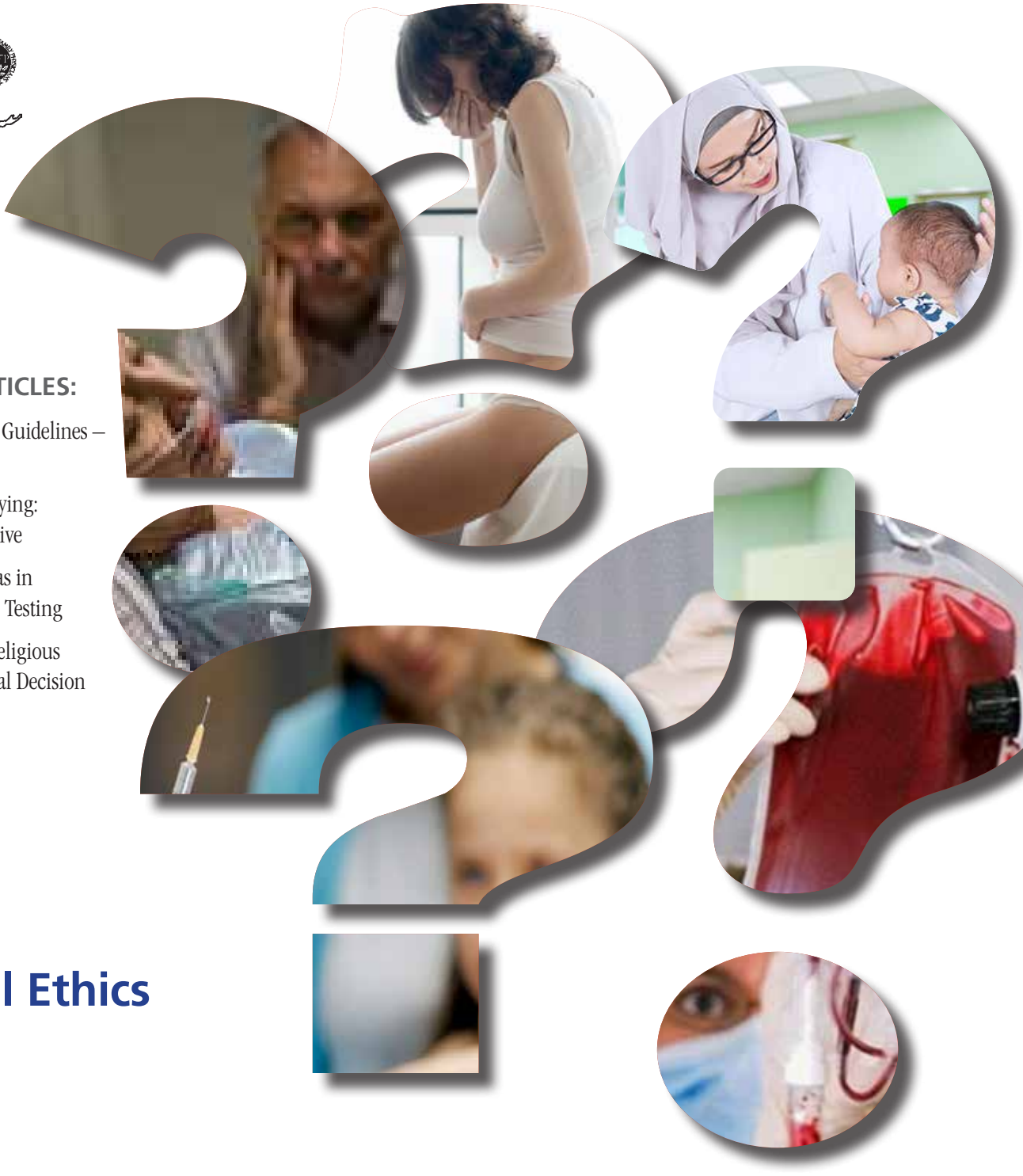
Volume six • Number two

Fall 2017

Family Doctor

A JOURNAL OF THE NEW YORK STATE ACADEMY OF FAMILY PHYSICIANS

New York State Academy of Family Physicians



FEATURE ARTICLES:

- Choosing Wisely Guidelines – Ethics
- Medical Aid in Dying: Another Perspective
- Ethical Dilemmas in Prenatal Genetic Testing
- The Impact of Religious Beliefs on Medical Decision Making

Focus:

Medical Ethics

ADDING CHOCOLATE TO MILK DOESN'T TAKE AWAY ITS NINE ESSENTIAL NUTRIENTS!

All milk contains a unique combination of nutrients important for growth and development. Milk is the #1 food source of three underconsumed nutrients of public health concern identified by the 2015 Dietary Guidelines for Americans: calcium, vitamin D and potassium. And flavored milk contributes only 4% of added sugars in the diets of children 2-18 years.

1. KIDS LOVE THE TASTE!

Milk provides nutrients essential for good health and kids drink more when it's flavored.

2. NINE ESSENTIAL NUTRIENTS!

Flavored milk contains the same nine essential nutrients as white milk – calcium, potassium, phosphorus, protein, vitamins A, D and B12, riboflavin and niacin (niacin equivalents) – and is a healthful alternative to soft drinks.

3. HELPS KIDS ACHIEVE 3 SERVINGS!

Drinking low-fat or fat-free white or flavored milk helps kids get the 3 daily servings* of milk and milk products recommended by the Dietary Guidelines for Americans.

4. BETTER DIET QUALITY!

Children who drink flavored milk meet more of their nutrient needs; do not consume more added sugar or total fat; and are not heavier than non-milk drinkers.

5. TOP CHOICE IN SCHOOLS!

Low-fat chocolate milk is the most popular milk choice in schools and kids drink less milk (and get fewer nutrients) if it's taken away.

GET THE FACTS ABOUT CHOCOLATE MILK

NYSAND

NEW JERSEY ACADEMY of Nutrition and Dietetics

New Jersey State School Nurses Association

National Medical Association Region 1

New York State Academy of Family Physicians

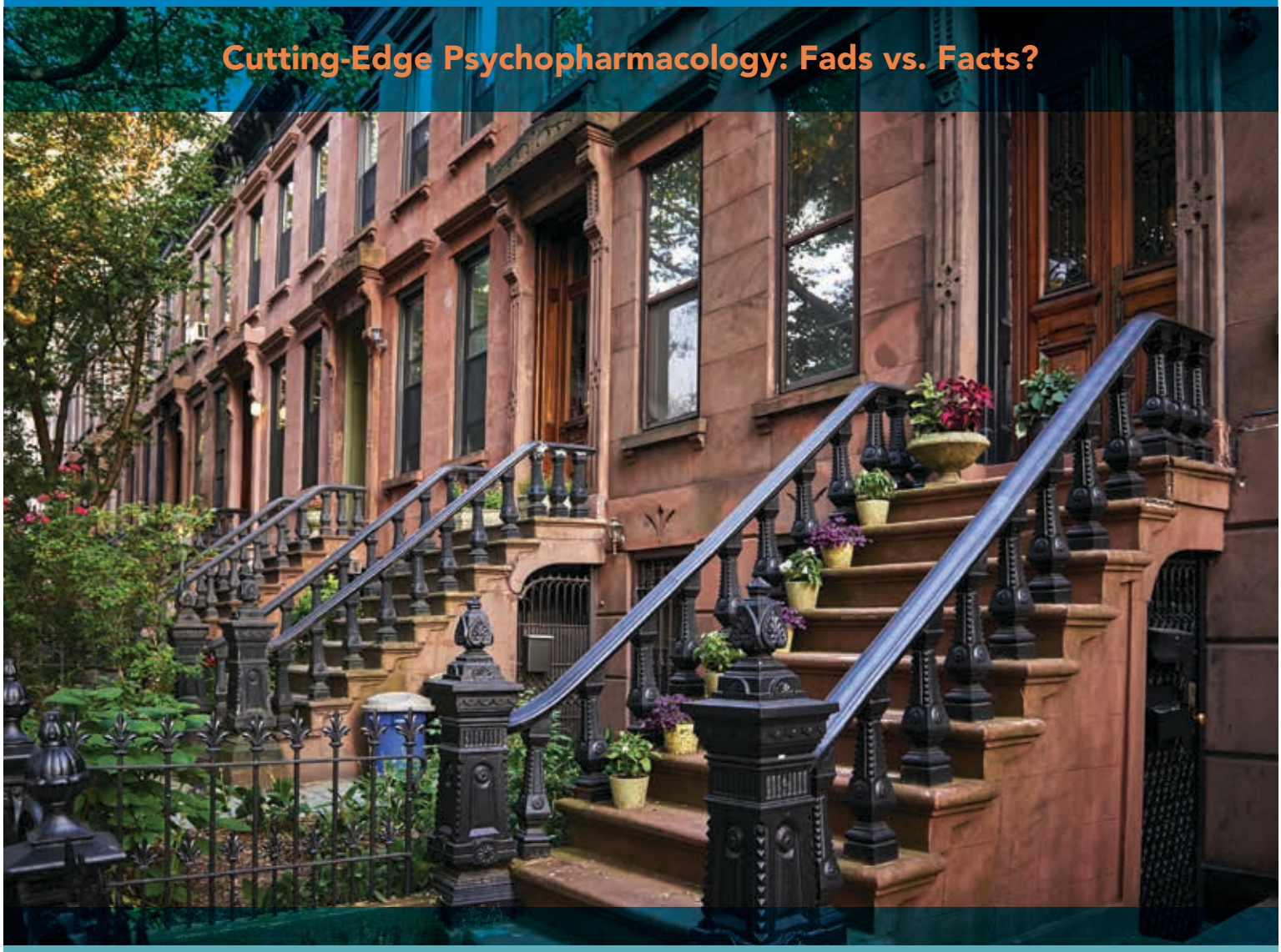
1. National Health and Nutrition Examination Survey (2007-2010), Ages 2-18 years.
2. Johnson RK, Frary C, Wang MQ. The nutritional consequences of flavored milk consumption by school-aged children and adolescents in the United States. J Am Diet Assoc. 2002; 102: 853-856.
3. National Dairy Council and School Nutrition Association. The School Milk Pilot Test. Beverage Marketing Corporation for National Dairy Council and School Nutrition Association. 2002. Available at: http://www.nationaldairycouncil.org/ChildNutrition/Pages/SchoolMilkPilotTest.apx.
4. National Institute of Child Health & Human Development. For Stronger Bones...for Lifelong Health...Milk Matters! Available at: http://www.nichd.nih.gov/publications/pubs/upload/strong_bones_lifelong_health_mm1.pdf Accessed on June 21, 2011.
5. U.S. Department of Health and Human Services. Best Bones Forever. Available at: http://www.bestbonesforever.gov/Accessed June 21, 2011.
6. Frary CD, Johnson RK, Wang MQ. Children and adolescents' choices of foods and beverages high in added sugars are associated with intakes of key nutrients and food groups. J Adolesc Health. 2004; 34: 56-63.
7. American Academy of Pediatrics, Committee on School Health. Soft drinks in schools. Pediatrics. 2005; 113: 152-154.
8. U.S. Department of Health and Human Services and U.S. Department of Agriculture. 2015-2020 Dietary Guidelines for Americans. 8th Edition. December 2015.
9. Greer FR, Krebs NF and the Committee on Nutrition. Optimizing bone health and calcium intakes of infants, children and adolescents. Pediatrics. 2006; 117: 578-585.
10. Murphy MM, Douglas JS, Johnson RK, et al. Drinking flavored or plain milk is positively associated with nutrient intake and is not associated with adverse effects on weight status in U.S. children and adolescents. J Am Diet Assoc. 2008; 108: 631-639.
11. Johnson RK, Appel LJ, Brands M, et al. Dietary Sugars Intake and Cardiovascular Health. A Scientific Statement From the American Heart Association. Circulation. 2009; 120: 1011-1020.
12. 2010-2011 Annual School Channel Survey, Prime Consulting Group, May 2011.
13. Patterson J, Saidel M. The Removal of Flavored Milk in Schools Results in a Reduction in Total Milk Purchases in All Grades,K-12. J Am Diet Assoc. 2009; 109: A97.

* DAILY RECOMMENDATIONS – The 2015 Dietary Guidelines for Americans recommends 3 daily servings of low-fat or fat-free milk and milk productsfor those 9 years and older, 2.5 for those 4-8 years, and 2 for those 2-3 years.

2018 Pediatric Psychopharmacology Update Institute

American Academy of Child & Adolescent Psychiatry
www.aacap.org

Cutting-Edge Psychopharmacology: Fads vs. Facts?



Save the Dates!

January 26-27, 2018

Laurence L. Greenhill, MD and Jeremy M. Veenstra-VanderWeele, MD, Co-Chairs
New York Marriott at the Brooklyn Bridge—Brooklyn, NY

Registration opens in September at www.aacap.org/psychopharm-2018.
Questions? Email meetings@aacap.org.

Practice Family Medicine at Glens Falls Hospital

Live and work in a region steeped in culture, history, recreation and natural beauty on the edge of Upstate New York's Adirondack Park.

The Opportunity:

- Join a well-established primary care practice that is part of a Hospital-based network of physician practices
- Practice a full spectrum of Family Medicine - Outpatient ONLY - Call is phone only and 1:10 weeks
- Lab, X-ray and Rehabilitation Services available on site
- Support of a full spectrum of medical specialties and Hospitalist program
- All of Glens Falls Hospital's Primary Care sites are PCMH (Patient Centered Medical Home), Level 3 certified
- Competitive salary and full benefits package including sign-on bonus and relocation

About Glens Falls Hospital:

Glens Falls Hospital is an integrated health care system, serving a five-county region of the southern Adirondacks. With 2,700 employees, over 300 affiliated providers, and 24 locations, we have the region's longest-established employed physician group. Specializations include primary care, cardiology, endocrinology, hematology/oncology, internal medicine, nephrology, otolaryngology, psychiatry, emergency and inpatient medicine, thoracic surgery, and wound healing. Patients are offered a wide range of services and community health improvement programs.

For more information:

Antoinetta M. Backus, *Manager, Physician Recruitment & Retention*
abackus@glensfallshosp.org • 518.926.1946

Glens Falls Hospital

100 Park Street, Glens Falls, NY 12801
GlensFallsHospital.org

Family Doctor, A Journal of the New York State Academy of Family Physicians, is published quarterly. It is free to members of the New York State Academy and is distributed by mail and email. Non-member subscriptions are available for $40 per year; single issues for $20 each.

New York State Academy of Family Physicians
260 Osborne Road
Albany, New York 12211
www.nysafp.org
Phone: 518-489-8945
Fax: 518-489-8961

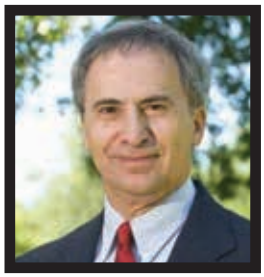
Letters to the Editor, comments or articles can be submitted by mail, fax or email to journaleditor@nysafp.org

Editor: Penny Ruhm, MS

Articles

Departments

Index of Advertisers



From the Executive Vice President

By Vito Grasso, MPA, CAE

Medical Ethics

We have contemplated an issue on medical ethics for quite some time and the variety of topics addressed by our contributing authors reflects the breadth of that theme. As you read through this issue you may also find that there is significant complexity to even the definition of ethical considerations in various situations that are associated with medical practice and health care.

Physicians are uniquely, and perhaps unfairly, challenged by potential ethical dimensions to even the most common occurrences in clinical practice. Decisions about what to do in situations involving some form of ethical issue are complicated, or confounded, by interests which may appear to conflict.

The relationship between medicine and pharma is often cited as an ethical quagmire for physicians. How the possible ethical dilemma is defined is important in determining whether an ethical issue exists at all. If a physician prescribes a product because it has proven to be effective, is it unethical for that physician to receive something of value from the manufacturer for using the product? If the physician used the product only because he/she received compensation for doing so, there would be general agreement that such behavior was unethical. What, however, is the ethical standard for prescribing a product that is preferred by a payer because doing so affects how the physician's performance and compensation are determined? Similarly, is it ethical for a physician to adhere to a health insurance plan's drug formulary if some of the products on the formulary are less effective than alternatives?

We are grateful to our authors, as always, for their unique and incisive contributions to framing the broad and complex topic of medical ethics. Each contributor to this issue has had experience which has helped frame his or her perspective on the ethical considerations of practicing family medicine. We hope you will find guidance in their shared experience as you confront the evitable ethical challenges of your own career.

" ...there is significant complexity to even the definition of ethical considerations in various situations..."

President's Post

By Sarah Nosal, MD, FAAFP

An Ethical Void

At a time in our history when our nation's moral compass seems to have gone askew, we may find ourselves struggling to escape a seemingly ethical void. Stepping back we imagine how we might recall this time in our history as we recklessly consider taking health and healthcare from our nation's children. As we strive to deny the autonomy and reproductive freedom of our nation's women. As American citizens struggle without food, water, shelter or electricity while we contemplate what debts they have yet to pay. When our legislators only consider supporting health for some in exchange for the dismantling of care of our impoverished or our disabled and elderly. Human lives have literally become a moving target and yet we persist despite the repeated senseless loss of human life.

Last week serving at our free clinic in the South Bronx, I spoke at length with one of our young medical student volunteers, born abroad and brought here by his family as a small child. This young man is now burdened with significant debt and only tenuous assurances about his future without a DACA (Deferred Action for Childhood Arrivals) solution or replacement in sight. This stellar student contemplates a life of physical labor after literally thousands invested in his education so he could serve as a physician in this country.

Struggling with what promise of hope we might give him, I realize we must step forward together with the strength of our New York State Academy to find inroads with our shared ethical principles. Working collaboratively with leaders across various specialty organizations we come together on the principles of health care as a human right and push our representatives to pull us from this ethical void. While there is no question of prioritizing the unique needs of the individuals and families in our exam rooms, we must also translate these stories into action on the part of our legislators.

Thank you for the work you do each day in your exam rooms, in your local legislative offices, as you write letters, tweet out, speak out and rally your communities. We are family physicians together - we are the NYSAFP! Please plan to join us in our state lobbying efforts in Albany on March 12, 2018.

Sarah C. Nosal, MD, FAAFP

Human lives have literally become a moving target and yet we persist despite the repeated senseless loss of human life.

Mark YOUR CALENDARS

S M T W T F S

UPCOMING EVENTS

2017

November 12
Fall Cluster (Board Meeting only)
Albany, NY

2018

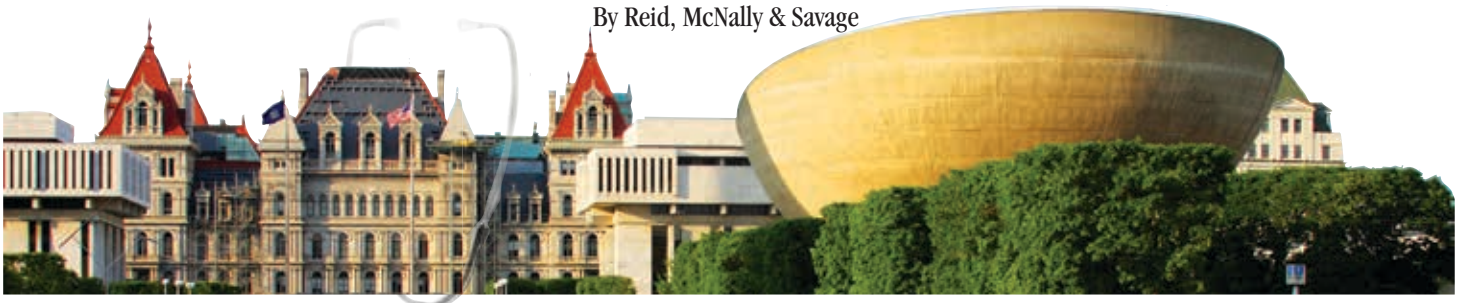
January 11-14
Winter Weekend
Lake Placid, NY

March 11-12
Winter Cluster and Lobby Day
Albany, NY

June 23-24
Congress of Delegates – 70th Anniversary
Hilton Garden Inn, Troy, NY

Albany Report

By Reid, McNally & Savage



As the New York State Academy of Family Physicians prepares its fall edition of the journal for print, we have prepared an Albany update focused on the 2017 session activities of the NYS Legislature and in particular the bills of interest to the Academy which passed both houses during the session.

