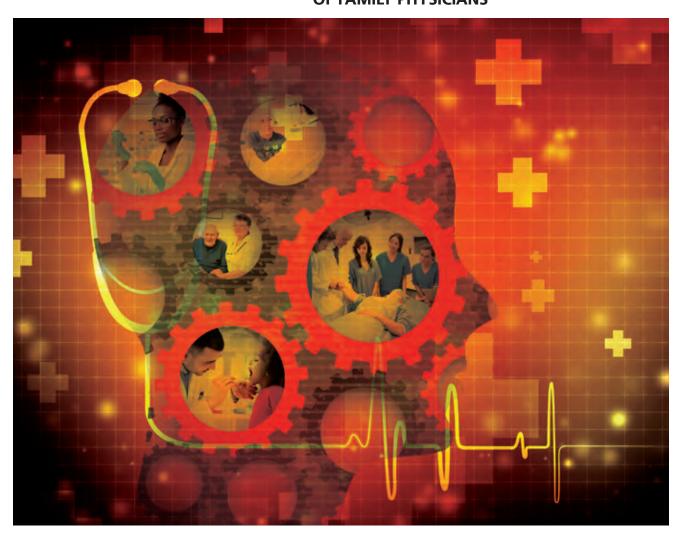
# Family Doctor A JOURNAL OF THE NEW YORK STATE ACADEMY OF FAMILY PHYSICIANS



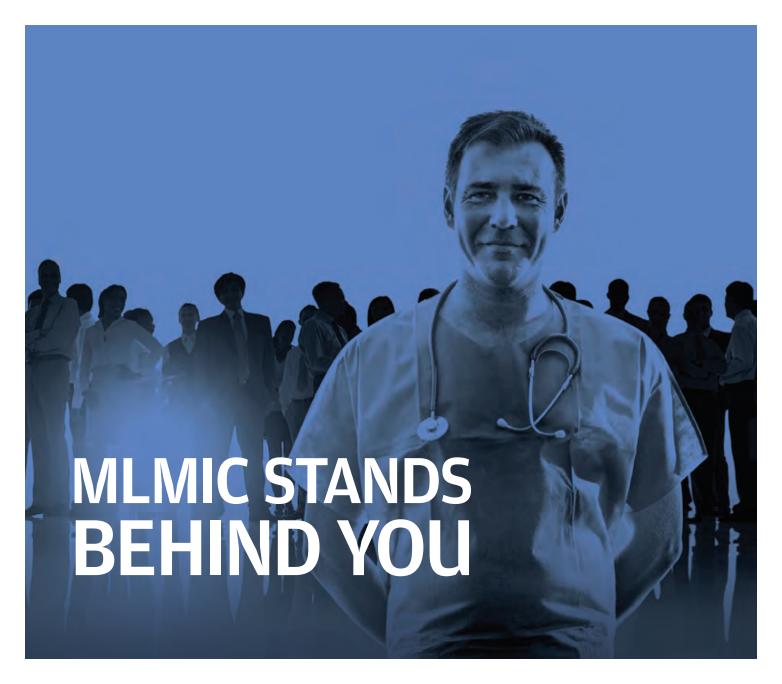
### **FEATURE ARTICLES:**

- Sexual Trauma and Chronic Pelvic Pain: Just Ask
- Restoring a Connection: Re-engaging Family Doctors in the Care of Hospitalized Patients
- Together with Patients: An Optimistic Perspective for the Practice of Family Medicine
- The Last Visit



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Perspectives in Family Medicine



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- Support initiatives to move Breakfast After the Bell for better participation.

















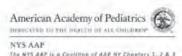
















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<sup>1</sup>U.S. Department of Agriculture Economic Research Service, Household Food Security in the United States in 2015

2018 National Dairy Council



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### **From the Executive Vice President**

By Vito Grasso, MPA, CAE

ew York currently has the greatest number of practices and providers recognized as a Patient-Centered Medical Home (PCMH) by the National Committee for Quality Assurance (NCQA) compared to all other states in the country; almost 16% of all PCMH practices and almost 15% of providers in the country operate in NYS. As of June 2018, there were 2,469 practices recognized as a PCMH, of which 98% achieved recognition from NCQA's 2014 level 3 and above. Smaller practices, with only one provider working at the site, currently make up the largest portion of PCMH-recognized practices.

There are many initiatives throughout NYS that focus on improving primary care, including NCQA's PCMH, the Adirondack Medical Home Demonstration (ADK), and NYS PCMH. NYS PCMH is an innovative model for primary care transformation launched by the New York State Department of Health (NYSDOH) on April 1, 2018. NYS collaborated with NCQA to develop this exclusive transformation model for all eligible primary care providers in New York State. NYS PCMH was intended to expand access to high-performing primary care to promote the IHI Triple Aim goals of improved health, better health care and consumer experience, and lower cost. On May 1, 2018, NYS Medicaid began providing incentive payments to providers recognized under NCQA PCMH 2014 level 3 standards; NCQA PCMH 2017 standards; or NYS PCMH. NYSDOH believes that high-quality, efficient primary care provided by clinicians recognized under NYS PCMH will lead to better health outcomes and reduced total cost of care for New Yorkers in the future. More information about NYS PCMH can be found on the NYSDOH website here: https://www.health.ny.gov/technology/ innovation plan initiative/pcmh/.

The NYS PCMH model recognizes investment in behavioral health integration, health information technology (HIT), care coordination, population health and the potential of multi- payer support through value-based payment. New York's Advanced Primary Care (APC) project was designed to transform practices over time using increasingly more intensive competency levels. The NCQA PCMH 2017 model aligned closely with New York's APC and allowed for the creation of NYS PCMH. A core benefit of the NYS PCMH initiative is the availability of technical assistance from

transformation vendors retained by the state to help practices achieve recognition. New York contracts with 15 such vendors and can provide technical assistance to practices anywhere in the state. Free technical assistance is available until expiration of the federal SIM grant on January 31, 2020.

A number of family physicians have participated in transformation including the NYS PCMH initiative.

Margaret Donat, MD, of Downstate Family Medicine Residence Program (FMRP) describes her experience with NYS PCMH: "It is a lot of work but definitely worth it. You get \$6 per patient per month, \$42 per patient per month for chronic care management and \$180 per encounter for transition of care management."

"PCMH has been good for my practice and brought in regular income for all my Medicaid patients, about 22% of my practice," said Dr. Jamie Loehr. "The 3-year cycle was a bear for six months but then easy to stay on top of the other two and a half years. We are just starting the annual cycle with New York, so I have less to say about that."

Support of transformation from commercial plans is important for sustainability of performing as a PCMH. The FMRP at Stony Brook has been PCMH recognized since 2011 and also participates in NYS PCMH. The Stony Brook program participates with 25 payers. At present 11 health plans participate in the NYS SIM program which underwrites the NYS PCMH initiative. Assunta DiValentino, DO, oversees the PCMH program for Stony Brook. They receive enhanced payment for PCMH status from four Medicaid Managed Care plans. Among the costs incurred by Stony Brook to operate as a PCMH are: additional staff for care coordination and increased administrative time for faculty and purchases necessary to be more patient centered including phlebotomy chairs, test strips for hemoglobin A1C machines, vaccination supplies, printing and marketing materials and on-site behavioral health.

