ethics Disaster Response Program," *Prehospital and Disaster Medicine* 32, no. S1 (2017): S50–S51.
15. Williams, Brundage, and Williams, "Moral Injury."
16. R. Bianchi, I. Schonfeld, and E. Laurent, "Burnout-Depression Overlap: Review," *Clinical Psychological Review* 36 (March 2015): 28–41.

17. D. Church et al., "Emotional Freedom Techniques to Treat Posttraumatic Stress Disorder in Veterans: Review of the Evidence, Survey of Practitioners, and Proposed Clinical Guidelines," *Permanente Journal* 21 (2017).
18. Church et al., "Emotional Freedom Techniques."

Medical Mistreatment Today: Three Stories

Continued from page 22

Endnotes

1. N. Martin, "Black Mothers Keep Dying After Giving Birth. Shalon Irving's Story Explains Why," "All Things Considered," NPR, December 7, 2017, npr.org/2017/12/07/568948782/black-mothers-keep-dying-after-giving-birth-shalon-irvings-story-explains-why.
2. A. Helm, "Kira Johnson Spoke 5 Languages, Raced Cars, Was Daughter in Law of Judge Glenda Hatchett. She Still Died in Childbirth," *The Root*, October 19, 2018, theroot.com/kira-johnson-spoke-5-languages-raced-cars-was-daughter-1829862323.
3. T. Christian, "New York Woman Dies During Childbirth Days After Tweeting Concerns About Hospital Care," *Essence*, April 29, 2020, essence.com/news/amber-isaac-dies-childbirth-bronx-hospital-tweet.
4. A. Villarreal, "New York Mother Dies After Raising Alarm on Hospital Neglect," *Guardian*, May 2, 2020, theguardian.com/us-news/2020/may/02/amber-rose-isaac-new-york-childbirth-death.

The Importance of Respectful Maternity Care for Women of Color

Continued from page 23

racism and sexism inherent in the past barbaric practices of exploitation, experimentation, and forced sterilizations have implications for today's maternal health outcomes. Devaluation of these women because of their race led to ignoring their pain and discomfort, as well as a lack of respect for their basic human rights. Unfortunately, devaluation still pervades the healthcare system today, leading to needless pregnancy-related deaths and complications. The devaluation of Black and Native women must be dismantled in order to improve the nation's maternal health outcomes, as well as the poor health outcomes we see mirrored along racial lines in the COVID-19 crisis. It starts with healthcare providers who

commit to doing the work to rid themselves and their institutions of bias and racism toward women of color. ✚