Some bills have still not yet been transmitted to the Governor for consideration, however each bill's status is noted in our summary below. To view the text or sponsor's memo for any of the following legislation, you can use the following link: http://assembly.state.ny.us/leg/

2017 Session Summary

The New York State Legislature finished the 2017 session in the late evening of June 21, 2017. Despite leaving Albany as planned on the last scheduled day of session, there were a number of issues that the Legislature did not reach agreement on, prompting Governor Cuomo to call the Legislature back to an extraordinary session on June 28, 2017. The Assembly passed an omnibus bill in the early morning hours of June 29th which was then passed by the Senate later that afternoon, officially bringing an end to the 2017 legislative session.

Final agreements that were reached prior to the end of the legislative session include:

- Legislation that addresses the problem of child marriage, raising the legal age at which an individual can marry to 17
- A "Buy American" program to require the use of American-made materials for all road and bridge projects
- A group of initiatives meant to curb the use of electronic cigarettes; notably the expansion of the Clean Indoor Air Act to include e-cigs and vaping
- $90 million for flood relief on the shores of Lake Ontario
- Legislation that would provide insurance coverage for cancers developed by volunteer firefighters during the course of their duty
- Expanded use of medical marijuana for those who suffer from post-traumatic stress disorder
- Prohibiting the use of elephants in entertainment acts
- Two year extender of mayoral control of the New York City public school system
- Three year extender of sales taxes in more than 50 New York State counties
- Naming the new Tappan Zee Bridge after former Governor Mario Cuomo

Throughout the session, the Academy actively lobbied over twenty distinct pieces of legislation as well as for funding to support primary care and the excess malpractice program in the state budget. When the session ended, the Academy saw success on a number of these bills including passage of legislation by both houses to prohibit the use of electronic cigarettes in all public places and legislation to expand Medicaid coverage of allergy testing. Additionally, NYSAFP was able to prevent advancement of harmful vaccine and chronic Lyme bills and a number of bad liability proposals.

Unfortunately, in the final days of the legislative session a bill was passed by both houses, over the strong objection of NYSAFP, organized medicine, hospital associations and malpractice carriers, to change the status of limitations from date of incident to date to discovery in cases related to cancer diagnosis and treatment. NYSAFP is now working with its other partners to weigh in with the Governor's office to seek a veto of the bill and to call for a much more comprehensive discussion on needed liability reforms in New York which could include this issue.

Health-Related Bills Passed by Both Houses

Several thousand bills were introduced during the 2017 session and just over 600 were passed by both houses of the Legislature. Provided below is a sector by sector health update of bills passed by the Senate and Assembly, which we thought would be of particular interest to NYSAFP. Due to space limitations, details of the bills are not included here. For full descriptions go to www.nysafp.org and click on advocacy.

Multiple Sectors

Reporting Requirements by DOH S5671-A, Hannon / A7747-A, Gottfried
This bill was signed into law by the Governor on July 25, 2017, Chapter 121 of the laws of 2017.

Health Care Services for County Jail Inmates S5409-A, Gallivan / A7985-A, Blake
This bill was signed into law by the Governor on July 25, 2017, Chapter 122 of the laws of 2017.

Establishes the Rural Health Council in Statute S4741, Hannon / A7203, Jones
This bill passed both houses. It has not yet been transmitted to the Governor.

Physician/Health Care Professionals

Report on Nurse Practitioners S3567-B, Hannon / A834-B, Gunther
This bill passed both houses. It has not yet been transmitted to the Governor.

Nurse Practitioner DNRs S1869-A, Hannon / A7277-A, Gottfried
This bill passed both houses. It has not yet been transmitted to the Governor.

Medical Malpractice S6800, DeFrancisco / A8516 Weinstein
This bill passed both houses. It has not yet been transmitted to the Governor.

Care by Physical Therapist Assistants in Workers Comp S3762-B, Griffo / A2859-B, Zebrowski
This bill passed both houses. It has not yet been transmitted to the Governor.

Authorizes the delivery of telehealth services at any elementary or secondary school S3293, Hannon / A4703, Jenne
This bill was signed into law by the Governor on September 12, 2017, Chapter 285 of the laws of 2017.

World Triathlon Corporation Events S2607, Little / A2802, Stec
This bill was signed into law by the Governor on July 25, 2017, Chapter 126 of the laws of 2017.

New York Road Runners Event S4811, Serrano / A5287, Glick
This bill was signed into law by the Governor on May 22, 2017, Chapter 29 of the laws of 2017.

Practitioners Registered to Certify Patients for Medical Marijuana Use S5627, Savino / A2882, Peoples-Stokes
This bill passed both houses. It has not yet been transmitted to the Governor.

Hospital/Healthcare Facilities

Certificates of Public Advantage S5342, Hannon/ A7748, Gottfried (DOH Departmental Bill #25)
This bill was signed into law by the Governor on June 29, 2017, Chapter 80 of the laws of 2017.

Enhanced Safety Net Hospital Program S5661-B, Little/A7763, Gottfried
This bill passed both houses. It has not yet been transmitted to the Governor.

Guidelines for Reporting Elder Abuse in Healthcare Settings S6676, Serino / A8258-A, Lupardo
This bill was signed into law by the Governor on September 13, 2017, Chapter 328 of the laws of 2017.

Provider/Consumer Health Care Protections S6454, Hannon / A8061, Gottfried
This bill was signed into law by the Governor on June 29, 2017, Chapter 82 of the laws of 2017.

Medicaid Carve-Out of School-Based Health Centers S6012, Seward / A7866, Gottfried
This bill passed both houses. It has not yet been transmitted to the Governor.

Long Term Care

Interagency Council for Coordinated Planning Relating to Older Adults S2847, Parker /A6976, Barron
This bill passed both houses. It has not yet been transmitted to the Governor.

Requires Hospice Programs to Comply with Home Care Worker Registry Requirements S6347, Hannon / A7846, Gottfried
This bill was signed into law by the Governor on August 21, 2017, Chapter 206 of the laws of 2017.

Expanded Payment for Reserve Bed Days in Healthcare Facilities S6559, Hannon / A8338, Gottfried
This bill passed both houses. It has not yet been transmitted to the Governor.

Increases the Percentage of "Swing Beds" in a Hospice Residence S6364, Hannon / A7775-A, Gottfried
This bill was signed into law by the Governor on August 251, 2017, Chapter 205 of the laws of 2017.

Extension of Long-Term Care Related Statutes S6153, Hannon / A7746, Gottfried
This bill was signed into law by the Governor on June 29, 2017, Chapter 49 of the laws of 2017.

Provisions for Home Care in Emergency Management Plans S5016-A, Lanza / A6549-A, Cusick
This bill passed both houses. It has not yet been transmitted to the Governor.

Pharmacy/ Pharmaceuticals

90-Day Refills S5171-B, Felder / A6371-B, Simanowitz
This bill passed both houses. It has not yet been transmitted to the Governor.

Expanded Drug Disposal Options for Unused Controlled Substances S6750, Hannon / A387-B, Gunther
This bill passed both houses. It has not yet been transmitted to the Governor.

Ensures coverage of not-for-profit pharmacies operated by an institution of higher education S6689, Amedore / A7922-A, Steck
This bill passed both houses. It has not yet been transmitted to the Governor.

Substitution of Interchangeable Biological Products S4788-A, Hannon / A7509-A, Gottfried
This bill passed both houses. It has not yet been transmitted to the Governor.

Public Health

Prohibits possession of e-cigarettes on school grounds S750, Ritchie / A611, Rosenthal
This bill was signed into law by the Governor on July 25, 2017, Chapter 102 of the laws of 2017.

Briana's Law S3165-B, Hamilton / A2115-B, Ortiz
This bill was signed into law by the Governor on August 27, 2017, Chapter 271 of the laws of 2017.

Allows individuals/entities to purchase and operate external defibrillators S5718, Hannon / A7532, Gottfried
This bill was signed into law by the Governor on July 25, 2017, Chapter 119 of the laws of 2017.

Authorizes schools to screen for childhood obesity S2724-B, Klein / A5151-B, Crespo
This bill was signed into law by the Governor on August 21, 2017, Chapter 183 of the laws of 2017.

Includes information on pediatric acute-onset neuropsychiatric syndrome in the health care and wellness education and outreach program S5750, Little / A7614, Jones
This bill was signed into law by the Governor on August 21, 2017, Chapter 199 of the laws of 2017.

Requires certain reporting when a person dies unexpectedly due to epilepsy S2422, Griffo / A2380, Brindisi
This bill was signed into law by the Governor on August 21, 2017, Chapter 175 of the laws of 2017.

Registration of Electronic Cigarette Retailers S2542-A, Hannon/ A4377-A, Rosenthal
This bill passed both houses. It has not yet been transmitted to the Governor.

E-Cigarette Restrictions in Workplaces S2543-A, Hannon/ A516-A, Rosenthal
This bill passed both houses. It has not yet been transmitted to the Governor.

Maternal Depression Treatment S4000, Krueger/ A8308, Richardson
This bill passed both houses. It has not yet been transmitted to the Governor.

Leave for Cancer Screening S5925, Hannon/ A2830-B, Dinowitz
This bill passed both houses. It has not yet been transmitted to the Governor.

Medical Marijuana Use S5629, Savino / A7006, Gottfried
This bill passed both houses. It has not yet been transmitted to the Governor.

Grants the Transplant Council Authority to Make Recommendations S2495, Hannon / A5123, Gottfried
This bill was signed into law by the Governor on May 12, 2017, Chapter 26 of the laws of 2017.

Study of High Incidence of Asthma in Manhattan S5559, Alcantara / A7214, Seawright
This bill passed both houses. It has not yet been transmitted to the Governor.

Study of High Incidence of Asthma in Brooklyn S5770, Hamilton / A947, Simon
This bill passed both houses. It has not yet been transmitted to the Governor.

Study of High Incidence of Asthma in the Bronx S3103, Serrano / A703, Sepulveda
This bill passed both houses. It has not yet been transmitted to the Governor.

Physical Education Requirements S5752, Lanza / A2597, Nolan
This bill passed both houses. It has not yet been transmitted to the Governor.

Crohn's and Colitis Fairness Act S3295, Hannon / A1982, Paulin
This bill passed both houses. It has not yet been transmitted to the Governor.

continued on page 12

Rory Staunton's Law S4971-A, Marcellino / A6053-A, Nolan
This bill passed both houses. It has not yet been transmitted to the Governor.

Authorizes Use of Epinephrine Auto-Injectors S6005-A, Murphy / A7635-A, Buchwald
This bill was signed into law by the Governor on August 21, 2017, Chapter 200 of the laws of 2017.

Insect Repellent Use at Summer Camp S6710-A, Little / A8420, Jones
This bill was signed into law by the Governor on July 25, 2017, Chapter 163 of the laws of 2017.

Newborn Health and Safe Sleep Pilot Program S3867-A, Hannon / A6044-A, Simotas
This bill passed both houses. It has not yet been transmitted to the Governor.

Financial Reports Filed by Certain Charitable Organizations S5183, Ranzenhofer/ A7656, Dinowitz
This bill was signed into law by the Governor on June 29, 2017, Chapter 78 of the laws of 2017.

Department of Health Actions: Designated Lead Poisoning Areas S1200-A, Alcantara / A1809-A, Dinowitz
This bill passed both houses. It has not yet been transmitted to the Governor.

Behavioral Health/ Foster Care

Training for CASACs S981, Amedore / A373, Rosenthal
This was signed into law by the Governor on February 1, 2017, Chapter 2 of the Laws of 2017.

Notice for Mental Health Service Reductions S2836, Ortt/ A2229, Gunther
This bill passed both houses. It has not yet been transmitted to the Governor.

Authorizes OMH to transfer custody of an inmate to an OMH facility for mental health treatment S5430, Gallivan / A7569, Weprin
This bill was signed into law by the Governor on August 21, 2017, Chapter 196 of the laws of 2017.

Kendra's Law S6726, Young / A7688, Gunther
This bill was signed into law by the Governor on June 29, 2017, Chapter 67 of the laws of 2017.

Adolescent Suicide Prevention Advisory Council S5500-C, Alcantara / A7225-B, De La Rosa
This bill passed both houses. It has not yet been transmitted to the Governor.

Comprehensive Care Centers for Eating Disorders S5927, Hannon/ A7949, Ortiz
This bill was signed into law by the Governor on August 21, 2017, Chapter 259 of the laws of 2017.

Foster Family Care Demonstration Programs S6081, Serino/ A8131, Lupardo
This bill was signed into law by the Governor on July 25, 2017, Chapter 153 of the laws of 2017.

Mental Illness Anti-Stigma License Plate S1210-C, Ortt / A6216-B, Gunther
This bill was signed into law by the Governor on August 21, 2017, Chapter 228 of the laws of 2017.

Developmental Disabilities/ Education

Adds Prader-Willi syndrome to the definition of developmental disability S1219, Ortt / A5974 Gunther
This bill was signed into law by the Governor on July 25, 2017, Chapter 114 of the laws of 2017.

Establishment of Medicaid Special Needs Trusts S4779, Hannon / A6743 Barrett
This bill was signed into law by the Governor on August 21, 2017, Chapter 187 of the laws of 2017.

Streamline Transition Process for Students with Disabilities S1692, Marcellino /A1036, Nolan
This bill passed both houses. It has not yet been transmitted to the Governor.

School District Information: Students with Dyslexia and Related Disorders S6581, Golden / A8262, Simon
This bill was signed into law by the Governor on August 21, 2017, Chapter 216 of the laws of 2017.

Complex Rehabilitation Technology (CRT) S4557-B, Ortt / A6120-B, McDonald
This bill passed both houses. It has not yet been transmitted to the Governor.

Early Childhood Advisory Council S972, Avella / A367, Lupardo
This was signed into law by the Governor on March 15, 2017, Chapter 14 of the Laws of 2017.

Provides Adult Siblings Access to Medical Records S2933-A, Gallivan / A7567, Gunther
This bill was signed into law by the Governor on August 21, 2017, Chapter 233 of the laws of 2017.

Involuntary Care S6154, Ortt/ A7604, Gunther (OPWDD Departmental Bill #102)
This bill was signed into law by the Governor on August 21, 2017, Chapter 198 of the laws of 2017.

Insurance

Expands coverage of tomosynthesis by certain health insurers S4150, Griffo / A5677, Seawright
This bill passed both houses. It has not yet been transmitted to the Governor.

Medicaid Rate for Hospice S5662-A, Valesky/ A6408-A, Dinowitz
This bill passed both houses. It has not yet been transmitted to the Governor.

Medicaid Coverage of Blood Clotting Factor Products S5774, Hannon/ A7581, Gottfried
This bill was vetoed by the Governor on June 28, 2017.

Medicaid Coverage of Allergy Testing S1222, Rivera / A807, Perry
This bill passed both houses. It has not yet been transmitted to the Governor.

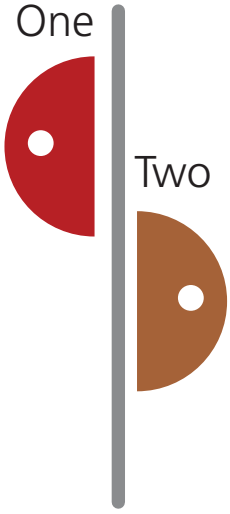
Prohibits Prior Authorization for Neonatal Intensive Care Services S6053, Hannon / A8051, Gottfried
This bill passed both houses. It has not yet been transmitted to the Governor.

Includes Topical Oxygen Wound Therapy in Medicaid Coverage S3421, Parker / A2906, Ortiz
This bill passed both houses. It has not yet been transmitted to the Governor.

VIEW ONE
NOT EVERYONE IS SWAYED

By Giancarlo De Carolis, MD and
Ani A. Bodoutchian, MD, MBA, FAAFP

There are many controversies in medicine but the relationship between the pharmaceutical industry and the physicians has been, without a doubt, quite a bone of contention. We believe that not everyone is negatively influenced by pharmaceutical companies.



What makes the general public perceive that physicians are influenced by marketing tactics when the primary benefit gained is the industry and the consumer? In relatively recent years, publications suggest that pharmaceutical companies may influence a physician's prescribing habits by offering gifts, such as free meals, merchandise, and advertising. This totally ignores the role of advertisement. Advertising, and not physicians, is the most rapid means of distributing consumer related information. It not only draws attention to the product but advertising has a proven success rate in marketing consumer goods. We have seen countless magazine ads with coupon inserts with a cash value towards the purchased goods or services, and these prove an excellent way of getting the consumer to be more educated and informed of options and what the market holds. Some of our best patients are those who have done their "homework" and come in with questions about advertised medications for discussion.

There are a growing number of physicians who, like ourselves, maintain that gifts from pharmaceutical companies do not influence the way in which we practice medicine, the decisions we make, or the medications we prescribe. This is supported by a number of peer-reviewed articles, which are included in our endnotes. In actuality, the interaction between pharmaceutical companies and physicians is valuable and advantageous to both physicians and their patients.

Every physician has heard their patients bemoan the rising costs of medications. This is particularly driven home when a patient has to choose between affording the medicine that keeps them alive and feeding their family. Economic hardships range from high co-payments, a high deductible, unemployment and, the icing on the cake, when their insurance will only cover a generic medication. We are sure those reading this article are all too familiar with their patients' plights when it comes to getting necessary medication.

A systematic review, with the objective of examining the relationship between exposure to information from pharmaceutical companies and the effect it had on physicians' prescribing, concluded that advertising by pharmaceutical companies can be useful in several

continued on page 15

VIEW TWO
THE PROOF IS CLEAR

By Verniese Brown, MD, MBA; Seeam Haque, MD, and
Ani A. Bodoutchian, MD, MBA, FAAFP

Regardless of income and one's moral compass, who does not enjoy a free meal, financial incentive and/or a luxurious perk? Really, what is the harm?

The overwhelming voice of the medical community states that physicians can be substantially influenced by pharmaceutical companies at the dangerous expense of the patients. Simply because one carries the title of physician, does not now mean that his or her judgment is not subject to the influence of financial, physical and emotional gain.

Pharmaceutical representatives approach physicians who they think will make an impact on their product's productivity. In the past three to four decades pharmaceutical budgets extended to support highly paid speaking engagements, trips, sporting events and golfing outings, lavish dinners with spouses, etc. While these over-the-top fringe benefits have now stopped, physicians and their office staff are now regularly enticed to dinners, lunches and promotional products. These "small gestures"- that those who claim they are not influenced by - are in actuality activating a reward system. As numerous studies and research have demonstrated, this reward system is firmly set on a financial level. After all, who can't use an extra few thousands of dollars in their wallet, especially when advocating for a drug that you prescribe all the time? No harm in that?

Let's now consider for a moment the physician who chooses treatment based solely for the patient's gain. If given the choice between two medications with equal simplicity, tolerability, efficacy, etc, the question becomes, why not choose the option with greater personal gain in the form of a financial incentive? Studies in the social sciences of industry prescribing habits suggest that even the gifting of low value items influences physicians psychologically. Such biases can be unconscious and inadvertent.[2]

Undoubtedly, a physician's greatest teacher is another more experienced physician. Pharmaceutical companies have paid physicians to present their drugs with eloquent speeches, interspersed with fancy numbers to persuade the prescribing practices of other physicians.