Dr. DiValentino explained that for Stony Brook there are some additional costs associated with the NYS PCMH standard, "To increase robustness of our pre-visit planning and huddles, we are planning to revise our office space which will entail removing



**President's Post**By Barbara Keber, MD, FAAFP

s this issue is dedicated to perspectives on family medicine, I will offer some of mine in this edition of our journal. As a family physician who has been practicing for over 35 years, my perspective may be somewhat different from those of you who are recently graduated from residency programs. That said, although things have drastically changed over that period of time, the soul of family medicine has remained the same. Those of us who choose this discipline for our own, have many different backgrounds and practice in diverse regions of the country and state. However, we all have similar feelings when it comes to patient care. Patients are at the heart of all we do, whether we work as ambulatory physicians in an urban HIV center, with residents in an underserved area, in a small private practice or for a large entity, or even as a teacher or administrator, everything we do is to improve things for our patient. We want to provide the best quality, safest care for each and every patient we touch and some that we touch only indirectly through our administrative or teaching efforts.

As the healthcare system in our country continues to go through it's metamorphosis, whatever the next iteration that occurs, family medicine must be at the center of that system in order for that system to flourish. As the organization in NY which represents the family physicians of our state, the NYSAFP must continue to fight for the ability of family physicians to provide the kind of continuous, accessible, cost effective, quality care our patients deserve. We can accomplish this by advocating to reduce the

burdens on our physicians in areas like prior authorizations and improved electronic health records; by working to reduce the cost of drugs that our patients need for chronic disease management; by working to enhance patient education on many topics of importance for public health such as vaccination acceptance or reducing the use of vaping; and by continuing to enhance the work force of family physicians in our state.

Family medicine has undergone many changes over the past decades, going from the original general practitioners to the current residency trained family physicians. The NYSAFP representing those physicians is playing a significant role in the advocacy for our patients and members at the national level. The AAFP is now recognized as a significant contributor to healthcare policy making and has raised the funding to be able to accomplish this through the AAFP Political Action Committee. We must increase the work force, continue to retain our scope of practice, enhance the training of more rural family physicians and improve the resiliency of our physicians through reduction in the burden placed on us by outside agencies. We can and we must accomplish these things for the good health of all the patients we serve.

We are more alike than we are different! Thank you all for your continued service to our patients.

Barbara Keber MD, FAAFP President NYSAFP 2019-2020

As the healthcare system in our country continues to go through it's metamorphosis, whatever the next iteration that occurs, family medicine must be at the center of that system in order for that system to flourish



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### From the Executive Vice President, continued

old furniture and carpeting, purchasing office furniture and paying for services associated with these renovations. We are also enhancing onsite behavioral health with NYS PCMH."

Jamie Loehr, whose practice became PCMH recognized in 2008 and is currently participating in NY PCMH, says it has been worthwhile, "Yes, it has been worthwhile, especially for the money from the Medicaid plans. I wish more plans would pay for PCMH recognition."

There are clearly benefits to operating as a medical home and the financial rewards have helped offset costs associated with achieving and maintaining PCMH status. The technical assistance available through the NY SIM project has been invaluable for practices.

Matt Devine, DO, and medical director of Highland Family Medicine in Rochester, said his practice has been a PCMH since 2011 and has endured an audit and multiple renewals. He says operating as a PCMH has been worthwhile but comes with its own challenges. "We pay an outside consulting firm to help keep us organized for the ongoing submissions/ resubmissions," he explained, "We have been able to get URMC DSRIP to cover the consulting fees over the last 2-3 years."

The project described was supported by Funding Opportunity Number CMS 1G1CMS331402 from the U.S. Department of Health & Human Services, Centers for Medicare & Medicaid Services. The content of this article is solely the responsibility of NYSAFP.

### IN THE SPOTLIGHT



### Winter Weekend is

January 23 – 26 at the Lake Placid Conference Center. It is worth up to approximately 20 CME credits. There are procedure workshops for attendings, as well as clinical and practice management presentations. A poster presentation and cocktail reception are a great opportunity for networking and meeting up with colleagues!

### **Upcoming Events**

2019

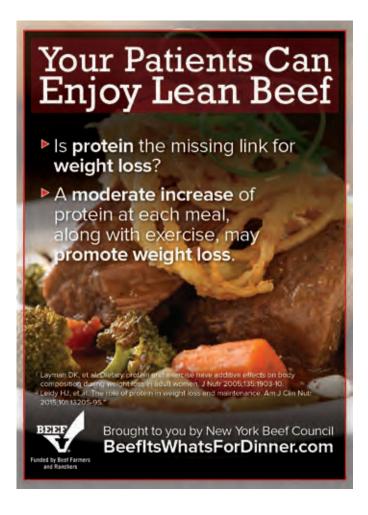
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March 15 – 16 Winter Cluster and Lobby Day Albany, NY

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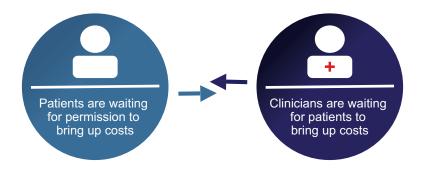
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# Cost of Care Conversations 1.0 Did You Know?

One in four patients in a recent West Health Institute/NORC at the University of Chicago national poll said they have skipped recommended medical tests or treatment due to cost

Having effective cost-of-care conversations with patients is a new necessity for providers. Being able to discuss patient financial responsibility is key to improving patient collections and keeping patients healthy.



# In each issue we will feature a different tip to help you effectively implement Cost of Care conversations with your patients.

### Tip #1: Integrate Cost of Care Conversations into Daily Workflows:

An excerpt from Rev Cycle Media, Strategies for Effective Cost-of-Care Conversation with Patients:

Carving out the time and resources needed for routine patient financial responsibility talks is the first step to having effective cost-of-care conversations that can boost the bottom line and patient outcomes.

Unfortunately, providers generally do not have a system for conducting cost-of-care conversations.

A new study<sup>1</sup> of two Kaiser Permanente regions found that clinical and non-clinical staff wanted to address patient financial responsibility concerns and questions, but they oftentimes had to find "creative workarounds to existing workflows."

The workarounds included "cheat sheets" near workstations and informal relationships with staff in other departments. The staff also reported that they had to access data sources they might not normally use (e.g., patient insurance contracts) and perform tasks beyond the scope of their job.

Identifying or hiring an employee who is responsible for having cost-of-care conversations would help integrate the discussions into clinic workflows, staff members at Kaiser Permanente advised.

Staff members also suggested that provider organizations give employees real-time access to data on costs, such as patient insurance benefits or fee schedules for specific services, so staff members can find out-of-pocket cost estimates at the point of care.

They also recommended that organizations implement EHR-based documentation systems that would help to identify and document patient financial needs, questions, and follow-up.

### **Effective strategies include:**

- assigning one staff member to serve as the out-of-pocket cost problem-solver to develop expertise and efficiency
- "creative workarounds": cheat sheets, informal interdepartmental relationships
- real-time access to data related to cost, insurance benefits, fee schedules etc.
- using the electronic health record (EHR) to document patients' financial need
- mining the EHR for cost data and insurance coverage

https://annals.org/aim/fullarticle/2732825/workflow-requirements-cost-care-conversations-outpatient-settings-providing-oncology-primary?searchresult=1

For additional resources on cost of care conversations, go to: www.nysafp.org/Conferences/How-do-I-start-the-conversation. *The above made possible through funding from the New York State Health Foundation.* 



# **Together with Patients:**

An Optimistic Perspective for the Practice of Family Medicine

By Juan Robles, MD

In 2014, while still in residency training, I set out to facilitate an after-hours weight loss group for my patients. I started the program to address a healthcare need in my community. Little did I know that this would become a defining moment in my professional life and practice in family medicine.