Endnotes

1. See, for example, E. Brochin, "Racism and Public Health—a New Announcement, a Growing Understanding," Massachusetts Association of Community Development Corporations, July 10, 2020, macdc.org/news/racism-and-public-health-%E2%80%93new-announcement-growing-understanding.
2. K. Mackey et al., "Racial and Ethnic Disparities in COVID-19-Related Infections, Hospitalizations, and Deaths: A Systematic Review," *Annals of Internal Medicine*, December 1, 2020.
3. M. Rees, "Racism in Healthcare: What You Need to Know," *Medical News Today*, September 16, 2020, medicalnewstoday.com/articles/racism-in-healthcare.
4. Centers for Disease Control and Prevention, "Pregnancy-Related Mortality Ratio by Race/Ethnicity: 2014–2017," *Pregnancy Mortality Surveillance System*, cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm.
5. K. Liese et al., "Racial and Ethnic Disparities in Severe Maternal Morbidity in the United States," *Journal of Racial and Ethnic Health Disparities* 6, no. 4 (August 2019): 790–98.
6. S. Ellington et al., "Characteristics of Women of Reproductive Age with Laboratory-Confirmed SARS-CoV-2 Infection by Pregnancy Status—United States, January 22–June 7, 2020," *Morbidity and Mortality Weekly Report*, Centers for Disease Control and Prevention, cdc.gov/mmwr/volumes/69/wr/mm6925a1.htm?s_cid=mm6925a1_w.
7. Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, "Determinants of Health," *healthypeople.gov/2020/about/foundation-health-measures/determinants-of-health#social*.
8. D. Owens and S. Fett, "Black Maternal and Infant Health: Historical Legacies of Slavery," *American Journal of Public Health* 109, no. 10 (October 2019): 1342–45.
9. J. Taylor, "Structural Racism and Maternal Health Among Black Women," *Journal of Law, Medicine & Ethics* 48, no. 3 (2020): 506–17.
10. K. Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs About Biological Differences Between Blacks and Whites," *Proceedings of the National Academy of Sciences* 113, no. 16 (April 19, 2016): 4296–4301.
11. Taylor, "Structural Racism."
12. Taylor, "Structural Racism."
13. N. Bozeman, "Nathan Bozeman," in *American Medical Biographies*, ed. H. Kelly and W. Burrage (Baltimore: Norman, Remington Company, 1920), en.wikisource.org/wiki/American_Medical_Biographies/Bozeman,_Nathan.
14. Taylor, "Structural Racism."
15. K. Norrgard, "Human Testing, the Eugenics Movement, and IRBs," *Nature Education* 1, no. 1 (2008): 170.
16. Norrgard, "Human Testing."
17. B. Theobald, *Reproduction on the Reservation: Pregnancy, Childbirth, and Colonialism in the Long Twentieth Century* (Chapel Hill: University of North Carolina Press, 2019), 39–41.
18. J. Lawrence, "The Indian Health Service and the Sterilization of Native American Women," *American Indian Quarterly* 24, no. 3 (Summer 2000): 400–19.
19. Lawrence, "The Indian Health Service."
20. Taylor, "Structural Racism."
21. D. Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Vintage Books, 1998), 90–92.
22. N. Narea, "The Outcry over ICE and Hysterectomies, Explained," *Vox*, September 18, 2020, vox.com/policy-and-politics/2020/9/15/21437805/whistleblower-hysterectomies-nurse-irwin-ice; see also P. Nicolas and M. Fabiszak, "Forced Hysterectomies in 2020: How Did We Get Here?," *Globe Post*, October 20, 2020, theglobepost.com/2020/10/20/forced-hysterectomies-2020.
23. Theobald, *Reproduction on the Reservation*, 34–35.
24. Hoffman et al., "Racial Bias."
25. D. Williams and T. Rucker, "Understanding and Addressing Racial Disparities in Health Care," *Health Care Financing Review* 21, no. 4 (Summer 2000): 75–90.
26. "Respectful Maternity Care: The Universal Rights of Childbearing Women," White Ribbon Alliance, January 2012, who.int/woman_child_accountability/ierg/reports/2012_015_Respectful_Maternity_Care_Charter_The_Universal_Rights_of_Childbearing_Women.pdf.
27. J. Taylor et al., "Eliminating Racial Disparities in Maternal and Infant Mortality: A Comprehensive Policy Blueprint," Center for American Progress, May 2, 2019, americanprogress.org/issues/women/reports/2019/05/02/469186/eliminating-racial-disparities-maternal-infant-mortality.
28. R. Haskell, "Serena Williams on Motherhood, Marriage, and Making Her Comeback," *Vogue*, January 10, 2018, vogue.com/article/serena-williams-vogue-cover-interview-february-2018.
29. Taylor et al., "Eliminating Racial Disparities."
30. Taylor et al., "Eliminating Racial Disparities."
31. J. Taylor, "Promoting Better Maternal Health Outcomes by Closing the Medicaid Postpartum Coverage Gap," The Century Foundation, November 16, 2020, tcf.org/content/report/promoting-better-maternal-health-outcomes-closing-medicaid-postpartum-coverage-gap.
32. T. Chalhoub and K. Rimar, "The Health Care System and Racial Disparities in Maternal Mortality," Center for American Progress, May 10, 2018, americanprogress.org/issues/women/reports/2018/05/10/450577/health-care-system-racial-disparities-maternal-mortality.
33. A. Waters and L. Asbill, "Reflections on Cultural Humility," *CYF News*, American Psychological Association, August 2013, apa.org/pi/families/resources/newsletter/2013/08/cultural-humility; and C. Sakala et al., *Improving Our Maternity Care Now* (Washington, DC: National Partnership for Women and Families, September 2020), nationalpartnership.org/our-work/resources/health-care/maternity/improving-our-maternity-care-now.pdf.