The unfortunate reality is that physicians are sometimes given second, third or even fourth hand information presented eloquently and often embellished with complicated biostatistics, about medications from trials performed by their own pharmaceutical

continued on page 16

ways.[1] This review found that pharmaceutical companies distribute information to physicians, which improves their knowledge and understanding of options when choosing medications for their patients. This allows for an overall improvement in the quality of the physician's prescription choices and results in better health outcomes for patients. Moreover, as the number of prescriptions rise, pharmaceutical companies are able to reduce the cost of the medications, a concept known as increasing price-elasticity.[1]

One study, published in 2010, examined the effects of mandatory guidelines prohibiting hospital doctors from accepting any form of benefits from the pharmaceutical industry. That study documented that "70 % of doctors in the institution with guidelines, compared with 92 % of those doctors in the hospital without guidelines, believed that the advertising practices of the pharmaceutical industry had no influence on their prescribing [behavior]."[3]

In another study, a mail survey was sent to 397 members of American College of Obstetricians and Gynecologists. This questionnaire was designed to assess the ethical opinion of accepting incentive items (such as free drug samples, informational lunches or merchandise) and if they have an effect on the practice habits of obstetrician - gynecologists. In one portion of the survey, the doctors were given four scenarios each of which had 5 questions regarding their ethical decisions compared to hypothetical situations. In another part of the survey, the doctors were asked eleven questions focusing on their professional interactions with the pharmaceutical industry and what their opinion was on marketing directly to consumers. The results of the survey agree with our view that physicians are not strongly influenced by the pharmaceutical industry and the analysis suggests that they generally behave in accordance with what they believe is ethical.[2]

Also included on this survey was a question of how and why participating physicians were distributing free samples of medications. The top reason provided was for patient financial need (94%) and also for patient convenience (76%).[2] Doctors accepting free pharmaceutical samples in order to give them to patients who could not afford them is a perfect example of how the interaction between pharmaceutical companies and physicians can be positive and beneficial to both physicians and their patients.

In theory, the concept of allowing physicians to accept gifts, including educational opportunities, from pharmaceutical companies may have an effect on their prescribing habits. In our experience, the interaction between pharmaceutical companies and physicians has proven to be beneficial to both parties. This interaction has provided us with a wealth of knowledge and information regarding our options when choosing the best medications for our patients. Samples, which are often provided, have helped to lower the cost of prescriptions drugs for patients who may otherwise not be able to afford them.

Since the pharmaceutical companies have a plethora of drugs that can be given away to benefit the patients in our practice, we say go for it! A pharmaceutical salespersons presence in our office with samples and/or promotional offers such as coupons should not suggest that we will prescribe a drug that is not the best possible fit for our patient. As physicians we have spent much of our lives dedicated to the betterment of others and I don't think we are easily swayed by a grilled chicken Caesar salad, steak dinner, pen or sticky pad. If anything, I think the possible suggestion of impropriety propels us to be very cautious in prescribing practices.

As doctors, we have spent many years crafting our practice and making difficult decisions and sacrifices. We are well educated professionals who are, hopefully, role models in our communities and are thought to have decent moral fiber. It is simplistic to think that marketing ploys from drug companies will dictate what medication should be prescribed for a patient.

As with all controversies, we will have to respect those who do not agree with our view. Ultimately, it is about caring for our patients and the communities we serve. It is about providing the best possible patient care, using the pharmaceutical industry as an ally, as opposed to a foe.

Endnotes

1 Spurling, Geoffrey K., et al. "Information from Pharmaceutical Companies and the Quality, Quantity, and Cost of Physicians' Prescribing: A Systematic Review." PLoS Medicine, vol. 7, no. 10, 2010, doi:10.1371/journal.pmed.1000352.

2 Morrgan, M A. "Interactions of Doctors with the Pharmaceutical Industry." Journal of Medical Ethics, vol. 32, no. 10, Jan. 2006, pp. 559–563., doi:10.1136/jme.2005.014480.

3 Gundermann, C, et al. "Der Einfluss Einer Krankenhausinternen Richtlinie Auf Die Einstellung Von ÃRzten Zur Pharmazeutischen Industrie." *DMW - Deutsche Medizinische Wochenschrift*, vol. 135, no. 03, 2010, pp. 67–70., doi:10.1055/s-0029-1244818.

References

Brett, Allan S., et al. "Are Gifts From Pharmaceutical Companies Ethically Problematic?" Archives of Internal Medicine, vol. 163, no. 18, 2003, p. 2213., doi:10.1001/archinte.163.18.2213.

Rutledge, Philip, et al. "Do Doctors Rely on Pharmaceutical Industry Funding to Attend Conferences and Do They Perceive That This Creates a Bias in Their Drug Selection? Results from a Questionnaire Survey." Pharmacoepidemiology and Drug Safety, vol. 12, no. 8, 2003, pp. 663–667., doi:10.1002/pds.884.

***Ani A. Bodoutchian, MD, MBA, FAAFP, CPE, FHM**, is a board certified in family medicine. She graduated from the Universidad Autonoma de Guadalajara School of Medicine in Mexico and is currently Assistant Professor of Family Medicine at Zucker Hofstra /Northwell School of Medicine and Associate Professor of Family Medicine and General Practice at St. George's University School of Medicine. She has numerous national publications and has presented locally, regionally, nationally, and internationally. She currently is treasurer of the Suffolk County Medical Society and sits on the Board of the NYSAFP.*

***Giancarlo De Carolis, MD,** is a third-year family medicine resident at Northwell Health Southside Hospital in Bayshore, NY. He received his medical degree from American University of Antigua where he graduated magna cum laude. His research has been accepted to the 2016 American Academy of Family Physicians Family Medicine Experience, as well as the 2016 and 2017 Society of Teachers of Family Medicine Annual Conferences.*

companies. Physicians are being blinded by the very savvy pharmaceutical industry that are not always and consistently using proven double blinded clinical trials that are published in reputable journals as a source of medical evidence. A study performed by Orlowski and Wateska, examined the impact on physician prescribing patterns for two intravenous medications in the inpatient setting before and after a luxurious, all-inclusive, all expenses paid symposium. Prior to the start of the symposium, a few physicians were surveyed about their likelihood of being coerced by such grand rewards. They believed that such experiences would not change their prescribing patterns. However, the study which examined inpatient prescribing practices several months before and after the symposium showed a significantly marked increase in the use of both drugs, much greater than the national average.[1]

Quite frankly, before doctors are doctors, they are humans. As humans, while goal oriented, we operate under emotional, environmental, and incentive influences on conscious or subconscious levels. We often gravitate towards objects, experiences, other people and opportunities that are pleasing, thereby engaging our innate reward system.

So, to our readers we ask, can we truly trust that our healthcare providers can get past the fancy presentations and financial incentives to prescribe based on integrity and what is best for the patient? Perhaps those of us on this side of the equation are pessimistic. Perhaps not every physician is a fortress of integrity and of untouchable moral fortitude.

Endnotes

1 Orlowski JP, Wateska L. The effects of pharmaceutical firm enticements on physician prescribing patterns: there's no such thing as a free lunch. Chest 1992;102: 270-273.
2 Dana J. Loewenstein G. A social science perspective on gifts to physicians from industry. JAMA 2003290252–255.

References

Spurling, Geoffrey K., et al. "Information from Pharmaceutical Companies and the Quality, Quantity, and Cost of Physicians' Prescribing: A Systematic Review." PLoS Medicine, vol. 7, no. 10, 2010, doi:10.1371/journal.pmed.1000352.

Miller, John Dudley. "Study Affirms Pharma's Influence on Physicians." JNCI: Journal of the National Cancer Institute, Volume 99, Issue 15, 1 August 2007, Pages 1148–1150, https://doi.org/10.1093/jnci/djm097.

William Fleischman, clinical scholar, Shantanu Agrawal, deputy administrator, Marissa King, professor, Arjun K. Venkatesh, assistant professor4, Harlan M Krumholz, professor, Douglas McKee, professor, Douglas Brown, division director, Joseph S Ross, associate professor."Association Between Payments from Manufacturers of Pharmaceuticals to Physicians and Regional Prescribing: Cross Sectional Ecological Study." BMJ 2016; 354 doi: https://doi.org/10.1136/bmj.i4189. 18 August 2016)

Verniese L. Brown, MD, MBA, *is a third year family medicine resident at Northwell Health SouthSide Hospital in Bayshore, New York. She graduated from American University of Antigua with a medical degree and Plymouth State University with an MBA in 2015. She has a strong interest in women's health and global issues and plans to work in an urgent care setting following residency.*

Seeam Haque, MD, *received his MD from St. George's University, West Indies in 2014 and is currently a family medicine PGY-3 resident at Northwell Health's Southside Hospital in Bayshore, NY. He has a distinct passion for critical care medicine, strategies for personal development, and youth programs. He is an active certified chaplain of the NYS Chaplain Task Force and has been involved in numerous relief missions from Haiti to Bangladesh.*

Ani A. Bodoutchian, MD, MBA, FAAFP, CPE, FHM, *is a board certified in family medicine. She graduated from the Universidad Autonoma de Guadalajara School of Medicine in Mexico and is currently Assistant Professor of Family Medicine at Zucker Hofstra /Northwell School of Medicine and Associate Professor of Family Medicine and General Practice at St. George's University School of Medicine. She has numerous national publications and has presented locally, regionally, nationally, and internationally. She currently is treasurer of the Suffolk County Medical Society and sits on the Board of the NYSAFP.*

Editor's Note: In an effort to demonstrate differing opinions on an ethical issue, Dr. Ani Bodoutchian, worked with the residents she trains on both views of this topic.

Let's Get Everyone Covered.

FIDELIS CARE®

Questions About Health Insurance?

Fidelis Care offers quality, affordable health insurance for qualifying children and adults of all ages through Qualified Health Plans and the New York State-sponsored Child Health Plus, Essential Plan, and Medicaid programs.

We want everyone to know that learning about quality, affordable health insurance is just a call, click, or visit away.

Enrollment Timeframes:

For those who are eligible

Starting November 1 — December 15, 2017
for coverage that begins January 1, 2018
for Qualified Health Plans through NY State of Health

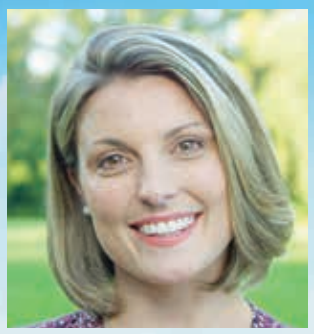
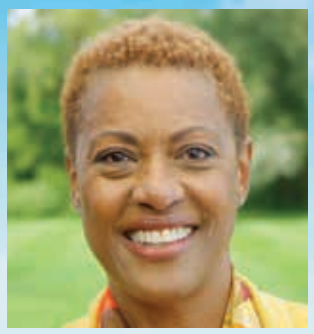
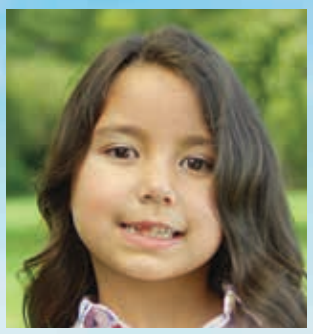
All Year Long
for Child Health Plus, Essential Plan, Medicaid
(New York State-sponsored health insurance)
Individuals must be eligible to apply for Medicaid

To Learn More:

Call
1-888-FIDELIS (1-888-343-3547)
1-800-421-1220 TTY

Click
Apply Through:
www.nystateofhealth.ny.gov
For those who are eligible

Visit
fideliscare.org/offices

nystateofhealth™ The Official Health Plan Marketplace

Child Health Plus New York State's Health Plan for Kids

Medicaid

To learn more about applying for health insurance, including Child Health Plus, Essential Plan, Qualified Health Plans, and Medicaid through NY State of Health, The Official Health Plan Marketplace, visit www.nystateofhealth.ny.gov or call 1-855-355-5777.

1-888-FIDELIS • fideliscare.org
(1-888-343-3547) TTY: 1-800-421-1220

@fideliscare

Choosing Wisely

As physicians, the basic medical ethical principles of beneficence, non-maleficence, justice, and respect for autonomy are at the core of every medical decision we make. At times it can be difficult to weigh these principles when assessing the use of medical testing and treatments, while also feeling that we are providing comprehensive care for our patients.

The ethical principle of non-maleficence endorses an obligation not to inflict harm on others and has been closely associated with the maxim Primum non nocere: "above all [or first] do no harm."[1] The principle of beneficence requires that we not only refrain from harming others, but also that we contribute to their welfare. The Hippocratic Oath clearly expresses an obligation of both non-maleficence and of beneficence: "I will use treatment to help the sick according to my ability and judgment, but I will never use it to injure or wrong them."

The American Board of Internal Medicine developed the Choosing Wisely campaign to encourage wise use of resources among physicians and to aid in identifying the appropriate use of medical testing. This article will discuss specific preventive medicine guidelines for cervical cancer that exemplify how the Choosing Wisely campaign addresses and encourages application of medical ethics. We will also discuss strategies for approaching this subject with patients.

Recent cervical cancer screening guidelines recommend against screening women younger than 21 years of age.[2,3] Cervical cancer is rare in adolescents and most abnormalities observed at that age would regress spontaneously. The American Academy of Family Physicians and American Society for Colposcopy and Cervical Pathology both acknowledge that screening earlier than 21 years of age poses the risk of harm - including unnecessary anxiety, cost, and additional testing such as biopsies and procedures – without any added benefit. The AAFP also applies the principle of non-maleficence to HPV testing in women under 30. These guidelines caution against the use of HPV testing, alone or in combination with cytology, in women younger than 30, specifically due to moderate harms of frequent testing and increased invasive procedures like colposcopy, coupled with the frequent spontaneous resolution of HPV in this age.[4]

Furthermore, annual cervical cytology screening has no advantage over screening at 3-year intervals in average risk women. The American College of Obstetrics and Gynecology does not recommend performing routine annual Pap tests in women 30-65 years of age.[5] Annual Pap tests could also subject the patient to more frequent anxiety, costs, and testing when compared to 3-year intervals. However, ACOG does recommend an annual well-women visit with consideration of a pelvic exam.

Cervical cancer screening guidelines address the crucial question of what age to stop cervical cytology/Pap tests. The AAFP does not recommend screening in women over the age of 65, as long as they had adequate prior screening and are not at high risk for cervical cancer.[6] The AAFP cites little to no added benefit of continuing cervical cytology in those circumstances, thus taking into account the principle of beneficence, as continued testing would not contribute to these patients' welfare. Similarly, the American College of Preventive Medicine advises against cervical cancer screening in low-risk women over the age of 65, as the incidence and prevalence of cervical cancer decreases between ages 40-50. The American College of Preventive Medicine notes that women patients with a history of total hysterectomy for benign disease do not benefit from cervical cancer screening. The guidelines also cite potential harm from false positive tests similar to those aforementioned: procedural risks like vaginal bleeding from biopsies and significant psychological risks such as anxiety.[7]

Discussing these guidelines with patients can be challenging: patients often become accustomed to specific screening intervals, may request additional testing that is not indicated, or lack an understanding of the medical reasoning. In order to investigate these challenges further, let us take a look at the case of Ms. M.

Ms. M is a 66-year-old woman, who just transferred to your practice having moved into the community to be closer to her grandchildren. She presents for a new patient visit, and a Pap smear. On history, she has been married to her husband of 20 years and is monogamous. Prior to that, she was married 18 years and that husband died in a farming accident. She reports that these are her only two partners. She reports her last Pap was at age 63 and was never told any were abnormal. Your assistant has pulled the gynecological testing results from Ms. M's previous health system, and your review shows her previously normal Pap smears without HPV co-testing. You explain to her that because she is over the age of 65 and does not have a history of abnormal Pap smears, she no longer needs Pap tests performed. Despite this brief review of the recommendations, Ms. M stills requests a Pap, insisting that she "is due."

By Sonya K. Narla, DO, MA; Lauren E. Nicholls, MD and Colleen T. Fogarty, MD, MSc, FAAFP

So how do we, as physicians, work with a patient who is used to Pap tests every 3 years, and still insists on it despite the recommendations? The first step is to gain a better understanding of the patient's concern or reasoning that underlies her request.

For patients who are used to an old routine or testing frequency, review of the guideline and the pathophysiology of the natural history of cervical cancer may be enough. Many women will be pleased to learn that they may not need a speculum exam if they have had prior adequate screening and remain asymptomatic.

For a woman who has underlying anxiety, it is important to identify the source of the anxiety and address it directly. For example, is Ms. M simply used to her 3-year routine and hesitant to change? Is she anxious because a new physician, whom she does not yet know, is changing her health care regimen? Address specific concerns in stepwise fashion. Reviewing the patient education materials in the Choosing Wisely resource list can be helpful so patients can see that this comes from a respected authority.[8] You can additionally discuss risks associated with unnecessary testing, as well as the potential costs associated with it.

In our case, given that the patient is close to the age cut-off, if simple reassurance cannot alleviate the patient's concerns, you could defer the gynecologic exam until a future appointment, giving the patient time to consider, and you could perform a "last Pap test" at a future visit. Though not wholly adherent to guidelines, this may be the crossroads of shared decision-making and medical testing.

Consider a second case of a 28-year-old intellectually disabled woman who states that she has never been sexually active. She has had previous attempts at a pelvic exam but was unable to tolerate them. If continuing on the principle of non-maleficence, should you continue to pursue the pelvic exam and Pap smear to definitively prove she is HPV and cancer free or abort the procedure as her risk of HPV is low without sexual activity and hence she has a presumed low risk for cervical cancer as well? Again, conduct a stepwise assessment of risks and benefits. For example, while she is not sexually active currently, nearly 80% of developmentally delayed women have been sexually assaulted at some point in their lives.[9] For unique cases such as this, you may revisit the discussion at a future visit and ask the patient to bring a trusted family member or caretaker along. While some patients prefer privacy, having another trusted and familiar face present can be helpful in shared decision-making for cases like this. Finally, utilize your resources to ensure the comfort of the patient should she decide to proceed with Pap testing. Social workers, case workers, care managers, psychosocial specialists, and others trained in integrative medicine techniques are helpful to provide support, explanation at the patient's level of understanding, deep breathing exercises, guided imagery and more. If you do not have these resources readily available in your clinic, you can use guided imagery, deep breathing, and meditation videos online – Johns Hopkins All Children's Hospital and University of Minnesota Center for Spirituality and Healing have particularly helpful videos at no cost.[10,11]

A common theme throughout these recommendations is the ethical assessment of beneficence and non-maleficence – how to best serve our patients by providing a health benefit, while also doing our best to prevent inflicting harm. Oftentimes shared decision-making is recommended to discuss these risks and benefits with patients.