I vividly remember the first patient care group visit I facilitated, nervously waiting for my patients to show up. It was past clinic hours; I had arranged the chairs of the waiting room area in a circle, with colorful pamphlets featuring tips on "How to Keep Your Weight off" placed around the table in the middle. The patients trickled in one by one. Milagros, a 60-year-old woman with diabetes and osteoarthritis of the knees, exclaimed, "Hello Dr. Robles! It's good to see you, I almost forgot about this. I'm glad you called to remind me, I really need to lose weight...my legs are killing me!" I was standing in a room with a group of people whom I would normally care for one-on-one. They stared and waited for me to say something profound. Instead, I allowed them to get to know each other. They introduced themselves and, over the course of the visit, they shared some very personal information about their lives and medical conditions.

Years of medical training had not prepared me for this. This was a unique experience; it was certainly not a class or the typical hierarchical doctor-patient interaction. I was just another member of the group. We all contributed to the discussion, and we taught each other by offering advice and sharing personal struggles and achievements. Many shared how they were affected by low self-esteem and poor body image, with a lack of support at home. "My husband makes fun of me when I get on the treadmill or do stretching exercises in the living room," said Lydia, one of the youngest members in the group. "I eat brown rice, is that bad or good Dr. Robles?" Jose asked. "What do you think?" I asked the group. In this one-hour session, I learned so much more about them than I had in our routine office visits. They were knowledgeable, funny, and inspiring, showing me sides to their personality that I had not previously seen while in the exam room.

Generally, a group medical visit (GMV) format includes a group educational session plus a brief one-on-one medical evaluation conducted by a licensed healthcare provider. Toolkits, strategies, and other resources for conducting and billing GMVs of various medical conditions are easily accessible and provide guidance. <sup>1-3</sup> There is also ample evidence to support the effectiveness and benefits of GMVs. For instance, regarding diabetes care, good quality systematic reviews have not only showed A1C reduction of 0.46% (CI 0.80 – 0.31%) but also have demonstrated increased patient satisfaction in group visits. <sup>4-5</sup> Qualitative reviews have also shed light on other quality of care outcome measures including decreased cost as a result of

reduced medical utilization, increased standard preventive services, and increased patients' perceived better quality of life. These reviews also point to potential benefits for providers including improved job satisfaction and relationships with patients. Personally, this has also given me the opportunity to participate in innovative and optimized models that increase access and delivery of care.

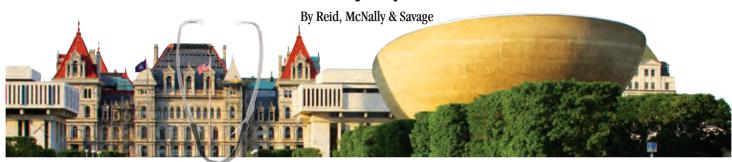
I have continued to facilitate a range of GMVs including obesity prevention, nutrition, and asthma groups since residency training. I have developed a deeper understanding and great appreciation for this and other innovative models of healthcare delivery as a complement to traditional approaches, and strongly believe that it is possible to provide quality patient care in creative ways while enjoying the role of the primary care physician that I once envisioned. I am, after all, the medical student who wrote passionately about healing patients and communities through the power of relationships and support for each other. After each group session, I feel deeply empowered by my patients' experiences and by the new connections I have made with them. Similarly, I feel more connected to the surrounding community, to my workplace, and my institution's mission. I therefore appeal to my colleagues and leaders to explore effective patient care opportunities that our healthcare system may offer and support, including GMVs, to bring us closer to our patients and to help us develop a deeper appreciation of the role we play caring for communities. We should foster creative solutions to keep us engaged and hopeful about the practice of family medicine.

### **Endnotes**

- 1 Group Visit Coding. American Academy of Family Physicians (AAFP). http:// www.aafp.org/practice-management/payment/coding/group-visits.html
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**Juan Robles, MD**, is a graduate of the Albert Einstein College of Medicine ('11) and completed his residency training in family medicine at Montefiore Medical Center in the Bronx ('14). His areas of interest include caring for marginalized populations, preventive care, nutrition literacy, group medical visits, and mentoring and advising in healthcare careers. He is junior faculty in the Department of Family and Social Medicine at Montefiore and an Assistant Professor of Family Medicine at the Albert Einstein College of Medicine.

### **Albany Report**



As the New York State Academy of Family Physicians publishes its fall edition of *Family Doctor*, we have developed an Albany Update focused on recent issues of interest that have picked up media attention over the summer.

# State Senate Task Force Travels to Canada to Discuss Single-Payer Model and Overdose Prevention Centers, Both Priority Issues for NYSAFP

Senate Health Committee Chairman Gustavo Rivera was in Toronto the last week of August to review Canada's single-payer health care system amid a debate over the proposal he and Assemblyman Richard Gottfried have introduced in New York.

The group, which included members of the Senate Task Force on Opioids, Addiction and Overdose Prevention, met with Canadian health care officials and other experts to discuss the single-payer model.

"The New York Health Act and the Overdose Prevention Centers Act are key policies being widely debated in New York as we face skyrocketing health care costs that are impeding access to quality care and an unprecedented rate of overdose deaths," Rivera said.

Also under discussion was the state's Overdose Prevention Centers Act.

Those traveling with Chairman Rivera included Senators Pete Harckham, Diane Savino, Roxanne Persaud and Health Committee ranker Pat Gallivan who is also the top Republican on the opioid task force.

"The goal of this trip is to learn how similar policies and programs have been successfully implemented in Canada and leverage their experience as we consider the implementation of these policies in New York State," he said. "It is our responsibility to pursue bold measures to improve New York's healthcare system and I believe this trip will provide us with the background and tools to achieve that goal."

NYSAFP will continue to advocate for the enactment of both measures when lawmakers return to Albany in January.

# Court Upholds Elimination of Religious Exemptions for School Vaccine Requirements; NYS Law Championed by NYSAFP

A state judge in late August upheld New York's new law eliminating the religious exemption to vaccinations for schoolchildren, ruling that

protecting residents from communicable diseases is within the state's interest.

Acting Supreme Court Justice Denise Hartman of Albany ruled against dozens of parents who filed suit in July, denying their request for a preliminary injunction that would have kept the state from enforcing the new vaccination law before the school year starts.

Governor Cuomo signed the bill into law in June shortly after lawmakers approved it following a session long push by NYSAFP and others amid a measles outbreak centered in Brooklyn and Rockland County. The law repealed parents' ability to send their children to school or daycare without vaccinating them by claiming the vaccinations violate their religious beliefs.

The parents' lawsuit and request for an injunction which is being led by Orange County attorney Michael Sussman and Robert F. Kennedy Jr., a prominent vaccine skeptic who helped organize opposition to the law, sought to block the law from taking effect while the lawsuit is being argued over during the coming weeks and months.

In a 32-page decision, Hartman pointed to a number of court decisions over the past century that have upheld a state's right to mandate vaccinations in order for students to attend public or private school.

"Because plaintiffs have not demonstrated a likelihood of success on the merits, the Supreme Court denies the request for a preliminary injunction; the legislative repeal of the religious exemption remains in effect," Hartman wrote.

Sussman said he plans to appeal the ruling to the state Appellate Division, Third Department, which was subsequently denied in early September. Following the denial, Sussman wrote in a Facebook post that the next step was to bring their argument to the Court of Appeals, the state's highest court.