Improving Communication and Care

Continued from page 29

9. P. Ohri-Vachaspati et al., "Healthy Food Access in Low-Income High-Minority Communities: A Longitudinal Assessment—2009–2017," *International Journal of Environmental Research and Public Health* 16, no. 13 (2019): mdpi.com/1660-4601/16/13/2354; and Healthy Places, National Center for Environmental Health, "Retail Food Stores: Grocery Stores/Supermarkets and Small Food Stores," Centers for Disease Control and Prevention, cdc.gov/healthypplaces/healthtopics/healthyfood/retail.htm.
10. P. Kaufman, C. Dicken, and R. Williams, *Measuring Access to Healthful, Affordable Food in American Indian and Alaska Native Tribal Areas*, EIB-131 (US Department of Agriculture, Economic Research Service, 2014), 12, ers.usda.gov/webdocs/publications/43905/49690_eib131_errata.pdf?v=0; US Water Alliance and Dig Deep, *Closing the Water Access Gap in the United States: A National Action Plan*, March 2020, closethewatergap.org/wp-content/uploads/2020/03/Dig-Deep_Closing-the-Water-Access-Gap-in-the-United-States_EXECUTIVE-SUMMARY-1.pdf; and C. Willig et al., "Improving Native American Elder Access to and Use of Health Care Through Effective Health System Navigation," *BMC Health Services Research* 18 (2018): Article 464, bmchealthservices.biomedcentral.com/articles/10.1186/s12913-018-3182-y.
11. Cecil G. Sheps Center for Health Services Research, "179 Rural Hospital Closures: January 2005–Present (135 Since 2010)," University of North Carolina at Chapel Hill, www.shepscenter.unc.edu/programs/projects/rural-health/rural-hospital-closures.
12. R. Logan et al., "Health Literacy: A Necessary Element for Achieving Health Equity," discussion paper, National Academy of Medicine, July 24, 2015, nam.edu/perspectives-2015-health-literacy-a-necessary-element-for-achieving-health-equity.
13. Centers for Disease Control and Prevention, "COVID-19 Racial and Ethnic Health Disparities," cdc.gov/coronavirus/2019-ncov/community/health-equity/racial-ethnic-disparities/index.html.
14. C. Doak, L. Doak, and J. Root, *Teaching Patients with Low Literacy Skills* (Philadelphia: J. B. Lippincott, 1985); and C. Doak, L. Doak, and J. Root, *Teaching Patients with Low Literacy Skills*, 2nd ed. (Philadelphia: J. B. Lippincott, 1996). For a free online version of the second edition, see hsp.h.harvard.edu/healthliteracy/resources/teaching-patients-with-low-literacy-skills.
15. National Center for Education Statistics, *Adult Literacy in America: A First Look at the Findings of the National Adult Literacy Survey*, NCES 1993-275, 3rd ed. (Washington, DC: US Department of Education, 2002), nces.ed.gov/pubs93/93275.pdf. See also National Center for Education Statistics, "National Assessment of Adult Literacy," US Department of Education, nces.ed.gov/naal/kf_demographics.asp#1 for a comparison of results from 1992 and 2003.
16. M. Kutner, E. Greenberg, and J. Baer, *National Assessment of Adult Literacy (NAAL): A First Look at the Literacy of America's Adults in the 21st Century*, NCES 2006-470 (Washington, DC: National Center for Education Statistics, 2006), nces.ed.gov/naal/pdf/2006470.pdf.
17. M. Kutner et al., *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy*, NCES 2006-483 (Washington, DC: National Center for Education Statistics, 2006), nces.ed.gov/pubs2006/2006483.pdf.
18. T. Davis et al., "The Gap Between Patient Reading Comprehension and the Readability of Patient Education Materials," *Journal of Family Practice* 31, no. 5 (1990): 533–38; M. Wilson, "Readability and Patient Education Materials Used for Low-Income Populations," *Clinical Nurse Specialist: The Journal for Advanced Nursing Practice* 23, no. 1 (January/February 2009): 33–40; and C. Estrada, "Anticoagulant Patient Information Material Is Written at High Readability Levels," *Stroke* 31, no. 12 (2000): 2966–70.
19. US Department of Education, "Data Point: Adult Literacy in the United States," NCES 2019-179, July 2019, nces.ed.gov/pubs2019/2019179.pdf.
20. See, for example, L. Stossel et al., "Readability of Patient Education Materials Available at the Point of Care," *Journal of General Internal Medicine* 27, no. 9 (2012): 1165–1170; and E. Squires and H. Ou, "Do We Have Effective Patient Education Materials for Age-Related Hearing Loss?," *American Journal of Audiology* 29, no. 1 (March 2020): 79–87.
21. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association, "Health Literacy: Report of the Council on Scientific Affairs," *JAMA* 281, no. 6 (1999): 552–57.
22. AMA Foundation, *Health Literacy and Patient Safety: Help Patients Understand*, 2007, YouTube video, 23:18, posted by "AMAFoundation," August 27, 2010, youtube.com/watch?v=cGtTZ_vxjYA&t=16s. See also the companion guide: B. Weiss, *Health Literacy and Patient Safety: Help Patients Understand*, 2nd ed. (AMA Foundation, 2007), partnershiphp.org/Providers/HealthServices/Documents/Health%20Education/CandLToolKit/2%20Manual%20for%20Clinicians.pdf.
23. Kutner, Greenberg, and Baer, *National Assessment*.
24. "Can Health Literacy REALLY Improve Patient Outcomes?," *The Loop*, University of Iowa, October 7, 2014, medcom.uiowa.edu/theloop/health-care/can-health-literacy-really-improve-patient-outcomes; and S. Stableford and W. Mettger, "Plain Language: A Strategic Response to the Health Literacy Challenge," *Journal of Public Health Policy* 28, no. 1 (2007): 71–93, jstor.org/stable/4498942?seq=1.
25. F. Warde et al., "Plain Language Communication as a Priority Competency for Medical Professionals in a Globalized World," *Canadian Medical Education Journal* 9, no. 2 (2018): e52–e59.
26. Plain Language Action and Information Network, *Federal Plain Language Guidelines*, 2011, plainlanguage.gov/guidelines.
27. Merriam-Webster, s.v. "diabetes mellitus," merriam-webster.com/dictionary/diabetes%20mellitus.
28. Centers for Disease Control and Prevention, "What Is Diabetes?," cdc.gov/diabetes/basics/diabetes.html.
29. Always Use Teach-Back, "Welcome to the Always Use Teach-Back Training Toolkit," teachbacktraining.org/home.