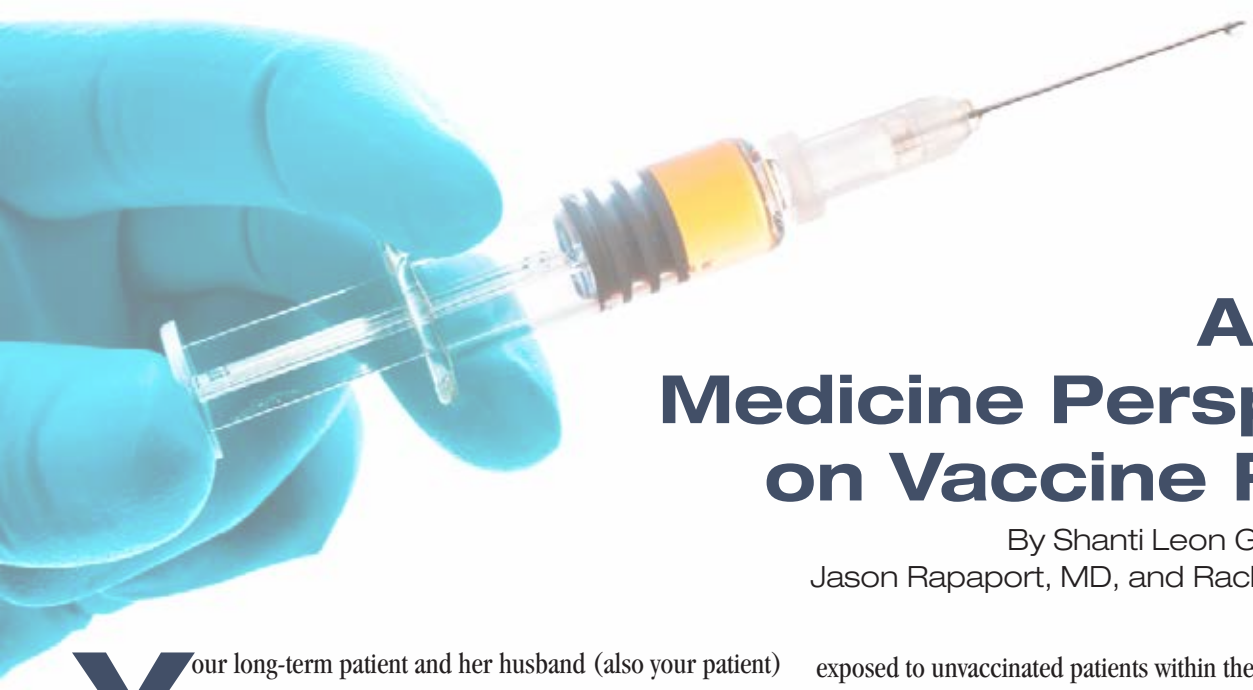
Endnotes

1 Principles of Biomedical Ethics 6th Edition. Beauchamp, Tom L., Childress, James F. 149-151
2 http://www.choosingwisely.org/clinician-lists/asccp-pap-tests-or-hpv-screening-in-women-under-21/
3 http://www.choosingwisely.org/clinician-lists/american-academy-family-physicians-pap-smears/
4 http://www.choosingwisely.org/clinician-lists/american-academy-family-physicians-hpv-testing/
5 http://www.choosingwisely.org/clinician-lists/american-college-obstetricians-gynecologists-annual-cervical-cytology-in-women-30-to-65/
6 http://www.choosingwisely.org/clinician-lists/american-academy-family-physicians-cervical-cancer-screening/
7 http://www.choosingwisely.org/clinician-lists/american-college-preventive-medicine-cervical-cancer-screening/
8 http://www.choosingwisely.org/patient-resources/pelvic-exams-pap-tests-and-oral-contraceptives/
9 Lumley, V., Miltenberg, R. (1997). Sexual abuse prevention for persons with mental retardation. American Journal on Mental Retardation, 101 459-472.
10 Johns Hopkins All Children's Hospital "Guided Imagery" https://www.youtube.com/watch?v=35ch88kmlls (15 April 2016)
11 UMNCSH "Guided Imagery for Stress Relief" https://www.youtube.com/channel/UCdq-wtHzlN9jS7l1e9j9yrQ (14 May 2010)

Sonya K. Narla DO, MA *is a PGY2 family medicine resident at the University of Rochester/Highland Hospital program, where she is on the global health track and is pursuing a focused area of interest in integrative medicine. Other interests include OMT, narrative medicine, and medical ethics. She earned her master's degree in bioethics from Case Western Reserve University.*

Lauren E. Nicholls, MD, *is a third year family medicine resident at the Highland Hospital/University of Rochester program. She sees her continuity panel at Jordan Health, Brown Square Health Center, an inner-city FQHC. Her medical interests include under-served care, appropriate/equitable use of resources, and resident wellness, and she plans to pursue a fellowship in palliative care and hospice.*

Colleen T. Fogarty, MD, MSc, FAAFP *is an Associate Professor of Family Medicine at the University of Rochester, Department of Family Medicine, where she is Medical Director of the Highland Family Medicine practice and Associate Chair for Clinical Practice and Interprofessional Education. She directs the Finger Lakes Center for Primary Care Clinician Education, as well as the Department of Family Medicine Faculty Development Fellowship. She is a member of NYSAFP and a Fellow of the AAFP.*



A Family Medicine Perspective on Vaccine Refusal

By Shanti Leon Guerrero, MD, MPH; Jason Rapaport, MD, and Rachel Rosenberg, MD

Your long-term patient and her husband (also your patient) are excited that their daughter and grandson are moving back to New York, and that you can now be the doctor for the whole family. You gladly accommodate the four-year-old boy on your schedule for a new patient visit and physical exam. But when you ask the child's mother if she brought his vaccine record, she shifts in her chair and informs you that she doesn't believe in vaccinating. When you gently probe her on her reasons, she tells you that she believes that vaccines contain dangerous chemicals and can cause a variety of problems in children, including autism and attention deficit hyperactivity disorder. As you try to explore these beliefs, she looks up at you and says firmly, "Doc, you're not going to change my mind on this. I'm not letting him get any vaccines."

What do you do?

Background

In recent years, there has been a dramatic increase in vaccine refusal rates and a subsequent re-emergence of vaccine-preventable infectious diseases that had previously been nearly eliminated in the United States.[1] Most notably, there have been several large outbreaks of measles in recent years, after a fraudulent research study falsely linked the measles-mumps-rubella (MMR) vaccination to autism.[2] Cases of pertussis have also been on the rise. Unfortunately, young and immunocompromised patients are at the highest risk of death from these highly contagious diseases.[3]

As vaccine refusal rates have been rising, there has been an effort from some physicians and patient advocacy groups to dismiss or exclude non-vaccinated children from primary care offices. These groups argue that patients who are young, are immunocompromised, or have a medical contraindication to vaccination should not be exposed to unvaccinated patients within the physician's office. In recent years, there have been many reported cases of vulnerable patients getting exposed to vaccine-preventable diseases in the health care setting. In one example, a young, immunocompromised patient undergoing chemotherapy for acute lymphoblastic leukemia was exposed to a patient with measles while at an office appointment, subsequently requiring observation under isolation for weeks.[4] The concern for interpatient transmissibility is of particular relevance to family physicians, whose practices include a wide range of susceptible patients, including young children, pregnant women and the elderly.

The larger specialty societies have an important voice in guiding the medical community regarding this challenging quandary. While the American Academy of Family Physicians (AAFP) has no recommendation statement to date on the dismissal of vaccine refusing families, the American Academy of Pediatrics (AAP) has developed recommendations on this issue. Last year, the AAP released a statement that endorsed the right of physicians to discharge patients whose families repeatedly refuse vaccination, although only as a last-ditch effort when rigorous attempts at physician engagement and education have failed.[5] The authors of this statement point out that in addition to the medical and public health reasons for considering dismissal, persistent vaccine refusal represents a foundational rupture in the dynamic between patient and physician that would permanently damage their working relationship and impair the ability to provide care in the future.[6]

The Family Medicine Perspective

Family doctors are in a unique situation with regards to the challenge of caring for vaccine-hesitant families. The "cradle-to-grave" philosophical foundation of family medicine is rooted in the mission

of caring for patients throughout their lifetime. The strength of the physician-patient relationship is enriched by the FP's ability to provide for multiple generations of a family. The dismissal of vaccine refusers may terminate care not only for the child, but also the parents, siblings, grandparents, or other loved ones that may also be on the provider's panel. The impact that this may have on the overall health of the entire family has the potential to be monumental, especially if the FP has been the primary care provider for years or if other family members have multiple or complex medical conditions.

There are additional important ethical challenges to patient dismissal when considering the important role FPs play in expanding access to populations with social, economic, or geographic barriers to care. Family doctors are essential components of the healthcare infrastructure in many underserved areas across the country, and children are an important group that benefit from the increased access to care that they provide. A 2005 report found that FPs perform 16-21% of child visits in the country, and serve as PCPs for up to one third of the country's child population.[7] This report also found that FPs care for a disproportionate number of rural, uninsured, and publicly insured patients.[7] Dismissal of patients due to vaccine refusal may lead to complete lack of reasonable access to healthcare for some of the country's most vulnerable children and families. Moreover, refusal to care for these patients may also create a larger pool of unvaccinated patients in another provider's panel, unfairly increasing the risk of contracting vaccine-preventable diseases for all patients in that practice.

Dismissal policies edge towards a slippery slope of physicians passing judgment on patients who do not comply with their recommendations. As primary care physicians, we discuss health behaviors on a daily basis with the goal of promoting health and preventing disease. Routine vaccinations are an essential cornerstone of preventive health care for children and an important part of family practice in many communities. However, the broader scope of family medicine means that FPs are often confronted with patients who fail to comply with medical recommendations to quit smoking, lose weight, use reliable contraception, undergo routine cancer screening, etc. If dismissal is considered acceptable for patients who are noncompliant with vaccinations, where should the line be drawn for other noncompliant patients?

A Harm Reduction Approach

In family medicine, we are dedicated to improving the health of *all* our patients. So how do we protect our patients who are vulnerable to infectious disease because of young age or immune-compromised status while still ensuring that children whose parents refuse to vaccinate get medical care? We can consider a harm reduction approach. For example, a family medicine office could set aside a particular session during the week where non-vaccinating patients can be seen, and during which time no potentially vulnerable patients will be seen. Family physicians can reassure families that they are willing to work with alternate vaccine schedules, even though we know that these schedules are not evidence based and are often constructed by the people who fuel the vaccine-refusal movement.

In family medicine, we are accustomed to having difficult conversations and working with patients who do not follow our recommendations. We are committed to promoting the health of patients, families and communities. We can use our creativity, patient-centeredness and longitudinal perspective to ensure that all of our patients, including those whose parents refuse vaccines, can achieve their best possible health.

Endnotes

1 Boom J., Cunningham R. (2014) Current Trends in Vaccine Hesitancy and Refusal. In: Understanding and Managing Vaccine Concerns. SpringerBriefs in Public Health. Springer, Cham.
2 Siddiqui M, Salmon DA, Omer SB. Epidemiology of vaccine hesitancy in the United States. Human Vaccines & Immunotherapeutics. 2013;9(12):2643-2648. doi:10.4161/hv.27243.
3 Sammons JS. Ready or Not: Responding to Measles in the Postelimination Era. Ann
4 Intern Med. 2014;161:145–146. doi: 10.7326/M14-0892. http://annals.org/aim/article/1865449/ready-responding-measles-postelimination-era. Accessed 3 August, 2017.
5 Jacks, T. "To the Parent of the Unvaccinated Child Who Exposed My Family to Measles".
6 Mother Jones, 2 February 2015. Accessed 3 August, 2017. http://www.motherjones.com/ environment/2015/02/open-letter-parent-unvaccinated-child-measles-exposure/
7 Edwards KM, Hackell JM, AAP The Committee On Infectious Diseases, The Committee
8 On Practice And Ambulatory Medicine. "Countering Vaccine Hesitancy". Pediatrics. 2016;138(3):e20162146. PubMed. Accessed 3 August, 2017.
9 Alexander K, Lacy TA, Myers AL, et al. Should Pediatric Practices Have Policies to Not
10 Care for Children With Vaccine-Hesitant Parents? Pediatrics. 2016;138(4):e20161597, PubMed. Accessed 3 August, 2017
11 Phillips RL Jr., Dodoo MS, McCann JL, et al. Report to the Task Force on the Care of
12 Children by Family Physicians. Washington, D.C.: Robert Graham Center;2005.

Shanti Leon Guerrero, MD, MPH, *is a third year family medicine chief resident at the Institute for Family Health- Harlem/Mount Sinai residency. She plans to practice full-spectrum family medicine with obstetrics in the future while continuing to advocate for the underserved and for a single-payer health system.*

Jason Rapaport, MD, *is a third year family medicine resident at the Institute for Family Health -Harlem/Mount Sinai residency.*

Rachel Rosenberg, MD, *is a faculty member and assistant program director at the Institute for Family Health -Harlem/Mount Sinai residency.*

Another Perspective

By James Cozens, MBBS

Editor's Note: At the NYSAFP Congress of Delegates in June of 2017, the NYSAFP membership supported resolutions in support of expanding end-of-life options for patients.

The 1997 Supreme Court decision in Washington vs Glucksberg[1] leaves physician assisted death to the purview of the states. Now five states (Oregon[2], Washington[3], Vermont[4], California[5], Colorado[6]) and the District of Columbia[7] have passed laws permitting physicians to prescribe lethal medications to patients. In January 2017 the "Medical Aid in Dying Act" was put before the Assembly here in New York.[8] All of the existing laws, as well as the proposed law before the New York Assembly, specify that the patient must have a terminal illness (six months prognosis), the patient must not be suffering from mental illness, and the doctor cannot administer a lethal injection but may instead prescribe a pill that the patient can swallow themselves.

The proposed New York law includes the following statement: "The highly publicized, planned death of Brittany Maynard has highlighted the need for terminally ill patients to be able to access aid in dying. Ms. Maynard, who was a native of California, was forced to move to Oregon to gain control of her dying process. Her death, and the accompanying press attention, led the California legislature to pass, and Governor Jerry Brown to sign, an aid in dying law on October 5, 2015."[8]

While the story of Brittany Maynard influenced the passing of the "End of Life Option Act" in California, the harrowing story of Harold Shipman in an opposite manner has affected the legality of physician assisted death in the United Kingdom. As an English medical graduate, now in my final year of a family medicine residency in New York State, I want to share my perspective on this topic highlighting events in Europe and Canada that I believe inform the New York debate.

"Few doctors have had as great an impact on British medicine as Harold Shipman", reads the opening line of his obituary in the British Medical Journal.[9] When Dr. Shipman was found hanging by his bed sheets from his prison cell window bars on the morning of January 13, 2004, he was the last in a long line of deaths at his own hands. He had been convicted of the murder of 15 patients in 2000, and was sentenced to life imprisonment with no possibility of release.[10] Subsequent investigation in 2001 concluded that Dr. Shipman had "unlawfully killed" 215 patients, and real suspicion remained over 45 others.[11]

His conviction followed the sudden and unexpected death of an 81 year old woman in 1998. In this case Dr. Shipman had forged a new will for the patient which left her entire estate to him. Her daughter informed the police of her suspicions and her mother's body was exhumed for post mortem. Concentrations of morphine were detected in her body consistent with levels previously known to have caused death by morphine overdose. Dr. Shipman was arrested on suspicion of murder, of attempting to obtain property by deception, and of forgery. Subsequently the police exhumed additional bodies and eventually Shipman was charged with the murder of 15 of his patients. At his trial Dr. Shipman pleaded not guilty to the 15 counts of murder, and one count of forgery, and was ultimately convicted on all counts. "None of your victims realized that yours was not a healing touch. None of them knew that in truth you had brought her death, death which was disguised as the caring attention of a good doctor" the judge declared when delivering the sentence.[10]

The "Shipman Inquiry" was launched after Shipman's conviction. After the Inquiry, the high court judge concluded: "In the 24 years during which Shipman worked as a doctor, I have found that, in addition to the 15 patients of whose murder he was convicted, he killed 200 patients. In a further 45 cases, there is real cause to suspect that Shipman might have killed the patient".[11] A pattern of killing emerged from the Inquiry; he would usually visit an elderly patient at home, administer an intravenous or intramuscular injection of strong opiate, and then use various methods of deception and forgery of medical records to cover up his role in the death.[12]

Since the events of Dr. Shipman were uncovered, many of the patients in the United Kingdom lost faith in the concept of a trustworthy general practioner[13] and demanded that the government ensure greater protection for patients from any physician that would seek to harm rather than help them.[14] Even acting against the law this single doctor managed to kill hundreds of patients against their will over decades. If physician assisted death were to be legalized, the potential for far more instances of similar behavior is seen by many in England as too great a risk to take.

Meanwhile, legislation in some European countries has increasingly been interpreted to allow physician assisted death in many more situations than originally intended. In 2016, Belgium's "Federal Commission on the Control and Evaluation of Euthanasia" reported that patients without a terminal disease, such as mentally ill patients suffering with depression, are receiving physician assisted death, and concluded that the practice is permissible under current laws in Belgium. Those permitted in Belgium included both lethal injection administered by a doctor, and pills that patients choose to take themselves.[15, 16]

Swiss law neither prohibits nor specifically permits either euthanasia or physician assisted suicide. As a result physician assisted death occurs in that country without criminal recompense, and there are not clear guidelines or limitations to its use. A clinic in Berne called "Dignitas" offers physician assisted suicide to people living outside of Switzerland. Since its opening in 1998, more than 100 people from the United Kingdom have ended their lives there.[17]

In 2008, a 23 year old English man who had been paralyzed from a cervical spine sports injury a year earlier travelled to Switzerland to die at the Dignitas clinic. He was "not prepared to live what he felt was a second class existence".[17] His parents, who had accompanied him, were faced with a criminal investigation on their return to the United Kingdom. The case was the first time the Crown Prosecution Service has considered a case on the "aiding, abetting, counseling, or procuring the suicide of another" relating to the Dignitas clinic.[18] It was ultimately decided that it was "not in the public interest" to press charges, and guidelines were revised following the case which state that "a family member is unlikely to be prosecuted for helping a loved one die if they were motivated by compassion".[19]

In Canada, the 2016 "Medical Assistance in Dying" Act legalized both physician assisted suicide (where the patient takes lethal medication themselves) and voluntary euthanasia (where the physician administers a lethal injection at the request of the patient). The Canadian law allows medical assistance in dying for patients without a terminal diagnosis, but requires that they have a "grievous and irremediable medical condition". A grievous and irremediable medical condition is defined as a serious illness/disease/disability in an advanced state of decline that cannot be reversed, associated with unbearable physical/mental suffering, and the patient "must be at a point where natural death has become reasonably foreseeable".[20]

The Medical Assistance in Dying Act in Canada has been interpreted to permit physician assisted death to non-terminal elderly patients who have requested it. In 2016, a family physician in Canada legally administered a lethal injection of sedatives to a 94 year old patient in his home. The patient had been recently hospitalized with pneumonia and heart failure exacerbation, had experienced frequent hospitalizations, but had no terminal disease to give a prognosis of less than 6 months. As the patient had decided to refuse future life prolonging treatments according to an advance directive, his natural death was considered "reasonably foreseeable". It was his own interpretation of "unbearable suffering" that was considered to meet the criteria, rather than an objective assessment of the symptoms caused by his medical conditions. He had capacity, and expressed a voluntary wish to die, citing he was unwilling to receive "assisted care", and was now unable to live at home independently. He had felt that he was a burden, and was lonely since his wife's death.[21]

As legislation on physician assisted death has been passed in various countries, as well as states within the United States, there is growing pressure on lawmakers in New York to liberalize laws on the practice. Legalizing physician assisted suicide would require that our society could trust that doctors ending the lives of others were acting within the mandate they had been given. I highlight the case of Harold Shipman as a serial killer who appeared to his patients as a doctor to be trusted, but as we see in hindsight took advantage of a society's trust in committing multiple atrocities. What is especially chilling is that, other than the final murder where he forged a will, he appears never to have sought material gain from the murders. He never admitted his guilt, but seems to have felt he was doing the right thing in ending the lives of the elderly under his care.

The trends in the laws in Belgium illustrate that although initially stringent restrictions on physician assisted death are put in place, when practitioners widen access beyond those restrictions a loosening of the guidelines tends to occur, rather than the initial rules being upheld. In Canada, the new law seems to have already been interpreted to allow patients to access physician assisted death outside of the scope that the practice was intended by the original law-makers, again without practitioners facing prosecution. In the United Kingdom, those that aid patients in travelling to Switzerland for the procedure do not face prosecution, although the practice remains against the law. Switzerland is a case study of a society with a complete lack of regulation, where physician assisted death is available to international customers for a fee.

As physician assisted dying becomes more acceptable in societies, I am concerned that the risk of coercion of the sick and disabled towards choosing such a death may increase. The feeling of being a burden, as well as the perpetual struggles with loneliness and chronic disease in an aging population my lead to inappropriate requests for physician assisted death. The dramatic example of Dr. Shipman shows that there is always the risk that someone may be willing to exploit the trust society gives them and cause intentional harm to patients without their consent. In a society where self-determination has become so important, the desire to "gain control" of the dying process as Brittany Maynard wanted, may lead us towards a future that we never intended.

Within the United States, physician assisted death seems to have been administered to date according to the state laws, to patients with terminal illness in the absence of mental illness, and hasn't involved lethal injection. It may prove that if legalized in New York, the practice would only be used by caring physicians with the intent of relieving patient suffering, and with the informed consent of those competent to make their own decisions. When we consider that some individuals desire increased autonomy in choosing the timing of their death, I wonder how we can balance that with the autonomy of others who want to be reassured that no one would ever be in a position to hasten death against their will.