## New York Has Officially Decriminalized the Use of Marijuana per a Law Passed in June

The new law, which downgrades the criminal penalty for the unlawful possession of pot from a misdemeanor to a fine, was signed by Governor Cuomo in July and took effect in the last week of August.

The law also removes criminal penalties for possession of less than two ounces of marijuana and creates a process where certain individuals with past marijuana convictions can have their records cleared.

According to The New York Times, nearly 160,000 people with low-level weed convictions will have them expunged from their record.

"Communities of color bave been disproportionately impacted by laws governing marijuana for far too long, and today we are ending this injustice once and for all," Cuomo said in statement in July after signing the legislation.

"By providing individuals who have suffered the consequences of an unfair marijuana conviction with a path to have their records expunged and by reducing draconian penalties, we are taking a critical step forward in addressing a broken and discriminatory criminal justice process," he continued.

Cuomo had also worked to make the legalization of marijuana a top priority for state legislators this year. However, a bill that would have legalized the sale of marijuana for recreational use in the state failed to advance in June, putting an end to hopes that the state would be able pass such a measure later this year.

Health Chairman Richard Gottfried, who co-sponsored the bill, was pleased for its success, but maintained that his ultimate goal is complete legalization.

"This is a great step forward for social justice," said Gottfried. "But we still need to pass the bill to legalize, regulate and tax adult use of marijuana, sponsored by Senator Liz Krueger and Assembly Majority Leader Crystal Peoples-Stokes of Buffalo, which I co-sponsor."

### **Governor Cuomo Enacts Ban on Flavored** E-Cigarettes; NYSAFP Has Been Advocating for a **Comprehensive Sales Ban of All Flavored Tobacco Products**

In wake of uncertainty of action announced by the Trump Administration to ban flavored e-cigarettes, in mid-September Governor Cuomo declared his intention to ban flavored e-cigarettes in the state. Regulations approved on September 17th by the Public Health and Health Planning Council will prohibit e-cigarette retailers from selling all flavors except for tobacco and menthol by October 4th or face fines of up to \$2,000 per violation. New York and Michigan are the first states to ban e-cigarette flavors.

NYSAFP and other health advocates have aggressively pushed for the ban of all flavored tobacco products including flavored e-cigarette, flavored little cigars, menthol cigarettes and others. These flavors, like cotton candy and bubble gum, are clearly marketed to kids which has resulted in an alarming reversal of what had once been a long, downward trend of teenage nicotine addiction due to smoking. This year's National Youth Tobacco Survey showed more than a fourth of high school students used e-cigarettes, setting another record high.

Local and statewide efforts remain underway to establish the regulations in statute and expand the flavor ban to include menthol and other flavored tobacco products.

### **DSRIP 2.0**

On September 17th, the New York State Department of Health (NYSDOH) provided notice of the State's intent to request approval from the Centers for Medicare and Medicaid Services (CMS) to extend the Delivery System Reform Incentive Payment (DSRIP) program for an additional four years through 2024. They are seeking an additional \$8 billion to do so. In particular, the State is seeking a continuation of DSRIP for the 1-year balance of the 1115 waiver ending on March 31, 2021 and conceptual agreement to an additional 3 years from April 2021 to March 31, 2024.

In the \$8 billion request, the state is seeking \$5 billion for its DSRIP program, \$1 billion for workforce development, \$1.5 billion to address the social determinants of health and a \$500 million Interim Access Assurance Fund that would support safety-net hospitals.

The chief goal of the program is to reduce avoidable hospital use by 25% over five years. To do so, health care providers around the state formed 25 Performing Provider Systems, which are made up of hospitals, nursing homes, primary care practices, community-based organizations and other participants. Nearly all of the PPSs are led by hospitals or health systems.

The Health Department said that those networks had achieved a 21% reduction in preventable hospital admissions and a 17% decrease in hospital readmissions through June 2018.

"The waiver extension seeks additional time and funding support for these successful initiatives to fully mature across the state and to complete the transformation of the way Medicaid pays for services—from fee-for-service, which rewards volume, to a value-based system where care is funded based on outcomes," the Health Department wrote in its announcement.

The waiver has allowed health care providers to use Medicaid funding for uses that would otherwise have been prohibited. For example, they can use money to address some of the social factors that affect health, such as access to food, transportation and housing.

Critics of the program have said too much of the money went to hospitals, and the pace of adoption of payment based on outcomes has been too slow. The state said that more than 60% of Medicaid managed-care payments are in value-based contracts.

"Transforming Medicaid to improve health outcomes and make it more cost-effective has been a priority in New York state under Gov. Cuomo's leadership," Health Commissioner Dr. Howard Zucker said. "Extending our Delivery System Reform Incentive Payment waiver is vital to building on our success."

A draft of the amendment proposal is available for review at: http:// www.health.ny.gov/health\_care/medicaid/redesign/waiver\_ amendment update.htm.

Written comments will be accepted by email at 1115waivers@health. ny.gov or by mail to NYSDOH. All comments must be postmarked or emailed by November 4, 2019. The State will then submit its request to the Centers for Medicare and Medicaid Services later in November.

# A Case of Sective Sect

By Lisa Newman, DO

Our experiences, starting from our time as medical students on rotations, and continuing throughout our careers and beyond, shape a lot of what we do in practice. A substantial part of how we practice medicine is built by these perspectives. We are constantly re-developing our points of view which in turn, directly shape our patient's care. Even the most clinically minded physicians can't help being affected by what happens in our patient's lives, especially under our care, even if it is out of our control. In this world of computers, EHR and corporate health care, we need to acknowledge that we are not robotic, that experience and feelings still are what drives our passions. Sometimes we can be so affected that it resonates for our entire careers. I had such an experience during my early days in family medicine. I thought I had a keen perspective, based on my training and practice thus far. What I learned is that perspective is ever evolving, and when things happen it changes the way we think, which affects our practice of patient care forever. We need to approach each case as an educational opportunity and entertain the medical and ethical aspects.

Dr. Bernard Lo, pioneer of medical ethics, states "A strong doctor-patient relationship has many dimensions, and physicians have an obligation to act in their patient's best interests. Technical expertise and sound clinical judgment are essential." This "technical expertise" is developed after years of study, or, "science" of medicine, and at least part of this "sound clinical judgment" is what is sometimes referred to as the "art" of medicine. In addition, the modern version of the Hippocratic Oath states "I will remember that there is an art to medicine as well as science." This can be varied from physician to physician and is why sometimes different paths can ultimately yield the same results. The same applies to working up a patient for a problem. There are standards of care we are held to, and then there are the additional tools to practice medicine that sometimes cannot be quantified. It can be described as a feeling, an instinct, or a sense. These ideas and perspectives we sometimes rely on as an ability that we possess to aid us in patient care. Thus, the experiences we have during our medical

careers, no matter how small, are essential to being successful at what we do. The didactic continuing education, although of utmost importance, is only a small part.

Recognizing a sick patient is perhaps the most important sense or skill a family medicine physician can have. It is the fundamental which all of our teaching and learning is based upon. We all endure the first years of medical school, countless hours spent over books and texts to learn disease states, and pathophysiology, the true science of medicine. We all work hard, eager to start clinicals to apply all we've learned and memorized of this science. Then it takes all of one day at the start of a third-year clinical rotation to realize there is more. This "art" is what makes it complex. Sometimes it can mean a different approach to diagnostic workup, sometimes can mean changing original plans to meet insurance requirements, and sometimes it influences what treatment we choose. Still, this "art" can be something hard to define: a feeling, an instinct, or a sense. The ability to recognize when someone is sick is also part of this art. A critically ill patient may be obvious, even to those of us not in medicine. But how do we sense less severe illness that can still be impactful? Most of us are concrete thinkers, following algorithms and guidelines in how we practice standards of care. You cannot go wrong with standard recommendations. But what happens when you let intrinsic senses guide you? And then they fail you?