The Invisible Work of Nurse Practitioners

Continued from page 34

11. D. Auerbach, P. Buerhaus, and D. Staiger, "Implications of the Rapid Growth of the Nurse Practitioner Workforce in the US," *Health Affairs* 39, no. 2 (February 2020).
12. Pohl et al., "Primary Care Workforce Data."
13. B. Japsen, "U.S. Primary Care Doctor Supply Has Improved but Not Everywhere," *Forbes*, February 18, 2019, forbes.com/sites/brucejapsen/2019/02/18/u-s-primary-care-doctor-supply-has-improved-but-not-everywhere/?sh=28413e7a5c6b.
14. C. Everett et al., "Physician Assistants and Nurse Practitioners as a Usual Source of Care," *Journal of Rural Health* 25, no. 4 (Fall 2009): 407–14, onlinelibrary.wiley.com/doi/abs/10.1111/j.1748-0361.2009.00252.x; and *Nurse Practitioners: A Solution to America's Primary Care Crisis* (Washington, DC: American Enterprise Institute, September 18, 2018), aeio.org/research-products/report/nurse-practitioners-a-solution-to-americas-primary-care-crisis.
15. M. Laurent et al., "Substitution of Doctors by Nurses in Primary Care," *Cochrane Database of Systematic Reviews*, no. 2 (2005), cochranelibrary.com/cdsr/doi/10.1002/14651858.CD001271.pub2/full; E. Lenz et al., "Primary Care Outcomes in Patients Treated by Nurse Practitioners or Physicians: Two-Year Follow-Up," *Medical Care Research and Review* 61, no. 3 (2004): 332–51; and C. Desroches et al., "The Quality of Care Provided by

