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
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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 inevitable ethical challenges of your own career.

“...there is significant complexity to even the definition of ethical considerations in various situations...”
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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.
**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

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EOE
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

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.
Authomizes 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, 11, A2802, Stc 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, Giick 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 25, 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.

Brian’sLaw 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, Grifo / 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.

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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 114 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 187 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 $5183, 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 bill 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, Ott / 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, Ott / 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, Ott / 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 $4779, 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) $4557-B, Ott / 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, Ott / 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.
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here 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. 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 companies.

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 ways. 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.

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ways. 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.

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].”

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.

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%). 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**


**References**


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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
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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.”

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. 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.

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. 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. 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.

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. 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. 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.”
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 concerns 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. 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.

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.

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

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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. 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. 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.

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. 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. 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.

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 to care. A 2005 report found that FPs care for a disproportionate number of rural, uninsured, and publicly insured patients. 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


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The 1997 Supreme Court decision in Washington vs Glucksberg leaves physician assisted death to the purview of the states. Now five states (Oregon, Washington, Vermont, California, Colorado) and the District of Columbia 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. 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.”

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. 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. Subsequent investigation in 2001 concluded that Dr. Shipman had “unlawfully killed” 215 patients, and real suspicion remained over 45 others.

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.

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.” 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.

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 practitioner and demanded that the government ensure greater protection for patients from any physician that would seek to harm rather than help them. 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.
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 may 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 Oath22, and I urge the reader to carefully consider the consequence of so doing.
Endnotes
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
16 https://www.theguardian.com/uk/2008/oct/18/11
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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.

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. 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. 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. The U.S. Food and Drug Administration also has a database with the active and inactive ingredients of FDA-approved medications which is updated on a regular basis. 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.

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


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.


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

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. 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.

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. 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.

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. 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. When used for PrEP, Truvada is indicated for daily use in ‘adults,’ without specification of age of adulthood. In contrast, Truvada has been used to treat HIV in patients 13 years and older since 2004.

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. 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. However, a meta-regression analysis did show decreased overall efficacy in young adult populations, thought to be due to lack of adherence. For example, only 12% of participants in the FEM-PrEP trial were found to be consistently adherent. Current studies are ongoing to measure the level of adherence in adolescents aged 15-19; preliminary data demonstrate similar adherence challenges.

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

Less is known about long term effects of Truvada in youth. Two studies in young MSM did not demonstrate renal toxicity in participants. 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. Havens et al. report similar results, in addition to noting a decrease in cortical BMD primarily. Serum markers consistent with endocrine dysfunction were theorized as the likely driver of the BMD loss. Vitamin D supplementation may prove protective. 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, it remains our best method of centering the often-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. Parental participation and family-based approaches to HIV prevention are preferable and recommended by the NYS Department of Health. 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. Poverty, drug use, and sex work can compound these risks. Complicating this picture further, high risk youth are also more likely to face family rejection, leading to additional health problems and barriers to care. 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. 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. 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.

**Practical Considerations**

On April 12th, 2017, HIV was re-classified by the NYS Department of Health as a sexually transmitted infection. 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. 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. Fortunately, PrEP is a safe, effective method of preventing HIV. 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**


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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 ⁴ 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 Aneuploidy⁷

<table>
<thead>
<tr>
<th>Name</th>
<th>Components</th>
<th>GA Range (weeks and days)</th>
<th>Detection Rate for Trisomy 21 (%)</th>
<th>Screen Positive Rate* (%)</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nuchal Translucency</td>
<td>US only</td>
<td>10-13w6d</td>
<td>64-70</td>
<td>5</td>
<td>-Able to assess individual fetus in multiple gestations</td>
<td>-Poor DR if done alone</td>
</tr>
<tr>
<td>First Trimester Screen</td>
<td>NT, PAPP-A, hCG</td>
<td>10-13w6d</td>
<td>82-87</td>
<td>5</td>
<td>-Early screening</td>
<td>-Lower DR than combined tests (see below)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-Single test</td>
<td>-NT required</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-Screens for other genetic defects</td>
<td></td>
</tr>
<tr>
<td>Quad Screen</td>
<td>hCG, AFP, uE3, DIA</td>
<td>15-22w6d</td>
<td>81</td>
<td>5</td>
<td>-Single test</td>
<td>-Lower DR than combined tests</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-No US needed</td>
<td></td>
</tr>
<tr>
<td>Non-Invasive Prenatal Screen</td>
<td>Fetal cell-free DNA analysis</td>
<td>10-term</td>
<td>99</td>
<td>0.5</td>
<td>-Highest DR</td>
<td>-Higher false positive rate in patients at low risk for Trisomy 21</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-Can be done at any gestational age &gt;10 weeks</td>
<td>-Result may not be reported if not enough fetal DNA</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-Low false positive rate in high risk patients</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-Result includes fetal sex</td>
<td></td>
</tr>
</tbody>
</table>

Combined test protocols include: integrated screening, sequential screening (which may occur in a stepwise fashion 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 risk⁸

Screen positive rate: proportion of unaffected pregnancies with elevated risk⁸
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. 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. 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. While the ethical principles remain constant, each patients’ values and circumstances are different, making prenatal genetic screening a dynamic process for family physicians.

Endnotes


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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. Today women constitute 46.7 percent. 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. International medical graduates also have the greatest tendency to practice in rural America, and about twenty percent will choose to do so. This is in contrast with the fact that seventy five percent of United States medical school graduates are white. 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. 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. 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. 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.

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. The disparity can be as great as nearly forty
thousand dollars in the case of a black male physician, or twenty thousand dollars in the case of Asian physicians. 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. 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. 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." 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. 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. 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. Furthermore, women are more likely to have their pain listed as psychogenic or emotional in nature. 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. 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. 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. 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. 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. 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. While some of this is due to suicide, over sixty percent is due to preventable conditions. 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
10. “Patients Refusing Care from Nurses of Different Races one of Medicine’s open secrets.” CBS Interactive Inc. 2/25/2013. Web

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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. 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. 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. 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. 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. 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. 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
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
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. The CDC’s Healthy People 2020 campaign has set a goal of decreasing the rate of unintended pregnancy by 10% between 2010 and 2020. 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. 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.

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.

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 rehabilitation themselves and not be burdened again with unwanted children and all that comes with that.” 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. 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. 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. Puerto Rican, Mexican, and Haitian patients were also primary test subjects for the birth control pill during the initial testing phases, without appropriate consent. 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.

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.” This disregard for reproductive autonomy is often referred to as reproductive coercion.

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.15,19 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.

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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). 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. 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, cultural humility, and supporting patients to identify their own family planning priorities. 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
19 http://www.upstream.org/
21 http://sistersong.net/reproductive-justice/
22 Ibid

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