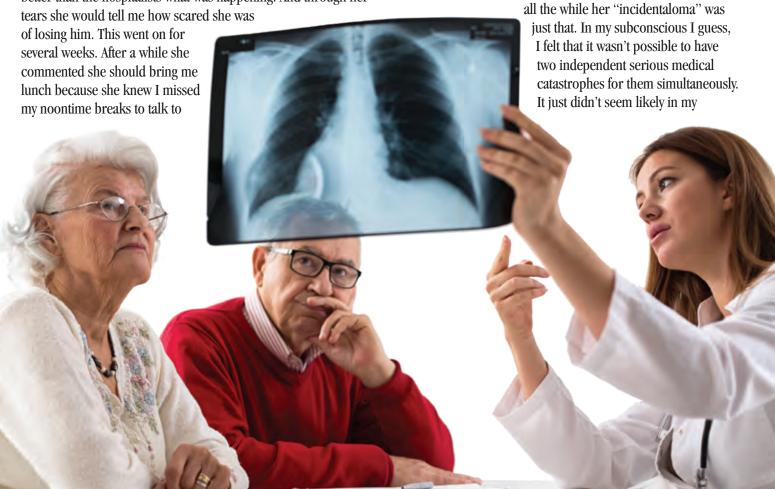
This brings me to my unusual story of Mr. and Mrs. C. I met them early on when I started in my rural office practice 17 years ago. Both in their early sixties and heavy smokers, he was soon diagnosed with an abdominal aortic aneurysm that needed repair, and she with type 2 diabetes mellitus needing to be on insulin. Smoking cessation was a necessity for them both and was one of our greatest accomplishments. After months of counseling and frequent visits for accountability and reassurance we were successful. He had his surgery, and she was concentrating on other lifestyle changes to improve her prognosis. They both felt "better than ever" and swore they would never restart the smoking habit. I saw them

often, as they preferred to make appointments together. We concentrated on managing all their risk factors, including treating both for COPD with inhalers. They gave a me a lot of credit for their good health and referred a lot of their friends my way. We became friendly and once they were feeling well our visits would include social factors. I learned about their families, her strict upbringing and strong faith, and his love for helping others. After retirement they both volunteered locally and became involved with our local Special Olympics. I also took care of many of their athletes who adored them. I remember feeling content, that I had truly made a difference in their lives and health. That they would go on to be healthy ex-smokers that we would keep a close eye on, do appropriate screening and care to assist them with a long, happy life.

One autumn a few years later, Mr. C. became ill with a respiratory illness. He declined rapidly and was hospitalized at a nearby community hospital. He was diagnosed with multi-lobar pneumonia and required intubation early on. He remained in intensive care for many days, with Mrs. C. staying by his side practically the entire time. We would be in close contact with the intensivists for frequent status updates. His prognosis continued to be poor. On her way there each day Mrs. C. would often stop at our office to meet with me, as she felt I could explain to her better than the hospitalists what was happening. And through her

her. Sometimes she would. She was trying to be strong, but we were understandably both scared. I had the advantage of medical knowledge and previous experience. After speaking daily with the hospitalists, I was certain he would not make it home. There were too many days on a ventilator, too many close calls, with no improvement. I tried to prepare her as best I could, not knowing what would happen. Together though, we kept faith.

One day while rushing to the hospital to see her husband, Mrs. C took a wrong turn and was involved in a minor motor vehicle accident. Her car was still totaled, and even though she did not feel injured, local medics insisted she be taken to the local trauma center. She was treated and released, no broken bones or organ damage. Her main concern that day was still getting to the community hospital to visit her husband. Due to the extent of car damage, even in the absence of symptoms she had had a full trauma work up, and a routine CT scan of the chest picked up a few pulmonary nodules, the largest of which was 7 mm. It did not look concerning but follow up imaging was recommended in 3 months, consistent with the guidelines. I saw her the next day for a recheck, and although she was sore and bruised, she was much more concerned about her husband, and so was I. Mr. C. seemed to take a turn for the worse, antibiotics were failing, and he continued to require mechanical ventilation. Subsequently, we focused our energies on his progress, thinking



experience, or even statistically. That CT scan went straight to my back burner and I had no bad feelings about her but continued to be very worried about him.

Mrs. C continued her daily treks to the hospital, spending more time at his bedside the next couple of weeks while he continued to decompensate. There were talks of removing the ventilator, but she was not ready. Her visits to me at lunchtime became fewer as she prepared for the worst. Each time I saw her she looked tired, pale, stressed. She was obviously losing weight and I told to make sure she was eating enough. She waved me off, stating she couldn't eat at a time like this. I reminded her of her diabetes and how it wasn't good to skip meals. She assured me her blood sugar was "fine", and that she still checked it often and had it under control. I also started to notice a cough she blamed on her low resistance and a cold that would just not go away. I never did see her for a formal visit since the initial recheck after the MVA. Just our hallway and occasional quick exam room chats on her way to the hospital. I kept telling her she ought to schedule, but she reported there would be time for that later. I didn't push, as my concern for her health was very little given her husband's grave condition.

My sense was wrong. After a couple of weeks, Mr. C., seemingly miraculously, was able to be extubated and was making progress. He was discharged to a nursing home temporarily and worked very hard at his rehabilitation, and was eventually able to return home. As we focused on improving his strength, he continued diligently with inhalers, respiratory follow up, and physical therapy. He and his wife even attributed his survival to our insistence that he quit smoking before this infection. Specialists repeatedly mentioned he was lucky to be alive. He wouldn't forget that and felt he was given a second chance. With time, he was back to routine activities, and even restarted coaching Special Olympics in our town and planning a muchneeded vacation for the two of them the following summer.

Then it hit — I can recall it like it was yesterday, and the feeling is the same. Exactly one week shy of the 3-month period to recheck her lung CT scan, Mrs. C. began having hemoptysis and went to the emergency room. A CT scan done then showed her 7 mm nodule was now 13 mm. There were many new lesions as well. She decompensated rapidly. Despite her husband's pleas she refused all treatment and within three weeks of that day, she passed away from metastatic non-small cell lung carcinoma. We were both devastated.

I felt my perspective was broken. Did I not recognize a "sick" patient? Did I do anything wrong? I was following the guidelines; however, I couldn't help but wonder — if he hadn't been so sick would I have paid more attention to her? Should I have been more aggressive? Did the stress of his illness somehow impact her health? I remember how we never had

a formal follow up visit. That she came to see me often at lunchtime and although I recognized that she looked stressed, I attributed this to her husband's illness rather than her own undiscovered failing health. I should have at least had her get on the scale and do an exam. I surely then would have realized that something more was wrong. Or at least I think I would have. Most of us are purists, it is part of our training to "not search for zebras" when we are faced with something. We rely on our training and incorporate our experiences and perspectives. Her weight loss and appearance fit with her stress over her husband's illness. But I still feel somewhat responsible, now ten years later. And this experience has changed the way I approach some things. It has made me lean more on the 3 months of the "3-6 months" range of so many recommendations. And I have much more awareness of weight trends and appearance in my physical exams.