As for my own practice, "I will not give a lethal drug to anyone if I am asked, nor will I advise such a plan" in the words of the Hippocratic Oath[22], and I urge the reader to carefully consider the consequence of so doing.

continued on page 24

Endnotes

1 https://supreme.justia.com/cases/federal/us/521/702/case.html

2 http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignity Act/Documents/statute.pdf

3 http://apps.leg.wa.gov/RCW/default.aspx?cite=70.245&full=true

4 http://www.leg.state.vt.us/docs/2014/Acts/ACT039.pdf

5 https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201520162AB15

6 http://www.sos.state.co.us/pubs/elections/Initiatives/titleBoard/filings/2015-2016/145Final.pdf

7 http://lims.dccouncil.us/Download/33261/B21-0038-Introduction.pdf

8 http://assembly.state.ny.us/leg/?default_ 9 BMJ 2004 Jan 24: 328(7433): 231 DOI: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC318504/

9 http://webarchive.nationalarchives.gov.uk/20090808163959/http://www.the-shipman-inquiry.org.uk/fr_page.asp

10 11 http://webarchive.nationalarchives.gov.uk/20090809051504/http://www.the-shipman-inquiry.org.uk/fr_page.asp?ID=187

11 http://webarchive.nationalarchives.gov.uk/20090809051507/http://www.the-shipman-inquiry.org.uk/fr_page.asp?id=188

12 http://webarchive.nationalarchives.gov.uk/20090809051509/http://www.the-shipman-inquiry.org.uk/fr_page.asp?id=192

13 Medico-Legal Journal 2015, Vol. 83(3) 115 http://journals.sagepub.com/doi/abs/10.1177/0025817215601931

14 https://www.lachambre.be/flwb/pdf/54/2078/54K2078001.pdf

15 https://www.washingtonpost.com/opinions/europes-morality-crisis-euthanizing-the-mentally-ill/2016/10/19/c75faaca-961c-11e6-bc79-af1cd3d2984b_story.html?utm_term=.7d4177dc2dbd

16 https://www.theguardian.com/uk/2008/oct/18/11

17 http://www.telegraph.co.uk/news/majornews/3689907/Parents-of-rugby-player-in-Dignitas-assisted-suicide-will-not-face-charges.html

18 http://www.telegraph.co.uk/news/uknews/8536475/Daniel-James-GP-knew-he-would-go-to-Dignitas-but-did-not-tell-police.html

19 https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html

20 http://www.nationalpost.com/m/wp/news/canada/blog.html?b=news.nationalpost.com/news/canada/the-right-to-die-on-ones-own-terms-at-94-sick-tired-and-living-alone-dad-got-the-death-he-wanted

21 https://www.nlm.nih.gov/hmd/greek/greek_oath.html

James Cozens, MBBS *is a third year family medicine resident at Albany Medical Center. Originally from England, he received his medical degree from the University of Nottingham. His medical interests include bioethics, patient advocacy, hospital medicine, palliative care, and geriatrics.*

The Impact of Religious Beliefs on Medical Decision Making

By Afnan Haq, MD, and Nada Al-Hashimi, MD

In a multi-cultural New York, we have patients from different ethnicities and religions, with differing sets of set of values, all of which influence their health-beliefs and health-care practices, methods of communication and decision making skills.

Most world religions also have dietary restrictions. Judaism and Islam prohibit any swine products while Hinduism abstains from using bovine products. Jehovah's witnesses do not believe in the usage of blood products.[1,2] Many people are vegetarian or vegan for religious reasons although that is certainly not always the case. These dietary restrictions are often not considered in healthcare management, although they can have a significant impact. It is important for physicians to consider a patient's religious beliefs when making a healthcare decision. This empathetic approach enhances a trusting patient-physician relationship.

It is the role of a primary care physician to promote proper diet for patients. Vegans have to supplement meat with other forms of proteins such as grains, beans and nuts. While supplementing proteins is an easy solution, it becomes complex when it comes to medication management. More than 1000 medications contain inactive ingredients derived from animal sources. In a study assessing compatibility of medications with Islamic practice, 23.8% of medications were considered impermissible and 57.1% were questionable based on the ingredients.[3] Lactose from cow's milk is used as filler in medications.[4] Vegans do not believe in consuming milk products derived from cows. Gelatin is also one of those ingredients and is often derived from connective tissues of pigs or cows, when making the shell in capsules.[2] Most practicing Muslims or Jews will choose the non-capsule form of the same medication for this reason.

Other inactive ingredients frequently found in medications are ethanol and stearic acid. Alcohol is prohibited in Islam, while stearic acid, derived from bovine fat, is used for lubrication in tablets.[2] In other cases, the active ingredient in a medication contains animal products. Heparin, a common injectable used in hospitals, is extracted from porcine intestinal mucosa or bovine lung.[8] These are just a few examples of drugs containing animal products.

If a situation arises where a patient cannot take a medication for personal or religious beliefs, the physician should open up a discussion about an alternative, if there is one. Inactive ingredients vary based on brand and a generic brand might not have the inactive ingredient. Even if it does, in the case of a gelatin capsule, the active solute can sometimes be sprinkled on food or a stearic containing tablet can be replaced with an injectable.[2] It is generally easier to find alternatives for medications with a prohibited inactive ingredient than those with a prohibited active ingredient.

Active ingredients with animal products can be replaced with plant-based products. There are "Halal pharmaceuticals", which produce drugs free from constituents prohibited in Islam. They are mostly plant based and Tayyib, a term given to products which meet Islamic quality standards.[4] It is crucial to educate patients about available treatment options, but also important for physicians to educate themselves about the ingredients in drugs. Manufacturers can provide a list of medications with ingredients which contain animal products.[2,7] The U.S. Food and Drug Administration also has a database with the active and inactive ingredients of FDA-approved medications which is updated quarterly.[9] Pharmaceutical sessions at national conferences are another good source for this kind of information.

Although some religions prohibit certain animals, many still uphold the sanctity of humans. For Judaism and Islam, if an alternative medical therapy option is not available, the use of swine products for life-saving measures is allowed, while Hindus are allowed to use products from a living cow.[5,6] Research has shown that with proper counseling and education about treatment options, patients of these religious groups are often willing to use a swine or bovine derived products.[5,6] It is crucial to have this discussion with patients, especially in life-threatening circumstances.

In some situations, a patient might refuse treatment for religious reasons even if it is a life-saving measure. Physicians should provide the patient and family with adequate information on the consequences of this decision, and allow ample time to make their decision if possible. In many cases, patients and family refuse regardless. A physician's beneficent duty to uphold the patient's best interest is important, however, it does not override autonomy.[9] While major changes have occurred in medical ethics with decision making shifting from health care providers to patients and family members, accepting this is easier said than done. Especially when a physician knows that a patient's disease is curable with medications. However, as long as the patient has decision making capacity, we need to respect the patient's decision.

New York is a very diverse state with people from many different backgrounds, and religious beliefs play a key role in medical decision making, especially in medication management. Educating both themselves and their patients about ingredients in common medications will demonstrate respect, and greatly enhance a physician's relationship with their patients.

Endnotes

1 Muramoto O. Bioethical aspects of the recent changes in the policy of refusal of blood by Jehovahs Witnesses. Bmj. 2001;322(7277):37-39. doi:10.1136/bmj.322.7277.37.

2 Hoesli T, Smith K. Effects of Religious and Personal Beliefs on Medication Regimen Design. ORTHOPEDICS. 2011; 34: 292-295. doi: 10.3928/01477447-20110228-17

3 Sarriff A, Abdul razzaq HA. Exploring the Halal Status of Cardiovascular, Endocrine, and Respiratory Group of Medications. The Malaysian Journal of Medical Sciences : MJMS. 2013;20(1):69-75.

4 Tatham K. Suitability of common drugs for patients who avoid animal products. BMJ. 2014;348:g401. doi:https://doi.org/10.1136/bmj.g401 .

5 Easterbrook C, Maddern G. Porcine and Bovine Surgical ProductsJewish, Muslim, and Hindu Perspectives. Arch Surg. 2008;143(4):366-370. doi:10.1001/archsurg.143.4.366

6 Eriksson A, Burcharth J, Rosenberg J. Animal derived products may conflict with religious patients' beliefs. BMC Medical Ethics. 2013;14:48. doi:10.1186/1472-6939-14-48.

7 Pellegrino E, omasma D. e Con ict between Autonomy and Beneficence in Medical Ethics: Proposal for a Resolution. Journal of Contemporary Health Law & Policy. 1987;3(1):23-46.

8 Tovar AM, Teixeira LA, Rembold SM, Leite M, Lugon JR, Mourão PA. Bovine and porcine heparins: different drugs with similar effects on human haemodialysis. BMC Research Notes. 2013;6:230. doi:10.1186/1756-0500-6-230.

9 Food and Drug Administration database. Inactive Ingredient Search for Approved Drug Products: Frequently Asked Questions. https://www.fda.gov/drugs/informationondrugs/ucm080123.htm#updates Updated July 14, 2017. Accessed September 17, 2017

References

Lie R. The Ethics of the Physician-Patient Relationship. Ethical Perspectives. 1997;4(4):263-270. doi:10.2143/ep.4.4.562990.

McCord G, Gilchrist VJ, Grossman SD, King BD, McCormick K, prandi A. Discussing Spirituality With Patients: A Rational and Ethical Approach. Annals of Family Medicine. July 2004:356-361. doi:10.1370/afm.71.

Afnan Haq, MD, *grew up in Queens, New York. She attended New York Institute of Technology (NYIT) and majored in biology. She attended medical school in Grenada, receiving her medical degree in 2017. She is currently completing her MBA at St. George's University and applying to residency programs.*

Nada Al-Hashimi, MD*, graduated from University of Baghdad with her medical degree. She completed her residency in family medicine at The Brooklyn Hospital Center where she was chief resident. Dr. Al-Hashimi is an attending physician in the Brooklyn Hospital Center and is board certified in family medicine.*

Game Changer: Update on HIV Pre-Exposure Prophylaxis for Minors in New York State

By Katie Lynch, MD, MA; Brooke A. Levandowski, PhD, MPA; Monica Barbosu, MD, PhD; Thomas Fogg, MS, MPH; Ivelisse Rivera, MD; and Timothy Dye, PhD

Introduction

New York State (NYS) continues to battle the relentless epidemic of HIV/AIDS. In 2015, an estimated 3,123 New Yorkers seroconverted, ranking NYS fourth among all states in new diagnoses.[1] Adolescents and young adults are at high risk of acquiring the virus. In NYS, individuals 24 years and younger account for 19.4% of new HIV/AIDS diagnoses.[2]

The risk of HIV/AIDS acquisition is increased for sexual, gender, racial, and ethnic minorities. Nationally, 30% of new HIV infections occur in men who have sex with men (MSM) under the age of 24, with 78% of those infections occurring in young MSM of color.[3] A modeling study by Matthew et al. (2016) predicts that 40% of Black/African American MSM will be HIV positive by the time they reach 30 years of age.[4]

Despite these data, optimism remains. Owing, in part, to the End the Epidemic Initiative (EtE2020) launched in 2014, NYS has had a 31% decrease in HIV incidence between 2009 and 2015.[2] In addition to identifying persons with HIV, linking and retaining patients in care, and maximizing viral suppression, the EtE2020 initiative calls for increased access to Pre-Exposure Prophylaxis (PrEP) for HIV.[5]

NYS Department of Health regulations have recently changed to further support these initiatives. Effective April 12, 2017, minors in NYS can legally access PrEP and HIV treatment without parental consent.[6] This paper explores medical, ethical, and practical implications relevant to this change, focusing on the provision of PrEP for HIV prevention in persons under 18 years of age.

Medical Considerations

In 2012, the Food and Drug Administration approved a combination pill containing 200mg of tenofovir disoproxil fumarate (TDF) and 300mg of emtricitabine (FTC) as the first medication used as PrEP.[7] When used for PrEP, Truvada is indicated for daily use in 'adults,' without specification of age of adulthood.[7] In contrast, Truvada has been used to treat HIV in patients 13 years and older since 2004.[8]

Efficacy and Adherence

Overall, Truvada has demonstrated efficacy ranging from 44%-92% among adult MSM, transgender women, natal women, intravenous drug users, and heterosexual populations.[9–12] However, efficacy is highly dependent upon adherence. In three randomized control trials providing age-stratified data, no significant difference in efficacy was found between participants aged 18-24 years and those 25 years and older.[8] However, a meta-regression analysis did show decreased overall efficacy in young adult populations, thought to be due to lack of adherence.[13] For example, only 12% of participants in the FEM-PrEP trial were found to be consistently adherent.[14] Current studies are ongoing to measure the level of adherence in adolescents aged 15-19; preliminary data demonstrate similar adherence challenges.[15,16]

These data suggest that adolescents and young adults may have difficulties with adherence. As PrEP becomes commonly prescribed for adolescents, innovative approaches to increasing adherence will emerge. High rates of mobile phone use among youth might provide a unique opportunity to offer support, provider-patient dialogue, pill tracking, follow-up reminders, and adherence interventions specifically tailored for this population.[17] There are currently a myriad of apps available for contraceptive reminders, which could be adapted. In the interim, prior PrEP trials with low adherence can offer practical lessons. Adherence has been bolstered by personal interest in HIV risk reduction, knowledge of PrEP efficacy, the formation of routine, partner support, contraceptive method choice, and adherence counseling.[18,19] As providers expand PrEP to adolescents without requiring parental consent, it is critical to address the importance of adherence in offering protection against HIV infection.

Safety

Truvada is a well-tolerated, safe medication.[20] Many patients report a "start-up syndrome" which may include gastrointestinal upset and headache, typically resolving by 3 months of use.[20] Two subclinical, reversible adverse events have been reported in adult study participants: decline in kidney function and bone mineral density (BMD) loss.[20] The risk of kidney function decline in adults is mitigated by the recommended regular monitoring of creatinine clearance while on Truvada.[20]

Less is known about long term effects of Truvada in youth. Two studies in young MSM did not demonstrate renal toxicity in participants.[21,22] Decrease in bone mineral density appears to impact participants regardless of age. In the ATN 110 trial, participants began the study with lower than average BMD, and, while no significant bone fractures or events occurred, BMD Z scores declined over time.[21] Havens et al. report similar results, in addition to noting a decrease in cortical BMD primarily.[22] Serum markers consistent with endocrine dysfunction were theorized as the likely driver of the BMD loss.[22] Vitamin D supplementation may prove protective.[22] Further study is necessary to test this hypothesis, and to determine the long-term effects of PrEP on renal function and BMD among adolescents and youth.

Ethical Considerations

Age and Informed Consent

Informed consent is a foundational element of bioethics. While the practical success of informed consent has been challenged[23], it remains our best method of centering the oft-competing four principles of medical ethics: autonomy, beneficence, non-maleficence, and justice. The practice carries greater significance when treating vulnerable populations such as children, however, the age at which children can consent is debated. The legal age of consent for most medical procedures is 18, however, recent empirical research demonstrates that adolescents as young as 13 are capable of making adult-level decisions when offered age-appropriate education.[24–26] Parental participation and family-based approaches to HIV prevention are preferable[27] and recommended by the NYS Department of Health.[28] However, when not feasible, clinicians can be assured that youth under the age of 18 are capable of providing informed consent on issues related to their sexual health.

Key Populations

As in adults, ethnic, racial, gender and sexual minority youth are at high risk for acquiring HIV.[17] Poverty, drug use, and sex work can compound these risks.[17] Complicating this picture further, high risk youth are also more likely to face family rejection, leading to additional health problems and barriers to care.[29] Qualitative research has shown that adolescent MSM whose parents are unaware of or reject their sexual identity will refuse to participate in HIV prevention-related research when guardian permission is required.[30] In some cases, this refusal may be well justified. One participant in the ATN 110 trial reported being threatened with eviction from their home by a parent due to use of PrEP.[21] Despite the elevated risk and lack of family support, there is strong evidence that these high-risk populations would be interested in using PrEP, particularly when it is affordable, readily available, and offered alongside personally relevant information and age-appropriate education.[3,31]

Practical Considerations

On April 12th, 2017, HIV was re-classified by the NYS Department of Health as a sexually transmitted infection.[6] As such, un-emancipated minors have now gained the ability to self-consent to HIV prevention and treatment. While this is a major advance for progressive HIV/AIDS policy, barriers to access remain. First, Truvada has been approved for prevention of HIV in adults only. While no age-limit is specified, use of Truvada for prevention in minors may be considered off-label. This off-label designation is important when helping a minor patient pay for the medication, as Gilead will not offer co-pay coupons or enrollment in their medication assistance program if the patient is under 18 years of age.

Second, Truvada is used both for prevention and treatment of HIV. Generally speaking, private insurance companies will cover Truvada for Prep, including for minors. However, insurance companies commonly require prior authorization to ensure that the patient has been tested for HIV and is HIV negative. This proves that the use of Truvada alone does not indicate the mismanagement of HIV, which would require the use of the remainder of an effective HAART regimen.

Lastly, and significantly, minors may be concerned about parental notification through explanation of benefits (EOB) statements. If a patient is insured through their parents' private insurance, it is possible to ask that the monthly EOBs be sent to a separate address. Unfortunately, this is not always successful. If a patient is insured through Medicaid, it is his or her name on the EOB, not his or her parent's name. Therefore, there is a greater chance that a request to send the EOB to another address will be honored.

Conclusion

Adolescents are at high risk for HIV [2,32] Health disparities associated with intersectional identities compound this risk for sexual, gender, ethnic, and racial minorities, and those living in poverty of engaging in drug use or sex work.[17] Fortunately, PrEP is a safe, effective method of preventing HIV.[20] As many minors are unwilling or unable to discuss their HIV risk factors with their parents, the recent NYS Department of Health decision to allow minors to consent to PrEP is a productive step forward.

However, more research is needed to evaluate the efficacy and adverse events associated with Truvada use in minors, and to develop youth-specific interventions to improve adherence. Moreover, cost and insurance coverage are significant barriers that must and will be addressed.

Endnotes

1 New York – HIV/AIDS 2015 State Health Profile.; 2015. https://www.cdc.gov/nchhstp/stateprofiles/pdf/new_york_profile.pdf.

2 New York State Department of Health AIDS Institute Bureau of HIV/AIDS. New York State HIV/Aids Annual Surveillance Report For Cases Diagnosed Through December 2015.; 2017.

3 Golub SA, Gamarel KE, Lelutiu-Weinberger C. The Importance of Sexual History Taking for PrEP Comprehension Among Young People of Color. AIDS Behav. 2017. doi:10.1007/s10461-016-1512-9.

4 Matthews DD, Herrick AL, Coulter RWS, et al. Running Backwards: Consequences of Current HIV Incidence Rates for the Next Generation of Black MSM in the United States. AIDS Behav. 2016. doi:10.1007/s10461-015-1158-z.

5 New York State Department of Health. 2015 Blueprint for Achieving the Goal Set Forth by Governor Cuomo to End the Epidemic in New York State by the End of 2020.; 2015.

6 Katherine Ceroalo. Expansion of Minor Consent for HIV Treatment Access and Prevention.; 2017.

7 Commissioner O of the. Consumer Updates - FDA Approves First Medication to Reduce HIV Risk. https://www.fda.gov/ForConsumers/ConsumerUpdates/ucm311821.htm. Accessed September 18, 2017.

8 Allen E, Gordon A, Krakower D, Hsu K. HIV preexposure prophylaxis for adolescents and young adults. Curr Opin Pediatr. 2017. doi:10.1097/MOP.0000000000000512.

9 Baeten JM, Donnell D, Ndase P, et al. Antiretroviral prophylaxis for HIV prevention in heterosexual men and women. N EnglJ Med. 2012.

10 Choopanya K, Martin M, Suntharasamai P, et al. Antiretroviral prophylaxis for HIV infection in injecting drug users in Bangkok, Thailand (the Bangkok Tenofovir Study): a randomised, double-blind, placebo-controlled phase 3 trial. Lancet (London, England). 2013. doi:10.1016/S0140-6736(13)61127-7.

11 Martin, Michaela, b; Vanichseni, Suphakc; Suntharasamai, Pravanc; Sangkum, Udomsakc; Mock, Philip A.a, b; Leethochawalit, Manojd; Chiamwongpaet, Sithisatd; Curlin, Marcel E.a, b; Na-pompet, Supawadeea; Warapronmongkholkul, Anchaleea; Kittimunkong, Somyote K for the BTSG. The impact of adherence to preexposure prophylaxis on the risk of HIV infection among people who inject drugs. AIDS.