Nurse Practitioners to Vulnerable Medicare Beneficiaries," *Nursing Outlook* 65, no. 6 (November–December 2017): 679–88.

16. All quotations and examples come from my observations during these two and a half years; for more information, see the discussion of methods in my book: L. Trotter, *More Than Medicine: Nurse Practitioners and the Problems They Solve for Patients, Health Care Organizations, and the State* (Ithaca, NY: Cornell University Press, 2020), 9–16.

17. Examining the gender dynamics of caregiving in more detail is outside the scope of this article, but it's worth noting that adult daughters provide significantly more care to their elderly parents than adult sons do—according to one study, more than twice as much in terms of hours; see A. Grigoryeva, "Own Gender, Sibling's Gender, Parent's Gender: The Division of Elderly Parent Care Among Adult Children," *American Sociological Review* 82, no. 1 (2017): 116–46; and *More Than Medicine* passim.

18. P. Braveman, S. Egerter, and D. Williams, "The Social Determinants of Health: Coming of Age," *Annual Review of Public Health* 32 (April 2011): 381–98.

19. "KHN Morning Briefing: Government Now Pays for Nearly 50 Percent of Health Care Spending, an Increase Driven by Baby Boomers Shifting into Medicare," *KHN*, February 21, 2019, khn.org/morning-breakout/government-now-pays-for-nearly-50-percent-of-health-care-spending-an-increase-driven-by-baby-boomers-shifting-into-medicare.

20. E. Glover, "Tennessee Nurses Association Pushing Law Makers to Pass New Legislation," Fox 17 WZTV Nashville, February 5, 2020, fox17.com/news/local/tennessee-nurses-association-pushing-law-makers-to-pass-new-legislation.

Write to us!

We welcome comments on AFT Health Care articles. Address letters to Editor, AFT Health Care, 555 New Jersey Ave. NW, Washington, DC 20001, or send comments via email to hc@aft.org. Letters selected for publication may be edited for space and clarity. Please include your phone number or email address so we may contact you if necessary.





Dansko footwear is proud to partner with the AFT. Members will receive 25% off when purchasing shoes from AFT's dedicated Dansko webpage at aft.org/members-only.



A Union of Professionals

AFT +
Member Benefits

Summer × 

Simplifying student debt.

- 1** App to **track** your situation
- 2** Our experts **double-check** everything
- 3** Minutes or less to **compare** plans and apply

Sign up or learn more at [**aft.org/benefits/summer**](http://aft.org/benefits/summer)



TRAUMA COVERAGE

Infectious Disease & Traumatic Event Insurance

Coverage provides specialized Trauma Counseling and immediate financial assistance for you and your family. As an active AFT member, you receive the Trauma Counseling benefit of this program **FREE** of charge.

- ✓ Free member-only benefit
- ✓ Convenient virtual counseling
- ✓ Secure and confidential



A Union of Professionals

AFT+

Member Benefits

Trauma Coverage™ is a comprehensive program filling the gaps left by traditional insurance. Enhance your AFT-provided counseling benefit with the financial benefits of Trauma Coverage. **MEMBER-ONLY RATES** available for you and your family at traumacoverage.com/aft/enhanced-benefits.