I start my first lecture each year to our new family medicine residents with a cartoon, showing several physicians and students around a patient's hospital bed with surrounding IV poles and monitors. The board above the patient's bed reads "SICK". It gets a laugh each time but the tone changes quickly. I tell them "we are successful if you all develop some degree of this sense." Or skill.... Or feeling... But what happens when this still fails? Too often, it does. As outlined above, sometimes it is not as obvious as the picture demonstrates. One of the most important reasons we go into family medicine is the feeling that you truly are a part of patients' lives. You get to know the whole family dynamic and assist with all that is happening. You are there for generations of births, illnesses, graduations, marriages, deaths. Not only are you their caregiver in the physician sense, you are support and someone to lean on in event of all things. They depend on you. And you depend on your knowledge, experience, skills, and senses to help them. These are all intertwined in our perspectives.

Mr. C. is still doing well today, he is using daily inhalers, continuing to refrain from ever smoking again, and preventive care has kept him healthy. I have watched him closely. And every now and again when he comes to the office during the noontime hour he'll bring me lunch.

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One

### **VIEW ONE**

# CARING FOR PATIENTS WITH COMPLEX MEDICAL AND SOCIAL NEEDS: LESSONS FROM PROVIDING PRIMARY CARE TO A SUPER-UTILIZER POPULATION

By Jennifer Park, MD, MPH

r. R. was a 60-year-old African American male who presented frequently to the emergency department with complications related to type 2 diabetes, hypertension, and major depressive disorder. Though he presented regularly to his primary care physician and a behavioral health counselor, he was often hospitalized related to complications of his chronic diseases. Patient education in both the inpatient and outpatient setting and tailoring medications did little to improve glucose levels or blood pressure control, and his cycle of hospitalizations every few weeks continued.

Mrs. H. was a 45-year-old Caucasian female with frequent emergency department encounters and hospitalizations over the last two years related to abdominal pain. Her medical diagnoses included gastroparesis and hypertension, though her gastroparesis studies were completed while being treated with opiates. She identified a primary care doctor but did not have regular contact with the office, although she did regularly engage in care with a gastroenterologist. Despite frequent outpatient specialist care, she continued to have emergency department visits several times a month related to the abdominal pain which was acutely treated with opiates and benzodiazepines.

Mr. D. was a 20-year-old Hispanic male with type 1 diabetes. Every few weeks, he presented to the emergency department with complications of hyperglycemia and had two hospital admissions in a six- month period for diabetic ketoacidosis. After each hospital based encounter, his discharge planning included a new prescription for insulin and education regarding its proper use.

Regardless of your practice setting, I am sure you have experience with patients with difficult to control chronic illnesses that result in frequent hospitalizations, often referred to as "super-utilizers." This particular patient population, though only a small percentage of patients that health care systems encounter, represents a disproportionate amount of health care dollars spent. Despite the increased spending, improved outcomes do not follow, and the patients often experience uncoordinated care, duplicate testing, and even harmful procedures. Work in this arena garnered national attention with the publication of "The Hot Spotters", a 2011 New Yorker article by Atul Gawande detailing the work of Dr. Jeffrey Brenner in Camden, New Jersey. Dr. Brenner utilized cost data, mapped the data onto geographical location, and identified two

#### **VIEW TWO**

# AIDING ASYLUM: HEALTHCARE HOTSPOTTING: HOW ONE PATIENT'S STORY EXEMPLIFIES THE NEED FOR HUMANISTIC CARE

By Blake Kruger, MPH; Shannon Coleman and Sangrok Oh, DO

Two

niversity at Buffalo's Hotspotting Scholars Program consists of an interdisciplinary team of students collaborating to address social determinants of health (SDH) through a partnership with a local family medicine residency. This year-round learning experience pairs study of the SDH with patient interactions to improve healthcare equity in Western New York. 'Hotspotting' originated from the Camden Coalition of Healthcare Providers in 2003 and has since spread across the United States, connecting health professionals with underserved community members to improve population health through targeted, patient-centered interventions.¹ After feedback from our initial student cohorts, we created a new program integrated with a local family medicine residency.

The aim of our program is to improve patient wellness by partnering students from the schools of medicine, social work, nursing, and pharmacy with socially vulnerable patients who frequently utilize hospital and emergency room services. Student dyads perform home visits with patients to identify and address SDH barriers that prevent the patient from achieving optimal care. Led by Sangrok Oh, DO, our hotspotting team meets monthly to discuss patient progress with resident representatives from family medicine and faculty from the four schools. A collaboration with educators from each discipline provides students with knowledge on relevant pathologies, strategies to mitigate SDH barriers, and motivational interviewing skills to facilitate patient ownership of their health. We aim to equip our patients with the ability to care for themselves without our assistance in the long-term.

The case of 'Leroy,' a 23-year-old African American male, exemplifies the impact SDH barriers have on patient quality of care, health outcomes, and resource utilization. Through Leroy's story, we will show the importance of incorporating the social and behavioral determinants of health into the provision of compassionate, patient-centered primary care, and how the hotspotting model may help improve the health of vulnerable patients.

Leroy is a patient with uncontrolled type 1 diabetes mellitus resulting in multiple ICU admissions for diabetic ketoacidosis (DKA). He was referred to the hotspotting team via family medicine in October 2018, after multiple failed attempts to improve care plan compliance and gain control of his medical condition. Leroy lives in his caretaker's apartment in a low-income neighborhood on Buffalo's east side, disconnected from remaining living relatives and lacking other social or economic support. In 1971, a major highway was constructed through

major "hot spots," locations with a high density of these individuals incurring the highest healthcare costs. He then used this information to deliver care targeted to this population, often bringing services to these individuals in the community.<sup>1,2</sup>

There is often a sense of frustration around care of patients like these, both in inpatient and outpatient settings. Much of this frustration stems from the difficulty in addressing factors outside of traditional medical care that are prompting healthcare utilization. Social determinants of health, defined by the World Health Organization as "the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life," remain largely out of the control of traditional medical care.<sup>3</sup> During my residency training as a family physician, I was often discouraged by my inability to solve these puzzles during traditional office visits. I knew that there were factors outside my control that affected my patients' chronic illness burden and frequent hospital visits, even asking about these details at visits. Despite my referrals to social work and behavioral health, providing lists of local food banks and housing resources, and scanning the medication lists to choose more affordable options, I often still saw the names of these patients pop up on the emergency department or inpatient list prior to our next follow up visit. Though our patient centered medical home provided useful strategies in delivering care to most patients, I found that the structure and supports in my outpatient clinic did little in helping me to offer patient centered care to this vulnerable subset. On the inpatient side, I lacked the knowledge of each patient's home life and social supports that comes with caring for an individual over time. High level of acuity also served as a barrier to discussing drivers of utilization. With sicker individuals, the time spent with the patient was typically focused on stabilizing and then working toward a discharge plan. Multiple specialists were often involved in care, and the patients often had difficulty reconciling the different instructions and recommendations. Though the electronic medical record should have served to bridge the information across all realms of care, the sheer amount of encounters, test results, and provider notes in the charts of patients with high utilization patterns made it impossible to review all information at the patient's bedside. Even in a system where the medical record was integrated between outpatient and inpatient settings, we were not always sure that patients would follow up at discharge or that medication or care plan changes would be communicated effectively with outpatient providers.