12 P.M. M, C. C, N. M, et al. Efficacy of preexposure prophylaxis for HIV-1 prevention among high-risk heterosexuals: subgroup analyses from a randomized trial. AIDS. 2013.

13 Fonner VA, Dalglish SL, Kennedy CE, et al. Effectiveness and safety of oral HIV preexposure prophylaxis for all populations. AIDS. 2016. doi:10.1097/QAD.0000000000001145.

14 Corneli AL, Deese J, Wang M, et al. FEM-PrEP: Adherence Patterns and Factors Associated With Adherence to a Daily Oral Study Product for Pre exposure Prophylaxis. JAIDS J Acquir Immune Defic Syndr. 2014.

continued on page 39

Ethical Dilemmas in Prenatal Genetic Testing: a Case-Based Approach

By Chen Wang, MD; Dana Schonberg, MD, MPH; Maria Gervits, MD; and Rebecca Williams, MD, MHPE, FAAFP

Introduction

Prenatal testing for genetic disorders, including screening, diagnostic, and carrier testing, is widely available. The American Academy of Family Physicians and American Congress of Obstetricians and Gynecologists recommend all pregnant women be offered prenatal genetic testing by screening or diagnostic testing.[1,2] Prenatal care providers will have many encounters to discuss these tests, but family physicians should also understand the tests and their associated ethical issues. Key ethical principles include: beneficence, non-maleficence, justice, and autonomy. Beneficence describes the duty of the physician to act with the intent of "doing good" for the patient. Non-maleficence describes the duty of the provider to act in a way that minimizes harm. Justice describes the equal distribution of benefit and burden among all groups in society, and autonomy describes the right of the patient to make his or her own medical decisions.[3-5] This article presents common cases in prenatal testing and discusses the ethical principles involved in assisting patients in these decisions.

Then number of available genetic screening tests has exploded since the 1970s ultrasound allowed visualization of anatomic anomalies suggestive of genetic disorders. In the 1980s serum analyte screening became available, and was followed by nuchal translucency in 2003.[6] In 2011 non-invasive prenatal testing (NIPS), also known as cell free DNA (cfDNA) became available. A brief summary of screening modalities is described in Table 1.

Table 1. Common Screening Tests for Aneuploidy[7]

Name	Components	GA Range (weeks and days)	Detection Rate for Trisomy 21 (%)	Screen Positive Rate* (%)	Advantages	Disadvantages
Nuchal Translucency	US only	10-13w6d	64-70	5	-Able to assess individual fetus in multiple gestations	-Poor DR if done alone
First Trimester Screen	NT, PAPP-A, hCG	10-13w6d	82-87	5	-Early screening -Single test -Screens for other genetic defects	-Lower DR than combined tests (see below) -NT required
Quad Screen	hCG, AFP, uE3, DIA	15-22w6d	81	5	-Single test -No US needed	-Lower DR than combined tests
Non-Invasive Prenatal Screen	Fetal cell-free DNA analysis	10-term	99	0.5	-Highest DR -Can be done at any gestational age >10 weeks -Low false positive rate in high risk patients -Result includes fetal sex	-Higher false positive rate in patients at low risk for Trisomy 21 -Result may not be reported if not enough fetal DNA -Result does not always represent fetal DNA
Combined test protocols include: integrated screening, sequential screening (which may occur in a stepwise faction or contingent on initial results), and serum integrated screening. These tests have a higher detection rate than FTS or quad screen alone but the same screen positive rate (5%). Disadvantages include the need for multiple tests and for sequential testing final result is not available until testing is complete.						

Abbreviations: AFP, alpha fetoprotein; DIA, dimeric inhibin-A; DR, detection rate; FTS, first trimester screen; GA, gestational age; hCG, human chorionic gonadotropin; NIPS, non-invasive prenatal screen; NPV, negative predictive value; NT, nuchal translucency; PAPP-A, pregnancy-associated plasma protein A; PPV, positive predictive value; US, ultrasound.

Detection rate: proportion of Trisomy 21 pregnancies with elevated risk[8]

Screen positive rate: proportion of unaffected pregnancies with elevated risk[8]

Case 1

JT is a 39 year old G4P3003 presenting at 9 weeks gestation for an initial prenatal visit. She is certain of her LMP and reports no history of medical conditions or surgical problems. She has had three normal pregnancies without complications, and three and spontaneous vaginal deliveries, without forceps or vacuum. Her physical exam is normal with pelvic examination consistent with gestational age. Thus, her only prenatal risk factor is advanced maternal age (AMA).[9]

Along with prenatal vitamins, diet and activity counseling, she is offered referral to a genetic counselor to discuss options for genetic testing due to AMA. JT says she does not want any genetic tests because she would never consider aborting a baby, no matter what the medical problem. She states that she will take "whatever God gives her."

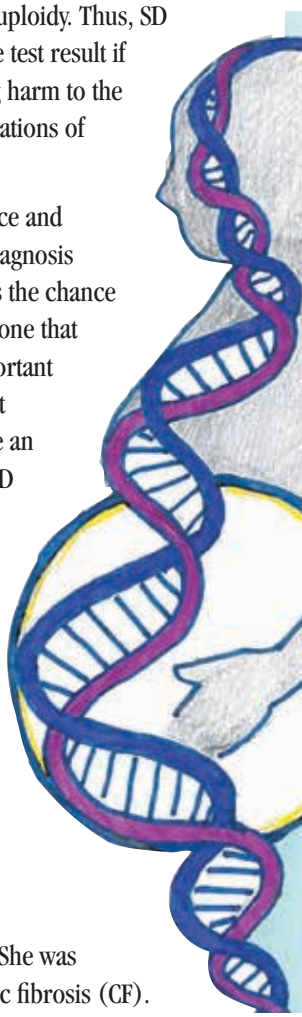
JT has made her decision. She has autonomy to make her own medical decisions. However, the ethical principal of autonomy also requires that she understands the screening methods and test procedures and that she is not being coerced into her decision. It is the physician's duty to inform her that her risk of delivering a baby with Down syndrome is increased compared to younger women because of her age. For a 39 year old woman the risk of Down syndrome is about 1 in 140; that is, if 140 women her age deliver a baby then 1 will have Down syndrome.[10] It is also the physician's duty to assess if there is coercion in her decision-making process. She reports that her husband agrees with her decision and that she understands that there are many tests available.

Before concluding the visit, JT asks when her ultrasound will be scheduled. She is curious to know whether she will have a girl or a boy. To simply order an anatomy scan may cause emotional harm to the patient because the anatomy scan is a primarily a test for congenital defects, and also a test for fetal sex. If she wishes to find out if the baby is a girl or a boy, she will also learn if there are congenital defects seen. The principle of non-maleficence requires that you provide this additional information about the ultrasound. She must know that the primary purpose of the anatomy scan is to identify congenital defects, some which are associated with genetic disorders. She should also know that the scan is intended to "do good." It may be helpful if a condition requiring early treatment is identified. JT decides to think about it and discuss with her husband before her next visit.

Case 2

SD is a 24 year old G5P2022 being seen at 13 weeks gestational age. She is requesting genetic testing to "get checked for everything" that could be wrong with the baby. Her two prior pregnancies were not affected by genetic problems and her current pregnancy has been uncomplicated thus far.

The ethical principles beneficence and non-maleficence are reflected in SD's request to be tested for as many abnormalities as possible. Screening could benefit the patient by reassuring her of a normal pregnancy or guiding further management in case of an abnormal finding. NIPS can detect more abnormalities than serum screening, including trisomies 13, 18 and 21, sex chromosome aneuploidies, chromosome microdeletions and microduplications. However, NIPS is only recommended for women who are at high risk of genetic disorders. High risk is defined as follows: women age 35 or older at delivery, an abnormal US finding suggestive of increased risk, a history of a prior pregnancy affected by trisomy, positive fetal screening aneuploidy or parental translocation with increased risk for Trisomy 13 or 21.[11] The sensitivity and specificity for detecting rare conditions is not well studied.[7] SD is at low risk for having a pregnancy affected by a chromosome abnormality given her age and history. Serum screening, not NIPS, is recommended for women with low risk. NIPS test could be more harmful for SD because the test has a lower PPV in low risk populations due to the lower prevalence of aneuploidy. Thus, SD has a higher likelihood of having a false positive test result if she had the NIPS test. In the interest of avoiding harm to the patient, the physician should explain these limitations of NIPS to SD.



Residual risk complicates the goal of beneficence and non-maleficence since there is the risk that a diagnosis will be missed prenatally. Any screening test has the chance of false positive and false negative results, even one that is appropriate for the patient's history. It is important to discuss all of these possibilities with SD, elicit her goals and values and then allow SD to make an informed decision about what is right for her. SD should also think what it would mean for her to receive a positive or negative result with NIPS. In the case of a positive screen, she should be offered diagnostic testing such as chorionic villus sampling (CVS) or amniocentesis, procedures with pregnancy loss rates from 0.1-0.9% for amniocentesis and 0.2-1.3% for CVS.[4] After a discussion with her physician, SD decides to have a first trimester screen.

Case 3

KJ is a 30 year old G1P0 at 15 weeks gestation. She was offered and accepted carrier screening for cystic fibrosis (CF). She learns that she is a carrier, and her reproductive partner undergoes testing, and he learns he is also a carrier. This was a surprise to KJ because she did not know of any family members with cystic fibrosis, though her paternal family history is unknown. She underwent amniocentesis that confirmed the pregnancy is affected by CF. She wants to terminate the pregnancy, a decision supported by her partner. Her family physician also takes care of KJ's parents and siblings in a close-knit community. KJ does not plan to tell her family about this pregnancy and termination because "they don't believe in abortion." She does not plan to tell them that she is a CF carrier, and asks her doctor not to disclose this either.

This situation illustrates the patient's right to privacy and confidentiality versus a physician's duty to prevent harm in others.[8] Family physicians

continued next page

who care for multiple members of a family may encounter this dilemma more often. In the course of genetic testing, it is possible to discover that family members are also at increased risk for disease. KJ's and her partner's family members may also be carriers of the CFTR mutation and may be at risk of children with cystic fibrosis. As with any health information, the physician cannot disclose genetic information without consent of the patient. Exceptions to confidentiality apply for violence or infectious disease, neither of which is the case here. The physician has a duty of confidentiality as requested by KJ. The physician also has a duty to warn others of their potential health risks. However, this duty is fulfilled by telling KJ of the possible risks to her family members.[12, 13] Discussing KJ's status with her family would not only violate KJ's privacy, but also is a violation of the family members' autonomy because people also have a right not to know. Carrier screening for CF is recommended universally so family members have the opportunity to find out for themselves if/when they are considering pregnancy.[14] Ideally, carrier testing should be done prior to conception so that couples have information for pregnancy planning, and the option of using reproductive technologies, if desired.

Conclusion

Providing prenatal care is an interdisciplinary effort involving family physicians, obstetrician-gynecologists, genetic counselors, and maternal-fetal medicine specialists. Genetic risk assessment and testing should be discussed as early as possible during the pregnancy so that time-sensitive options are available. Family physicians should be able to initiate an assessment of genetic risk and offer common screening and carrier tests. Genetic counselors also have a role in prenatal and preconception care. They should be used for consultation when the physician does not feel prepared to counsel a patient or when high risk circumstances occur.[1] Examples of high risk circumstances: positive screening or diagnostic tests, positive family history of genetic disorder, advanced maternal age, history of previous child with genetic abnormalities, recurrent pregnancy loss.[15] It is common practice in many locations to offer genetic counseling to all pregnant patients and patients planning conception when certified genetic counselors are easily accessible. However, genetic counseling may not be readily available at other practices. Certified genetic counselors can be located via the National Society of Genetic Counselors database.[16]

Discussion of genetic testing should involve shared decision making and be consistent with the patient's values. Innovative, interactive decision-making tools for prenatal testing are being tested.[17] While the ethical principles remain constant, each patients' values and circumstances are different, making prenatal genetic screening a dynamic process for family physicians.

Endnotes

1 Medicine., A.C.o.O.a.G.C.o.P.B.O.C.o.G.S.f.M.F., Practice Bulletin No. 162: Prenatal Diagnostic Testing for Genetic Disorders. Obstetrics and Gynecology, 2016. 127(5): p. 108-122.
2 Anderson, C., et al. , Fetal chromosomal abnormalities: antenatal screening and diagnosis. Am Fam Physician 2005. 79(2): p. 117-123.
3 Gillon, R., Medical ethics: four principles plus attention to scope. BMJ, 1994. 309(6948): p. 184.
4 Dale, H.L., et al. , Ethical issues in genetic testing. Journal of Midwifery and Women's Health, 2005. 50(3): p. 234-240.
5 What are the basic principles of medical ethics? Medical Ethics 101 2016 [cited 2017 August 20]; Available from: https://web.stanford.edu/class/siw198q/websites/reprotech/New%20Ways%20of%20Making%20Babies/EthicVoc.htm.
6 Wapner, R., et al, First-Trimester screening for trisomies 21 and 18. NEJM, 2003. 349: p. 1405-1413.
7 Committee on Practice Bulletins—Obstetrics, C.o.G., and the Society for Maternal-Fetal Medicine, Screening for fetal aneuploidy. Practice Bulletin No. 163. Obstetrics and Gynecology, 2016. 127(5): p. 123-137.
8 Cuckle, H., et al, Down syndrome screening in the first and/or second trimester: model predicted performance using meta-analysis parameters. Seminars in perinatology, 2005. 29: p. 6.
9 Gregg, A., et al, Noninvasive prenatal screening for fetal aneuploidy, 2016 update: a position statement of the American College of Medical Genetics and Genomics. Genetics in Medicine: official journal of the American College of Medical Genetics, 2016. 18(10): p. 1056-65.
10 Hooks, E., et al, Chromosomal abnormality rates at amniocentesis and in live-born infants. JAMA, 1983. 249(15): p. 1056-1065.
11 Medicine, S.o.M.-F., SMFM Statement: Maternal serum cell-free DNA screening in low risk women. 2014.
12 Disclosure, A.S.o.H.G.S.I.S.o.F., ASHG statement: Professional disclosure of familial genetic information. Am J Hum Genet, 1998. 62(2): p. 474-483.
13 Offit, K.e.a., The "duty to warn" a patient's family members about hereditary disease risks. JAMA, 2004. 292(12): p. 1469-1473.
14 Committee Opinion No. 690: Carrier Screening in the Age of Genomic Medicine. Obstetrics and Gynecology, 2017. 129(3): p. 595-596.
15 Pletcher, B.A., et al, ACMG practice guideline: Indications for genetics referral: a guide for healthcare providers. Genetics in Medicine: official journal of the American College of Medical Genetics, 2007. 9(6): p. 4.
16 Counselors, N.S.o.G. Find a genetic counselor. [cited 2017 September 20]; Available from: http://www.nsgc.org/p/cm/ld/fid=545.
17 Kuppermann, M., et al. , Effect of enhanced information, values clarification, and removal of financial barriers on the use of prenatal genetic testing: a randomized clinical trial. JAMA, 2014. 312(12): p. 1210-1217.

Chen Wang, MD, *is maternity care fellow at the Department of Family and Social Medicine at Albert Einstein College of Medicine/Montefiore Medical Center in the Bronx, NY, where she completed a family medicine residency.*

Dana Schonberg, MD, MPH, *is Assistant Professor in the Department of Family and Social Medicine at Albert Einstein College of Medicine/Montefiore Medical Center.*

Maria Gervits, MD, *is a member of the maternity care faculty in the Department of Family and Social Medicine at Albert Einstein College of Medicine/Montefiore Medical Center.*

Rebecca Williams, MD, MHPE, FAAFP, *is Assistant Professor, Albert Einstein College of Medicine and Director of Maternity Services for the Department of Family and Social Medicine at Montefiore Medical Center.*

Discrimination in Medicine

By Sheila Ramanathan, DO

"I want to see the Doctor. Not you. I don't like your kind. I want to see a white doctor, a man," a patient gasping for air in an emergency room says to the dark-skinned resident assessing her vitals.[1]

"Speak slowly, I don't understand you people," a male patient says as an ethnic attending discusses a complicated procedure to obtain consent.

"You're much too pretty to be a doctor, are you married? You would be perfect for my grandson!" exclaims an elderly patient as a young female attending attempts to listen to her heart.

"I'm not a fan of these damn foreigners and Jews coming in here," a patient proclaims loudly when his team of medical students, residents, and the foreign medical school graduates enter the room.

As the physician workforce moves away from being a field composed primarily of white men, opportunities abound for patients to discriminate against doctors. These kind of comments are more frequently becoming public despite a likely longstanding history. Such events are now in the limelight followed by a murky web of legal, financial, and ethical considerations.

Much like the face of the United States, a country that embraces immigration, the face of a typical patient's doctor has changed. In 1970 women comprised eleven percent of medical school seats.[2] Today women constitute 46.7 percent.[2] Female physicians are increasingly present compared to 1970, however they represent less than half of the physician population in general practice or in specialties, even though women are equal in terms of medical school admission rates.

International medical graduates comprise twenty six percent of the American workforce, and twenty four percent of specialty residency programs.[3] International medical graduates also have the greatest tendency to practice in rural America, and about twenty percent will choose to do so.[4] This is in contrast with the fact that seventy five percent of United States medical school graduates are white.[5] The physician workforce is becoming substantially more diverse than the traditional, scholarly, silvery-haired, white male typically portrayed in Rockwellian imagery. Despite the change in the classic physician mold, resistance comes not necessarily from physicians, but from patients in many circumstances.

Discrimination against medical professionals is a problem not only for the mental health of providers, but also has monetary and legal ramifications. Resistance in the general population to the changing face of medicine has led to shifts with regard to the demographics of patient care. Minority physicians are overrepresented in minority patient care responsibilities, and US-educated, non-white physicians care for over half of minority patients and over seventy percent of non-English-speaking patients.[6] This is despite the fact that they comprise less than thirty percent of the US-educated physician workforce. Non-white physicians also tend to care for underserved and unhealthier patients.[6] A 2008 study shows that increased representation of minorities in the physician workforce could lead to the improvement of classically disparate health outcomes among racial groups.[7] This segregational mindset may inadvertently facilitate a patient's discriminatory demands. Despite the influx of women and minorities into the physician workforce, training in relation to patient requests such as those outlined above is difficult to find. A handy emergency room algorithm described in the New England Journal of Medicine for addressing racism in an emergent setting is the only tool produced to assist physicians with this issue but neglects providers in other fields and settings of care.[8]

There are very real-world implications for financial compensation. Despite over seventy percent of minorities and eighty percent of white physicians going into specialty medicine there is a pronounced income inequality.[9] The disparity can be as great as nearly forty

continued on page 32

thousand dollars in the case of a black male physician, or twenty thousand dollars in the case of Asian physicians.[9] While some of this may be due to geographic distributions, self- versus hospital employment, and specialty or primary care, each can heavily impact reimbursement. There are clear financial consequences from patient discrimination.

Hospitals, nursing homes, and healthcare facilities have a long history of acquiescing to the demands of patients regarding the racial or sex makeup of personnel. A recent case in Flint, Michigan highlights the confusion surrounding the issue. Nurses from Flint's Hurley Medical Center filed suit against the hospital for adhering to a swastika tattooed father's request that no black nurses care for his newborn infant in the neonatology unit.[10] Physicians tend to address such requests internally within a group as opposed to involving administration. It may be time for such accommodations to change given the demographic makeup of our physician workforce.

It is clear that patients demonstrate mistreatment and discrimination against physicians. In a 2015 survey of Stanford pediatric residents, fifteen percent had seen or experienced discrimination by patients.[11] Curriculum was created to address this issue in the form of case presentations. Initially determining that a patient's presentation is medically stable and that the request is not due to an underlying pathology or a possible reversible cause, is important to document and confirm clinically. This strategy then allows residents to practice turning the focus of the request to doing what is best for the patient, helping the physician to depersonalize the incident and "cultivate a therapeutic alliance."[11] The focus of that conversation is to indicate that the health of the patient is of utmost priority and should be higher than any prejudice that a patient or a family member may feel.