The national discussion of hotspotting and super-utilizer initiatives led to efforts with the system I trained in which culminated in a formal program called Care Connections. This voluntary program served as a transitional primary care clinic for adult patients with multiple hospitalizations related to chronic disease and unmet psychosocial needs. With goals of reducing hospitalizations and cost to the healthcare system, the interdisciplinary team included primary care providers (physicians and nurse practitioners), social workers, a behavioral health counselor, nurse case managers, chaplains, a pharmacist, an attorney, and patient care navigators who served as a point of contact for patients at home, in the community, or within

the medical system. A history of trauma, either in childhood or adulthood, was almost universal among the patients we cared for, and mental health needs were often not well addressed prior to their enrollment. An embedded behavioral health counselor was crucial in helping to address these unmet needs and to help the patient establish a long term plan for mental health care. Our clinic was housed within the hospital so while we offered extensive outpatient visits, we were also able to offer consultative services in the emergency department and hospital setting at the time of patients' arrival. This allowed us to have discussions with all teams involved in care and deliver a clear message and plan to our patients. We were also able to advocate on behalf of our patients with the inpatient care team, providing insight into the factors outside of medicine playing into the hospitalization. There was a clear transition of care from inpatient to outpatient setting since we were involved in all aspects of care.

In revisiting the patient cases I opened with, the combined efforts of our interdisciplinary team shed light onto factors driving these individuals' hospitalizations that had not previously been addressed. Mr. R.'s depression was a major driver of worsening physical health. He lived in a group home without access to regular cooking or refrigeration equipment, making it difficult to follow the instructions he was provided time and time again on healthy diet. He had no access to regular transportation, and walking to appointments, stores, and community resource offices was difficult due to neuropathy as a result of poorly controlled diabetes. His major goal was to move out of the city and into a quieter town where he could live in his own apartment. As our team helped him work toward his goal of finding alternative housing, we were able to establish transportation services and food bank delivery for him. Previously unwilling to discuss medical options for mental health, he became more open to the possibility of expanding mental health treatment. With any concerning patterns in glucose management, we were able to follow up closely as an outpatient, and Mr. R. was able to decrease his emergency department visits and hospitalizations.

On engaging with Mrs. H., our team noted a pattern of being willing to engage with only one specialist during hospitalizations. She had developed trust with her outpatient gastroenterologist who she felt was the only provider who listened to her and acknowledged her pain. If her requests for benzodiazepines and opiates were not met for her abdominal pain flares, she and the admitting physician would often have a negative interaction. By engaging with her gastroenterologist, we were able to discuss weaning these medications since we feared they were actually making symptoms worse. With a clear message coming from everyone involved in her care, she began to develop an outpatient treatment plan to address her pain. She slowly developed trust in the team and was willing to discuss how family and social stressors had a role in her flares. With counseling services available to her during hospitalization, our team was able to help her shorten her hospital stays and become more engaged in her family's activities that she had previously avoided out of fear of her pain symptoms interrupting.

Mr. D. spent a much shorter time with our program than many patients. When reviewing his emergency department patterns, it became clear that he was having difficulty affording his medications. He had just been hired for a job but did not yet qualify for insurance benefits. He was reliant on samples of insulin through his primary care office, and when samples were not available, he went without insulin, resulting in hospitalizations to treat DKA. Days in the hospital jeopardized his ability to maintain employment. Our case managers and social worker helped to enroll Mr. D. in a pharmaceutical support program, and with his correct medications on board, he was successful in continuing employment.

In the team based setting of Care Connections, the patient was truly the most important member of the team. Patient identified goals, as elicited by the patient's care navigator, were discussed by the entire group and helped to drive our care forward. These goals were sometimes about their chronic medical conditions, such as quitting smoking to become eligible for an organ transplant or to improve their lymphedema in order to enjoy walks through their yard again. More often, the patient's goals were outside of traditional medical care: obtaining stable housing, preventing hospitalization to visit their son at boot camp, or to reconnect with family members they had been estranged from. This speaks to the importance of the social determinants of health, and with the strengths of our interdisciplinary team and strong connection with community services, we were able not only to help the patient take steps forward in meeting their goals but were able to celebrate the effect these changes had on their physical health. In patients whose chronic health conditions put them on a trajectory toward end of life, the ability to have a meaningful goals of care discussion including the realities of CPR and supportive care, allowed us to educate patients and their families in a way that is difficult to do in traditional office visits. Supporting patients and families through the end of life based on their wishes was considered an equal success by our team.

As described above, this intervention was designed to be a temporary one, with a goal of creating a care plan which could be transitioned back to the patient's original primary care provider. For many patients this transition happened after several months with the Care Connections team, most back to the primary care provider they had been seeing prior to enrollment. The relationship we were able to build with patients allowed us to find a better fit for a primary care provider in the event that patients did not have a good rapport with their previously assigned doctor. Some patients required more than the planned three to six-month intervention, and the team as a whole discussed whether we were actively working on goals that could benefit from extra time with our clinic. Though most cases resulted in a successful transition, there were a few patients who were never successful back in a traditional primary care setting. These patients tended to be re-integrated with us if hospital admissions became more frequent and there were factors that our team could help address.

Our team worked with a learning collaborative of five programs in Pennsylvania, sharing data of our programs' outcomes. These superutilizer efforts resulted in decreases in emergency department visits, hospitalizations, days in the hospital, and health care charges for the targeted populations. These efforts also informed the creation of ambulatory care support throughout the system for patients at risk of frequent hospitalization. Collecting data and measuring outcomes continues to be part of the success of the Care Connections model, which recently celebrated its sixth anniversary.

When considering patient cases such as those described above, it is obvious that traditional medical care was not serving these individuals well. With many patients experiencing chronic disease, unmet mental health needs, and significant psychosocial stressors, it can be difficult for a solo practitioner to coordinate care in a way that changes this trajectory. Creating a practice setting with wraparound services in a single setting or within a single team is not something that is required for most of our patients. But, for the small percentage of patients who find themselves in a cycle of constant emergency department visits and hospitalizations, the traditional way of delivering medical care is simply not succeeding. I continue to be grateful to the healthcare team and patients that shaped my learning during fellowship. The ability to practice truly patient centered care and the privilege of sharing in the patient stories of survivorship and resiliency will color the way I engage with my patients for the span of my career. I currently serve as a primary care physician in a traditional outpatient office and continue to struggle with cases like the ones described above despite my fellowship training. Without the support to really coordinate and integrate patient care, I see a handful of my patients get lost in a cycle of hospital admissions. As family physicians, we are uniquely positioned to look holistically at the needs of our patients and push for innovations in health care that better serve some of our most vulnerable patients. By advocating for our patients on systems, payer, and policy levels, we can help to create changes that affect those factors which feel out of our control.

#### **Endnotes**

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Jennifer Park, MD, MPH, is a family physician providing primary care as part of New York-Presbyterian Medical Group Hudson Valley in Peekskill. She graduated from the Lancaster General Health Family Medicine Residency in Lancaster, PA prior to completing two years of fellowship training in population health. During that time, she earned a Masters of Public Health through the University of Pennsylvania and spent her clinical time with the innovative Care Connections team, offering comprehensive services to patients with frequent hospital admissions. Her clinical interests include system wide efforts to improve patient care, and her current research involves the role of community health workers in reducing emergency department encounters for patients with mental health diagnoses.

### view two, continued (Healthcare Hotspotting)

Buffalo's east side, separating some of Buffalo's most vulnerable communities from much of the city's resources. The decades since have seen diversion of funding to other municipal projects, further isolating this section of the city.<sup>2</sup> Today, significant health disparities are observed in the region, primarily impacting low-income African American individuals.<sup>3</sup> Leroy's experiences in this community are typical of those of many low socioeconomic status Buffalo residents.