Physicians also have a long history of discriminating against patients, and racial discrimination only scratches the surface of current problems facing patients who seek access to care. The Tuskegee Syphilis trials demonstrated how the medical community exploited and compromised the trust of African American patients. Recent research indicates that out of a study of two hundred and twenty-two residents and medical students, about half demonstrated false beliefs concerning biological differences between white and black patients.[12] Interestingly, among those that demonstrated these beliefs it was shown that they undertreat the pain of black patients. Those who did not demonstrate these beliefs were found to treat patients appropriately in case scenarios regardless of race.[12] This study is consistent with findings concerning minority health disparities. While the majority of physicians are not consciously or overtly racist or prejudiced, there is a clear unconscious bias that can occur. Simple consciousness of these biased behaviors can have a lasting impact on the health of minority patients.

While outcomes may not be as severely negative as with some minorities, women have also been found to be subject to substantial discrimination in relation to the treatment of their pain, and myths concerning the ability of women to withstand pain are rampant in the decision-making process. The concept that women have a natural ability to sustain pain due to the rigors of childbirth and have strong coping mechanisms for suffering, permeate medicine.[13] Furthermore, women are more likely to have their pain listed as psychogenic or emotional in nature.[13] Women have an increased risk of being misdiagnosed, sometimes with deadly consequences due to presenting "atypically" from traditional symptoms. Most women will not present with chest pain during an acute coronary syndrome which may lead to delays in appropriate treatment.[14] There are steps being taken to overcome these oversights in medicine, however much remains to be addressed. There are efforts to incorporate sex-specific curricula into medical school, such as the Laura Bush Institute for Women's Health in Texas. While the effects of this curriculum and change in mindset may take time to become mainstream, the alternative of single gender medicine as a one size fits all is hardly the gold standard of medical care.

Another sizeable group that is overlooked in terms of healthcare outcomes are the disabled. Disabled patients comprise over twelve percent of the population, and unfortunately many disadvantages exist that lead to worse health outcomes compared to the general population.[15] It has been an uphill battle to adequately fund social services available to the disabled and transition pediatric services to adolescent and adult care. As such, persons with disabilities routinely have higher rates of chronic illness and they are less likely to receive preventative care such as mammograms and Pap smears, leading to worse overall outcomes. In a study, it was shown that about one fifth of medical offices were unable to schedule a typical wheelchair bound fictional patient with history of stroke.[15] Reasons to accommodate disabled patients, although illegal, include lack of wheelchair accessible ramps for entry, inadequate patient transfer lifts, or even bariatric scales. Allowing greater financial support for offices obligated to treat disabled persons, as well as global training of medical staff regarding management of disabled persons would assist with bridging these gaps.

Aside from the visible forms of discrimination, physicians are known to discriminate against patients with certain diagnoses, including mental health or substance use.[16] This is a type of discrimination that can only happen with medical staff, since it requires being privy to a patient's medical history. Patient profiling and diagnostic overshadowing are described as a hidden human rights emergency according to the World Health Organizations Quality Rights Project.[17] Patient profiling of those with psychiatric illness has led to adverse outcomes in those with mental health conditions due to the routine underutilization of screening and treatment guidelines. Diagnosis of multiple mental health conditions causes patients to die twenty-five years earlier than the general population.[18] While some of this is due to suicide, over sixty percent is due to preventable conditions.[18]

Regardless of whether discrimination is by physicians or by patients, medical providers can improve outcomes in any patient population by creating awareness and understanding our own biases and the consequences they can lead to in relation to patient care. Simple consciousness and

mindfulness can lead to improved patient outcomes along with greater fulfillment when physicians are meeting patients where they are and are capable of working with difficult cases. Current efforts have been made to create a relationship of trust and respect toward patients, which in turn will lead to improved physician training and satisfaction and hopefully, a reduction in physician burnout.

Endnotes

1 Yasmin, Seema "When Patient's Discriminate against Doctors: A Muslim Physician Weighs In" Medscape News and Perspective Commentary, April 14, 2017 Web
2 Boulis, Anna K, Jacobs, Jerry A, "The Changing Face of Medicine" Cornell University Press 2008 page 2
3 Ranasinghe, Padmini "International Medicine Graduates in the US Workforce" The Journal of the American Osteopathic Association, Vol 115. April 2015, pgs 236-241
4 Fordyce MA, Doescher MP, Chen FM, Hart LG. Osteopathic physicians and international medical graduates in the rural primary care physician workforce. Fam Med. 2012;44(6):396-403
5 "Diversity in the Physician Workforce Facts and Figures 2010" Association of American Medical Colleges, Diversity Policy and Programs. Summer 2010, pgs. 17-23
6 Marrast, Lyndonna M, et al "Minority Physicians' Role in the Care of Underserved Patients Diversifying the Physician Workforce May Be Key in Addressing Health Disparities" JAMA Intern Med. 2014;174(2):289-291.
7 Street RL Jr, O'Malley KJ, Cooper LA, Haidet P. "Understanding concordance in patient-physician relationships: personal and ethnic dimensions of shared identity." Annals of Family Medicine.2008 May-Jun;6(3):198-205.
8 Paul-Emile, Kimani, et al, "Dealing with Racist Patients" New England Journal of Medicine, February 25, 2016. 374;8 pg. 709.
9 Grisham, Sarah, "Medscape Compensation Report 2017" Art Science Code LLC, April 5, 2017 Web
10 "Patients Refusing Care from Nurses of Different Races one of Medicine's open secrets." CBS Interactive Inc. 2/25/2013. Web
11 Whitgob, Emily E, et al "I Don't Want Someone Like You Taking Care of My Child: Identifying Strategies to Address Discrimination Toward Physicians by Patients and Families" Academic Pediatrics, July-August 2015, Issue 4, pp e6-e7.
12 Hoffman, Kelly M. et al,"Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites" Psychological and Cognitive Sciences PNAS, pp. 1-6, March 1, 2016
13 Hoffmann, Diane E. and Tarzian, Anita J., The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain (2001). Journal of Law, Medicine & Ethics, Vol. 29, 2001. pp. 13-27.
14 Graham, Garth, "Acute Coronary Syndromes in Women: Recent Treatment Trends and Outcomes" Clin Med Insights Cardiology, Feb 8, 2016, issue 10 pp 1-10.
15 Krahn, Gloria E, "Persons with disabilities as an unrecognized health disparity population" AM J Public Health, vol 105, April 2015. Web.
16 Wallace Jean E, "Mental health and stigma in the medical profession" Health: An Interdisciplinary Journal for the Social Study of Health, Illness, and Medicine. January 25, 2017 Vol. 16 issue 1, pgs 3-18.
17 "Mental Health and Development: Targeting people with mental health conditions as a vulnerable group" World Health Organization 2010. Mental Health and Development Report. Pgs. 3-65
18 Parks, Jack, "Morbidity and Mortality in People with Serious Mental Illness" National Association
19 of State Mental Health Program Directors, Oct 2006, pp 3-53.

Sheila Ramanathan, DO *graduated from Lake Erie College of Osteopathic Medicine and trained in rural family medicine in Watertown, NY at Samaritan Medical Center. She is currently board certified in family medicine and continues to practice rural healthcare in Keene, NH as part of the Dartmouth Hospital System*

Questions in Medical Ethics

By Lisa Morrow, DNP, FNP, L.Ac; Mohammed Ali, MD; Sekinat Durosinmi, LPN; Sri Lakshmi Kadiyala, MD; Maureen Kwankam, MD; Harlene Mand, MD; Amar Ouadi, MD and Jose Tiburcio, MD

As medicine evolves, healthcare becomes a bridge across many cultures and faiths. The authors of this article self- identify with seven different faiths and were raised in seven different countries. Yet each of these health care provider's basic foundation remains to "first do no harm" according to the Hippocratic Oath. New procedures, imaging, analyses and medications are constantly presented to providers to ascertain if they are beneficial. The need for an expert's opinion may raise several ethical questions. Is there a conflict of interest on the part of the expert? What do we do when what a patient requests differs from what we would want personally or for our family or loved ones? As the international pool of healthcare providers deepens, we should take a moment as providers, and as patients to reflect not only on our commonalities but on the rich cultural and faith based roots that have helped us establish our moral axis especially in regards to typical questions about medical ethics. Reproductive health, end of life care and decision making, the management of pain, and the allocation of limited resources, all can raise ethical questions, yet contribute to the rich diversity which influences our decision making. Respecting our roots can help us better assimilate the evidence base and work together.

Patients and providers arrive in the United States often seeking refuge from political and financial turmoil, but also because of the quality and access to healthcare. This does not however, infer anyone has changed their belief systems. While personal beliefs may be different from cultural norms, there are expectations within each faith about appropriate healthcare. It becomes up to us as providers to make a safe place for all of us to discuss our beliefs, which may be related to our country of origin and with what faiths we were raised.

Reproductive healthcare may be challenging to bring up with patients. Many providers have the luxury to fall back on meaningful use- the difficult questions on our computer screens appear with boxes for us to check off.[1,2] Providers uniformly speak with their patients about pregnancy planning, contraception and prevention of sexually transmitted infections, regardless if someone had ever previously spoken to them about these topics.[3] Across faiths, there is agreement that patient care is the common denominator, with evidence base and current literature trumping personal bias in care management decisions.

Guidelines based on evidence may stipulate the newest medication or procedure, but how do we decide the management plan when there are multiple appropriate options? There is usually some wiggle room when choosing which evidence to use for patient education or to support a clinical decision. You can generally find high quality studies that support multiple, differing management plans. How would a provider decide between an older medication with known side effects, and the newer medication in the class that the patient saw on mass media? Academic detailing encourages the spread of information based on evidence rather than on advertising and marketing.[4,5] This evidence base is certainly biased. Those who have the time and money can fund studies, and most studies even those citing bias and confounders are created within a bubble that will never approximate actual clinical care. Yet, we choose to respect this evidence because it blurs our common insecurities about not always having one correct solution. As believers in the scientific method, we want to approximate best practice even though there is often not one correct solution.

Several models of patient-provider relationships are often discussed in medical training including paternalistic, informative, interpretive and deliberative.[6] Medical care today approximates a consumer product, where patients have access to vast amounts of information and patients may expect an egalitarian relationship with their provider. Does it diminish the value of the medical training of the provider if the patient has access to the same information the provider uses to make clinical decisions? The driving force behind the relationship between the provider and patient should in some part come from patient preference.[7] In most countries outside the USA, a paternalistic model is most likely to be found. This is quite contrary to the expectations we have in North America where patients often make an educated choice from a selection of options.

Another common pair of topics in medical ethics are end of life decision making and opiate medications for pain control. There is no standardized response by patients or providers regarding end of life and palliative measures, though the process of guidelines is in progress.[8] On one end of the spectrum, comfort must be provided as every available effort is made to cherish the life that was given. Yet, many providers and families or patients themselves will resort to measures legalized in specific states to

end suffering.[9] When providers feel that they cannot make the clinically best judgement because of lack of experience or if they feel their faith would be compromised by a patient's preference, a referral to a specialist with another perspective may provide relief to all involved. The concept of hastening death is not looked upon positively by most religious faiths, but in practice, each case is unique and needs comprehensive understanding.

If there are not enough resources (appointments, medications, vaccines), how do we decide on allocation? When the flu vaccine was first developed, health care providers who were at highest risk of exposure received preference. Now, that the flu vaccine is plentiful, many patients decline prophylaxis. How do we decide the manner in which we educate (convince?) our patients about vaccinations – from the evidence, from personal or clinical experience, or based on the patient having autonomy? How do we select the evidence from which to advise our patients, and do we educate different patients differently on the same topic? Instead of vaccines, if the limited resource is a liver transplant available only in this country, how do we respond to patients presenting from their own countries where the organ is not available?

Our experience in practice will affect our self-identification as providers over time and with patient interactions. Watchful waiting verses aggressive management of a case may vary depending upon the outcomes we are seeing in the moment. Improved and worsening outcomes occur both after non-adherence to our medical advice, but also from side effects from medications or procedures. In theory, most faiths encourage that everything be done to save a life, however this "everything" cannot be standardized across the globe, or even throughout the United States.

These questions are likely best answered if we personally take stock of what we would want for ourselves or loved ones, if we were to presume a patient had full coverage, and we were to assess how we prioritize the roles in our own community. From our personal foundation of ethics, within the family, home, school, work, will come clarity on how we make medical decisions. Since we are not all coming from the same background, but will still be working together, it also makes sense to learn to understand our colleagues' motivations for their own choices and management plans. Once we have better understanding, we are able to communicate better with all stakeholders in the conversation including the patient and their loved ones, our colleagues and administration, and insurance companies and pharmaceutical companies. Medical ethics courses offered in training can further enhance shared communication.

Endnotes

1 Green, Jennifer, et al. "Prospective Associations Among Youth Religiosity and Religious Denomination and Youth Contraception Use." Journal of Religion and Health (2017): 1-15.

2 Schwarz, Eleanor Bimla, et al. "Promoting safe prescribing in primary care with a contraceptive vital sign: a cluster-randomized controlled trial." The Annals of Family Medicine 10.6 (2012): 516-522.

3 Callegari, Lisa S., et al. "Addressing potential pitfalls of reproductive life planning with patient-centered counseling." American journal of obstetrics and gynecology 216.2 (2017): 129-134.

4 Avorn, Jerry. "Academic detailing:"marketing" the best evidence to clinicians." Jama 317.4 (2017): 361-362.

5 Larkin, Ian, et al. "Association between academic medical center pharmaceutical detailing policies and physician prescribing." Jama 317.17 (2017): 1785-1795.

6 Emanuel, Ezekiel J., and Linda L. Emanuel. "Four models of the physician-patient relationship." Jama 267.16 (1992): 2221-2226.

7 Chawla, Neetu, and Neeraj K. Arora. "Why do some patients prefer to leave decisions up to the doctor: lack of self-efficacy or a matter of trust?." Journal of Cancer Survivorship 7.4 (2013): 592-601.

8 Landzaat, Lindy H., et al. "Development of Entrustable Professional Activities for Hospice and Palliative Medicine Fellowship Training in the United States." Journal of Pain and Symptom Management (2017).

9 Pols, Jeannette, Bernike Pasveer, and Dick Willems. "The particularity of dignity: relational engagement in care at the end of life." Medicine, Health Care and Philosophy (2017): 1-12.

***Lisa Morrow, DNP, FNP, L.Ac**, completed her Masters of Science in oriental medicine at Swedish Institute of Health Sciences, her Bachelor of Arts in Latin American Literature at UC Berkeley, and her Doctorate, Master's and Bachelor's in Nursing Sciences at Columbia University School of Nursing. She is nationally board certified in acupuncture and family nursing practice.*

***Mohammed Ali, MD**, is a family physician who completed his medical school training in Austin, Texas and his residency in family medicine as one year of fellowship at Bronx Lebanon Hospital Center, He will continue his wound care subspecialty training in South Carolina.*

***Sekinat Durosinmi, LPN,** has more than a decade of experience serving the community, collaborating with medical professionals and creating teams that feel more like family.*

***Sri Lakshmi Kadiyala, MD,** received medical training in India and is Assistant Clinical Professor at American University of the Caribbean, Clinical Assistant Professor at Ross University, and an attending physician in the Department of Family Medicine, at Bronx Lebanon Hospital Center. She is compassionate about the care she offers, learning about human nature every day.*

***Maureen Kwankam, MD,** received medical training in Italy, by way of Cameroon, and has been an attending physician for a decade in the Department of Family Medicine at Bronx Lebanon Hospital Center.*

***Harleen Mand, MD,** is a 3rd year resident physician at Bronx Lebanon Hospital, Family Medicine, striving to learn and make a difference in the lives of the patients he serves.*

***Amar Ouadi, MD,** is board certified in family medicine, and is on the faculty at Bronx-Lebanon Hospital, Family Medicine; American University of the Caribbean School of Medicine, and Ross University Medical School.*

***Jose Tiburcio, MD,** received his medical degree from Pontificia Universidad Catolica, in the Dominican Republic and completed his residency at Bronx-Lebanon Hospital Center. He attends to his patients and teaches his residents based on the concept that prevention is better than treatment of disease.*

Reproductive Coercion and Contraceptive Counseling: The Role of the Family Physician

By Martha Simmons, MD, and Ivonne McLean, MD

Unintended pregnancy remains a public health issue, and access to abortion is diminishing in many parts of the US due in large part to a significant increase in state laws restricting abortion care.[1] The CDC's Healthy People 2020 campaign has set a goal of decreasing the rate of unintended pregnancy by 10% between 2010 and 2020.[2] This has led to the rise of "Long Acting Reversible Contraception (LARC) First" counseling recommendations in which efficacy is stressed and intrauterine devices (IUDs) and the contraceptive implant are highly recommended as first line for all patients.[3,4] While IUDs and implants are highly effective and work well for many patients, pressuring patients to choose LARC ignores the complexity and breadth of reasoning that goes into choosing contraception for each individual. Additionally, refusing to remove LARC when patients have side effects, or desire fertility, raises ethical concerns. In the following article, we use a case-based approach to explore the concept of provider bias and coercion within the relevant historical context. We posit that honoring a patient's autonomy extends to decisions regarding contraception and pregnancy, and suggest "patient-centered care" as one model to reduce unconscious provider bias.[5]

Case 1:

May 15, 2017- Judge Sam Benningfield, General Sessions Court of White County, Tennessee puts forth the following:

> *For good cause shown including judicial economy and the administration of justice, it is ORDERED any White County inmate serving a sentence for the General Sessions Court who satisfactorily completes the State of Tennessee, Department to Health Neonatal Syndrome Education (NAS) Program be given (2) days credit toward completion of his/her jail sentence. Any such female inmate who receives the free Nexplanon implant or any such male inmate who has the free vasectomy as a result thereof shall be given an additional thirty (30) days credit toward completion of his/her jail sentence.* [6]

Judge Benningfield's order, which has since been rescinded, ignited ethical questions reminiscent of forced sterilizations in the 1950s. When asked about his recommendation, he explained he wanted to address the increase in the number of children born addicted to opioids. In an interview, the Judge stated he was "trying to help these folks begin to think about taking responsibility for their life and giving them a leg up- you know, when they get out of jail- to perhaps rehabilitate themselves and not be burdened again with unwanted children and all that comes with that."[7] Later, Judge Benningfield also clarified he thought about the order solely with good intentions for those appearing in court. In a 2-month period, 24 Nexplanon implants were placed and 38 vasectomies were performed.

To understand some of the ethical implications associated with the White County order, it is helpful to put Judge Benningfield's actions in historical context. Throughout the history of the United States, multiple examples exist of policies that curtailed reproductive rights, including forced childbearing, denial of contraceptive options, and separation of parents and children during the slavery period.[8] In the 1950s and 1960s, southern states subjected black patients to medically unnecessary sterilizations in state-run hospitals, and often informed consent was misleading or absent.[9,10] During that time, sterilization also increased among Puerto Rican patients; while a decade later, up to 25% of Native-American patients had been sterilized under coercion and without an appropriate consent process.[11,12] Puerto Rican, Mexican, and Haitian patients were also primary test subjects for the birth control pill during the initial testing phases, without appropriate consent.[13] Unfortunately, forced sterilization continued as recently as 2010, when over 150 patients in California prisons were sterilized without informed consent by physicians who had been incentivized by the State.[14,15]

A representative from the American Civil Liberties Union of Tennessee stated, "Though the program was technically 'voluntary,' spending even a few days in jail can lead to the loss of jobs, child custody, housing, and vehicles. To the individual faced with these collateral consequences of time spent behind bars, a choice between sterilization or contraception and a reduced jail sentence is not much of a choice at all."[16] This disregard for reproductive autonomy is often referred to as reproductive coercion.[17]

Case 2:

Dani (name changed) was an 18-year-old patient who came to my clinic for her post-partum visit. I had delivered her first child, a healthy baby girl, a few weeks earlier. After talking about mood and breastfeeding, the topic turned to birth control. Dani wanted to start oral contraceptive pills (OCPs). This was not our first discussion regarding contraceptive options. We had discussed the topic almost weekly during her prenatal care and she had been undecided during most of her pregnancy, stating she didn't want anything "inside her body." In truth, Dani had conceived her daughter while taking oral contraceptive pills. Two years prior, at the age of 16, Dani had had an abortion after she found out she was pregnant while on oral contraceptive pills. I was conflicted. "Dani, I hear your apprehension about an IUD or a Nexplanon, but I don't think OCPs are the best method of birth control for you. If you want them again, I am happy to prescribe them, but I will also prescribe a prenatal vitamin, as we may be here again in less than 12 months." I paused and elaborated, "The implant

dispenses progesterone, but the procedure is less invasive than the IUD." I left the room and came back 10 min later. Dani now wanted the Nexplanon, but was scared she would have to keep it even if it was not agreeing with her. I assured her she did not have to keep the LARC if she did not want to, and congratulated her on choosing a more effective method.

Case #1 presented a clear case of reproductive coercion initiated by the justice system; however, more subtle forms of provider-led coercion around reproductive health are much more common. Regarding LARC, since 2014 there have been numerous public health initiatives designed to increase the number of implants and IUDs provided for patients of all ages.[18,19] Several researchers and reproductive health advocates have pointed out that provider bias often influences such recommendations, ignores patient autonomy, and disproportionately affects young individuals of color.[20] Would I have recommended the same, or had so many repetitive conversations regarding more effective birth control, if Dani were a 35-year-old college professor? Am I being overly zealous, because LARC only recently became a covered service for my patients in poor urban settings?

In response to reproductive inequalities within a larger social context, reproductive justice (RJ) has risen as a lens through which providers can approach reproductive health. RJ is a term coined by black women in the mid-1990s. Sistersong defines reproductive justice as "…the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities."[21] Reproductive justice not only includes reproductive health, but also incorporates other social justice issues such as environment, food security, housing, immigration, and other issues that affect people's ability to have a family- or not have a family- in the way they want.[22] As such, this framework states that people have the right to choose the contraceptive option that best fits their values and preferences, even if it is not the most statistically effective method or what the provider may personally prefer. The right of an individual to choose not to use LARC, have the LARC removed when they so desire, and, above all, have easy access to LARC when and if they want it, is also affirmed.[23] Hence, while "shared decision- making" has become ubiquitous in our health care system, it is important to identify the various factors that influence such a model. Specifically, provider conscious or unconscious biases are often overlooked, but play a large role in physician-patient interactions.[24] For example, a provider's belief that a young Latinx patient will use non-LARC contraception ineffectively may lead that provider to deny or postpone a patient's request for an IUD or implant removal. Our pre-conceived notions of who is a "good candidate" for one method versus another may distort our counseling. Moving towards true "patient-centered contraceptive care" is one way to reduce the impact of our unconscious biases.

Case 3:

Shakia (name changed) was a 17-year-old patient of my practice. Like many of the teens that I see in my practice at an FQHC in East Harlem, she has had a hard life. Her mother is incarcerated for drug use and she has been in foster care since age 14. I placed her contraceptive implant (brand name Nexplanon) when she first told me that she had become sexually active. One year later, she requested the removal of her implant. When asked why, she stated that she has a new boyfriend and she felt he would be a great father. She wanted to become pregnant.

Objectively, this patient does not have access to the resources needed for successful parenting. She is young, housed in foster care, and does not have strong family support. However, New York State law allows for minors to seek health care without parental/guardian consent for reproductive healthcare/contraception, mental health care, and screening for and treatment of sexually transmitted infections.[25] Despite opinions that she is too young or too inexperienced to parent, the law allows her to make this choice. Providers' views about patients' readiness to parent can be biased.[26] While bias is a common human condition,[27] the implications of such thinking or behavior are long-ranging and can further alienate patients, particularly adolescents who are being introduced to health care.[28]

Talk of "teen pregnancy," and more specifically teen birth, serves as a signifier of morally or socially acceptable ('fit') parenthood. Furthermore, births among adolescents occur disproportionately in low-income communities and communities of color. When teen pregnancy is automatically understood to be socially inappropriate, without recognizing the structural realities that give rise to, and may sometimes even confer benefit to, early childbearing, racial and class bias can flourish.[29]

In studies of non-white patients, many report feeling that providers are more likely to recommend LARC for poor black patients than their white counterparts and less likely to remove LARC when requested. These same patients admit that they would be more likely to try a LARC method if assured by their provider that they would remove it when asked.[30] Lindsay Stevens' qualitative interviews with providers uncovered a gut-wrenching story of a patient self-removing her contraceptive implant to achieve pregnancy when her clinician refused.[31] As history has shown us in the context of abortion prior to Roe, people will fight fiercely for reproductive autonomy. Reproductive justice posits that protecting the right to become pregnant when desired is as important as protecting the right to end an undesired or mistimed pregnancy.[32] To be clear, we are in no way attempting to romanticize or diminish the public health impact of teen pregnancy. It's certainly appropriate to have a conversation with Shakia about what parenting would look like, the potential impact on her life, and what her future goals are; however, if after a clear and open conversation Shakia still wants her implant removed, we must remove it.

continued on page 38

As we hope to have shown with these cases, multiple factors influence decisions regarding reproductive health. Addressing system-level barriers in reproductive health, including institutionalized racism as described extensively by Camara Jones, is one arm of a three-fold process which would also address personally mediated racism (provider conscious or unconscious bias) and internalized racism (when a person of color starts to internalize the biased or racist opinions or beliefs around them).[33] As mentioned in case #2, a possible solution to such challenges is to provide contraception and reproductive health counseling and services through the lens of reproductive and social justice. To address personally-mediated racism, the first step is acknowledging that we may have unconscious reactions to patients, scenarios, and situations that may negatively influence our own decision-making and the recommendations for our patients.[34,35] We should question the basis of our decisions, e.g. why would we advise one patient to keep their IUD, but remove another patient's IUD without reservation? Other recommendations include: values clarification,[36] cultural humility, and supporting patients to identify their own family planning priorities.[37] Transparency around recommendations and acknowledging that mistakes have been made in the past regarding contraception and coercion can also lead to improved provider-patient relationships and increased trust. In essence, providing judgment-free care based on a patient's preferences and keeping their priorities at the center of each decision-making process would move past shared decision-making to true patient-centered care. Providing such patient-centered, judgement-free care is essential to gaining the trust of communities and ultimately impacting health outcomes.

Endnotes

1 https://www.guttmacher.org/fact-sheet/induced-abortion-united-states
2 HealthyPeople.gov, Healthy People 2020, Family planning objectives, 2011, https://www.healthypeople.gov/2020/topics-objectives/topic/family-planning/objectives.
3 American College of Obstetricians and Gynecologists. "Increasing access to contraceptive implants and intrauterine devices to reduce unintended pregnancy." Committee Opinion 642 (2015).
4 American Association of Pediatrics. Policy statement: Contraception for adolescents. Pediatrics 2014;134(4): e1244-1256.
5 Higgins JA, Kramer RD, Ryder KM. Provider Bias in Long-Acting Reversible Contraception (LARC) Promotion and Removal: Perceptions of Young Adult Women. American Journal of Public Health. 2016;106(11):1932-1937. doi:10.2105/AJPH.2016.303393.
6 http://www.aclu-tn.org/wp-content/uploads/2017/07/2017MayStandingOrderBenningfield.pdf
7 http://www.cbsnews.com/news/opioid-crisis-tennessee-judge-neonatal-abstinence-syndrome-birth-control-inmate/
8 Roberts, D. Killing the black body: Race, reproduction, and the meaning of liberty. New York: Pantheon Books. 1997.
9 Romero, Diana, and Madina Agénor. "US fertility prevention as poverty prevention: An empirical question and social justice issue." Women's Health Issues 19.6 (2009): 355-364.
10 Roberts, D. Killing the black body: Race, reproduction, and the meaning of liberty. New York: Pantheon Books. 1997.
11 Amnesty International. Maze of injustice: The Failure to protect indigenous women from sexual violence in the USA. New York: Amnesty international. 2007.
12 Brave Heart-Jordan, M. The return to the sacred path: Healing from historical trauma and historical unresolved grief among the Lakota. PhD diss., Smith College School of Social Work. 1995.
13 Asbell, B. The Pill: A biography of the drug that changed the world. New York: Random House. 1995.
14 Sterilization of Female Inmates: Some Inmates Were Sterilized Unlawfully, and Safeguards Designed to Limit Occurrences of the Procedure Failed. California State Auditor Report 2013-120. June 2014. http://auditor.ca.gov/pdfs/reports/2013-120.pdf
15 McCLain, Dani. Long-Acting Contraception Makes Teen Pregnancy Rates Plummet. So Why Are Some Women Still Skeptical? The Nation. October 28, 2015. https://www.thenation.com/article/long-acting-contraception-makes-teen-pregnancy-rates-plummet-so-why-are-some-women-still-skeptical/
16 Dwyer, Colin. Judge Promises Reduced Jail Time If Tennessee Inmates Get Vasectomies. NPR. July 21, 2017 http://www.npr.org/sections/thetwo-way/2017/07/21/538598008/judge-promises-reduced-jail-time-if-tennessee-inmates-get-vasectomies
17 Reproductive and sexual coercion. Committee Opinion No. 554. American College of Obstetricians and Gynecologists. Obstet Gynecol 2013;121: 411–5.
18 American Association of Pediatrics. Policy statement: Contraception for adolescents. Pediatrics 2014;134(4): e1244-1256.
19 http://www.upstream.org/
20 Gubrium AC, Mann ES, Borrero S, et al. Realizing reproductive health equity needs more than long-acting reversible contraception (LARC). Am J of Public Health. 2016; 106(1):18-19.
21 http://sistersong.net/reproductive-justice/
22 Ibid
23 Luna Z, Luker K. Reproductive Justice. Annual Review of Law and Social Science. 9 (2013) 327-352.
24 Higgins JA, Kramer RD, Ryder KM. Provider Bias in Long-Acting Reversible Contraception (LARC) Promotion and Removal: Perceptions of Young Adult Women. American Journal of Public Health. 2016;106(11):1932-1937. doi:10.2105/AJPH.2016.303393.
25 https://www.nyclu.org/en/publications/reference-card-minors-rights-confidential-reproductive-and-sexual-health-care-new-york
26 Stevens, Lindsay M. "Planning parenthood: Health care providers' perspectives on pregnancy intention, readiness, and family planning." Social science & medicine 139 (2015): 44-52.
27 Ross HJ. Everyday Bias: Identifying and Navigating Unconscious Judgments in Our Daily Lives. Rowman and Littlefield, 2014.
28 Higgins JA, Kramer RD, Ryder KM. Provider Bias in Long-Acting Reversible Contraception (LARC) Promotion and Removal: Perceptions of Young Adult Women. American Journal of Public Health. 2016;106(11):1932-1937. doi:10.2105/AJPH.2016.303393.
29 Gubrium, Aline C., et al. "Realizing reproductive health equity needs more than long-acting reversible contraception (LARC)." American journal of public health 106.1 (2016)
30 Higgins, Jenny A., Renee D. Kramer, and Kristin M. Ryder. "Provider bias in long-acting reversible contraception (LARC) promotion and removal: Perceptions of young adult women." Journal Information 106.11 (2016).
31 Stevens, Lindsay M. "Planning parenthood: Health care providers' perspectives on pregnancy intention, readiness, and family planning." Social science & medicine 139 (2015): 44-52.
32 Luna Z, Luker K. Reproductive Justice. Annual Review of Law and Social Science. 9 (2013) 327-352.
33 Jones CP. Levels of Racism: A Theoretic Framework and a Gardener's Tale. American Journal of Public Health. 200;90(8): 1212-1215.
34 Ross HJ. Everyday Bias: Identifying and Navigating Unconscious Judgments in Our Daily Lives. Rowman and Littlefield, 2014.
35 Jones CP. Levels of Racism: A Theoretic Framework and a Gardener's Tale. American Journal of Public Health. 200;90(8): 1212-1215.
36 Upadhyay UD, Cockrill K, Freedman LR. Informing abortion counseling: an examination of evidence-based practices used in emotional care for other stigmatized and sensitive health issues. Patient Education Couns. 2010; 81(3): 415-421.
37 Higgins JA, Kramer RD, Ryder KM. Provider Bias in Long-Acting Reversible Contraception (LARC) Promotion and Removal: Perceptions of Young Adult Women. American Journal of Public Health. 2016;106(11):1932-1937. doi:10.2105/AJPH.2016.303393.

Martha Simmons, MD, *is faculty at the Institute for Family Health Harlem Residency in Family Medicine and an Assistant Professor in the Department of Family and Community Medicine at Mount Sinai Hospital. She completed the Reproductive Health Care and Advocacy Fellowship at the Institute for Family Health in 2016. Dr. Simmons is a graduate of Tufts University School of Medicine.*

Ivonne McLean, MD, *is a Reproductive Health Care and Advocacy Fellow at the Institute for Family Health in New York City. She is also a Fellow in the 2018 Leadership Training Academy and a graduate the University of Massachusetts Family Medicine Residency in Worcester, Massachusetts.*

Game Changer continued from page 27

15 S. H, B. R, R. L, et al. An HIV pre-exposure prophylaxis demonstration project and safety study for young men who have sex with men in the United States (ATN 110). J Int AIDS Soc. 2015.
16 Gill K, Marcus R, Dietrich J, et al. An analysis of baseline and early data from the Plus Pills study: an open-label trial of pre-exposure prophylaxis for South African adolescents. In: International AIDS Conference. ; 2016.
17 Pettifor A, Nguyen NL, Celum C, Cowan FM, Go V, Hightow-Weidman L. Tailored combination prevention packages and PrEP for young key populations. J Int AIDS Soc. 2015. doi:10.7448/IAS.18.2.19434.
18 Corneli A, Perry B, Agot K, Ahmed K, Malamatsho F, Van Damme L. Facilitators of adherence to the study pill in the FEM-PrEP clinical trial. PLoS One. 2015. doi:10.1371/journal.pone.0125458.
19 Celum CL, Delany-Moretlwe S, McConnell M, et al. Rethinking HIV prevention to prepare for oral PrEP implementation for young African women. J Int AIDS Soc. 2015. doi:10.7448/IAS.18.4.20227.
20 Grant RM, Lama JR, Anderson PL, et al. Preexposure Chemoprophylaxis for HIV Prevention in Men Who Have Sex with Men. N Engl J Med. 2010;363(27):2587-2599. doi:10.1056/NEJMoa1011205.
21 Hosek SG, Rudy B, Landovitz R, et al. An HIV Preexposure Prophylaxis Demonstration Project and Safety Study for Young MSM. J Acquir Immune Defic Syndr. 2017. doi:10.1097/qai.0000000000001179.
22 Havens PL, Stephensen CB, Van Loan MD, et al. Decline in bone mass with tenofovir disoproxil fumarate/emtricitabine is associated with hormonal changes in the absence of renal impairment when used by HIV-uninfected adolescent boys and young men for HIV preexposure prophylaxis. Clin Infect Dis. 2016;64(3):317-325.
23 Corrigan O. Empty ethics: The problem with informed consent. Sociol Heal Illn. 2003. doi:10.1046/j.1467-9566.2003.00369.x.
24 Fisher CB, Arbeit MR, Dumont MS, Macapagal K, Mustanski B. Self-Consent for HIV Prevention Research Involving Sexual and Gender Minority Youth. J Empir Res Hum Res Ethics. 2016;11(1):3-14. doi:10.1177/1556264616633963.
25 Lally M, Goldsworthy R, Sarr M, et al. Evaluation of an intervention among adolescents to reduce preventive misconception in HIV vaccine clinical trials. J Adolesc Health. 2014;55(2):254-259. doi:10.1016/j.jadohealth.2014.01.006.
26 Alexander AB, Ott MA, Lally MA, et al. Adolescent decision making about participation in a hypothetical HIV vaccine trial. Vaccine. 2015;33(11):1331-1337. doi:10.1016/j.vaccine.2015.01.049.
27 Garofalo R, Mustanski B, Donenberg G. Parents Know and Parents Matter; Is It Time to Develop Family-Based HIV Prevention Programs for Young Men Who Have Sex with Men? J Adolesc Heal. 2008. doi:10.1016/j.jadohealth.2008.01.017.
28 Adolescent Consent According to New York State Law.
29 Ryan C, Huebner D, Diaz RM, Sanchez J. Family Rejection as a Predictor of Negative Health Outcomes in White and Latino Lesbian, Gay, and Bisexual Young Adults. Pediatrics. 2009. doi:10.1542/peds.2007-3524.
30 Mustanski B, Fisher CB. HIV Rates Are Increasing in Gay/Bisexual Teens. Am J Prev Med. 2016;51(2):249-252.
31 Smith DK, Toledo L, Smith DJ, Adams MA, Rothenberg R. Attitudes and program preferences of African-American urban young adults about pre-exposure prophylaxis (PrEP). AIDS Educ Prev. 2012. doi:10.1521/aeap.2012.24.5.408.
32 UN. Global Report 2012: UNAIDS Report on the Global AIDS Epidemic. Jt United Nations Program HIV/AIDS. 2012.

Katie Lynch, MD, MA *earned her medical degree and MA in medical humanities, compassionate care, and bioethics from Stony Brook University. She currently works at the University of Rochester in the OBGYN Research Department and is part of the NYS Department of Health AIDS Institute Detailing Initiative, which seeks to educate providers throughout New York State about PrEP.*

Brooke A. Levandowski, PhD, MPA *is a Research Assistant Professor in the Department of Obstetrics and Gynecology at the University of Rochester Medical Center, and Research Assistant Professor in the Department of Family Medicine at SUNY Upstate Medical University. She received a Master's in Public Administration from Syracuse University's Maxwell School of Citizenship and Public Affairs and a PhD in Epidemiology from the University of North Carolina at Chapel Hill's School of Public Health.*

Monica Barbosu, MD, PhD, *received her MD and PhD from "Iuliu Hatieganu" University of Medicine and Pharmacy, in Romania, and her MBA specialization in medical management from the Simon School of Business, at the University of Rochester. She is faculty in the department of OB-GYN, Clinical and Translational Science Institute, at the University of Rochester Medical Center and serves in a leadership role in all of the NYSDOH AI funded efforts for the University of Rochester Medical Center.*

Thomas T. Fogg, MS, MPH, *is a senior administrator at the University of Rochester Medical Center and serves as the Deputy Director of the CEI Resource Center of Excellence, the AIDS Institute PrEP Detailing Project and will serve in that role for the AIDS Institute Knowledge Management Hub.*

Ivelisse Rivera, MD, *obtained her medical degree from the University of Puerto Rico. As faculty for the Department of Obstetrics and Gynecology at the University of Rochester School of Medicine and Dentistry, Dr. Rivera also holds active roles within the New York State Department of Health's Clinical Education Initiative and is Operations Manager and Trainer for the AIDS Institute's PrEP Academic.*

Timothy Dye, PhD, *is a medical anthropologist and social epidemiologist who specializes in applied public health, particularly within marginalized, isolated, and global populations, and with a content focus on social and cultural determinants of health. His most recent work focuses on the use and integration of biological and public health information systems to address the social and medical determinants of high-risk conditions of pregnancy and infancy.*

The authors would like to thank Karen Teelin, MD and Wendy Holz, NP, for their guidance on insurance-related issues, and Annabel Victor-Halliday for her editorial help.

New York State Academy of Family Physicians
260 Osborne Road
Albany, NY 12211

ARE YOU PREPARED
TO DELIVER VALUE-BASED CARE?

The New York eHealth Collaborative's Advanced Primary Care (APC) practice transformation services lead to advanced:

- Patient-centered care
- Population health
- Care coordination
- Access to care
- Health information technology
- Outcomes-based payment models
- Quality and performance

Receive up to two years of free technical assistance and support to transform your practice and prepare to thrive under value-based payment arrangements.

apc@nyehealth.org | **(646) 619-6420** | **www.nyehealth.org/apc**

ENROLL TODAY

Practices with sites that provide primary care services including internal, family, and pediatric medicine are eligible to participate in Advanced Primary Care. Practices currently receiving federally-funded transformation technical assistance (e.g. TCPI, DSRIP-supported PCMH) are not eligible to participate.

NYeC
NEW YORK eHEALTH COLLABORATIVE