Leroy was diagnosed with type 1 diabetes mellitus at age thirteen, when he connected with a pediatric endocrinologist and self-reports reliably attending primary care and specialist appointments. As time passed, his personal life became less stable and compliance with medication, health monitoring, and appointment attendance deteriorated. Leroy was referred to our hotspotting program at the age of 22 after his eighteenth DKA admission over two years and countless attempts by his care team to improve compliance and well-being. At the time of referral, Leroy made little-to-no attempt to monitor his blood glucose levels or diet and abstained from injecting his insulin until his health conditions became dire. Leroy agreed to participate in the program but remained minimally engaged in conversation throughout the intake interview process, avoiding eye contact and responding with short, mumbled phrases. He was initially reluctant to discuss the details of his disease progression or management but expressed interest in his hotspotting dyad helping him find employment and better manage his medications to enhance control and freedom in his daily life.

Following intake, Leroy's hotspotting dyad established regular, non-judgmental communication with Leroy. The development of this relationship improved his health literacy, financial stability, food security, appointment attendance, medication compliance, and trust in the healthcare system. Independence was an initial goal discussed with Leroy at intake: namely, to find steady employment. Leroy explained that he could not take action on other aspects of his life (affording his own apartment, affording regular groceries, and accessing reliable transportation) until he achieved some level of financial independence and security. To achieve this security, Leroy's team assisted him with writing his résumé. Motivation was a barrier; two months of regular encouragement and reminders for Leroy to call his high school for his GPA to complete the document were required. Afterwards, Leroy finished his résumé, sent out several applications and independently found steady work for 30 hours a week. He now reports tolerating this work more than his former jobs and has held his position for four months, a feat he previously struggled to achieve due to repeated illness-related absences. Employment allows for more independence in Leroy's daily life, and creates opportunities for improvement in his diet, appointment attendance and self-care.

With this initial success, Leroy was motivated to pursue other aspects of independence including food security and the ability to directly communicate with his care team. Leroy's reliance on his caregiver to provide groceries prevented proper dietary regulation and caused tension in their relationship. With assistance from his hotspotting dyad,

Leroy completed the application for SNAP in January of 2019 and has since been successful in providing his own groceries. Unfortunately, Leroy's diet remains uncontrolled and unmonitored, exemplifying how his motivational deficit may pose a greater barrier to lifestyle change than monetary burden. Nevertheless, achieving greater food security has improved Leroy's quality of life, increased his personal freedom and reduced his guilt associated with relying on his caregiver. Leroy's dependence on his caregiver was further reduced by hotspotting providing him with 'minutes' for his previously inactive cell phone. Now Leroy regularly contacts his team, makes appointments, calls pharmacies, and researches health information over the phone.

Importantly, Leroy has demonstrated improved ownership of his health management. He now self-reports taking prescribed medications more regularly, yet the most noticeable improvement is seen in his appointment attendance record. The year prior to Leroy's referral to hotspotting, he did not attend any specialist appointments and frequently missed visits with his primary care providers. Through frequent reminders, scheduling assistance, and encouragement by the hotspotting team, Leroy's compliance has improved regarding family medicine, diabetes education, and endocrinology appointments (**Table 1**).

<b>Table 1.</b> Depicts appointment interactions by attendance, 'no-shows,' and cancellations.				
Time Period	Attended	'No-Shows'	Cancelled	
08/2017 – 08/2018	1	9	2	
09/2018 - Present	7	4	3	

Leroy's poor medication and appointment compliance can be attributed to the discomfort of insulin injections and glucometer readings, which he describes as "... poking (himself) all day with needles." At referral Leroy was prescribed long-acting Lantus and post prandial doses of Humalog. After referral to hotspotting, he took initiative in finding an alternative medication, discovering inhaled insulin after doing online research. Leroy spoke about switching to inhaled insulin with his dyad and care team and significant effort was made to switch Leroy's Humalog to rapid-acting inhalable insulin, Afrezza. Over the past six months, discussions with insurance, Leroy and his endocrinology team revealed that Leroy could not be prescribed Afrezza because he smokes cigarettes. Fortunately, an alternative switch to a mixed insulin in twice daily doses was well-received by Leroy. Since switching to mixed insulin, Leroy selfreports more frequent administration and fewer severe symptoms over the course of an average week, however he continues to miss several doses each week and makes no attempt at administering the short-acting insulin he is also prescribed. Unfortunately, this modest progress in medication and appointment compliance is not mirrored in the frequency of DKA admissions, which continue to occur nearly every month and are responsible for three "cancelled" appointments since joining our program. (Table 1). Despite this,

both Leroy's dyad and care team cannot emphasize how instrumental hotspotting has been in improving his overall wellness. 'Hard' health outcome measures only tell part of the story. The vitally important 'soft' outcomes that stem from Leroy's improvements in food security, not feeling like a burden to his caretaker, and decreasing the needed frequency of diabetes-related injections have improved Leroy's attitude towards his self-worth, health, and his future.

Although Leroy has improved his quality of life, further progress in improving short-acting insulin adherence and decreasing his frequent hospital admissions can still be made. Leroy's habitual DKA admissions continue to occur due to lack of dietary management, blood glucose monitoring, and inadequate insulin administration. Although reportedly taking his mixed insulin more regularly, he admits only checking his blood glucose levels once or twice each week and has no desire to increase frequency or use a continuous glucose monitoring system. When discussing the events leading up to DKA admissions, Leroy reports the same pattern each occasion. He experiences fatigue and responds by lying in bed, unmotivated to seek food or his medication. This lack of action results in exacerbation of his fatigue and other symptoms, causing him to continue to skip meals and insulin doses until circumstances become dire enough for DKA symptoms to appear.

In addition to improving glucose monitoring, dietary adherence, and insulin administration, Leroy's care team would like to assess his mental health to ensure that psychologic barriers are not barring Leroy from receiving appropriate care. Although he appears to understand the severity of his disease, when asked questions or about his emotions related to his disease, Leroy responds with frustration and by disengaging from conversation. His motivation to proactively manage his disease when symptomatic remains severely low, despite the progress regarding appointment and medication compliance. It may be that Leroy's improvement may more accurately reflect the tremendously increased attention and resources focused on him through the hotspotting program than true acceptance of his diabetes. Leroy's motivational barriers must be overcome to ensure progress does not revert once this focused attention is reduced.

Leroy's story is uniquely relevant to the practice of family medicine and, we believe, illustrates best practices in primary care. The improvement seen in his health is, in part, a result of the improving relationship between Leroy and his care team. By achieving more autonomy, security, and an improved quality of life, his attitude towards his self-worth, health, and future have lifted. These improvements were made by targeting SDH barriers that prevented access to optimal care and wellness. Although progress has been made, Leroy's hotspotting dyad is still actively working to improve Leroy's glucose monitoring, dietary adherence, and insulin administration. Nevertheless, we believe that without the hotspotting program helping Leroy address his social and behavior determinant barriers, Leroy would be living in a far more precarious health situation than he is today.

Our Hotspotting Program builds relationships with patients, assesses their potential barriers to care, and engages in motivational interviewing to facilitate self-care. Barriers to providing regular care of this kind for more patients in a primary care setting include time constraints, financial viability, patient and caregiver despair, lack of patient knowledge, and lack of quick access to community resources which may help patients address SDH while the patient is in the office. In spite of these circumstances, it is our responsibility to provide compassionate, patient-centered care to every patient, especially the indigent and dispossessed. We hope that Leroy's story will help others in providing the humanistic, patient-centered care that is central to the practice of family medicine.

#### **Endnotes**

- 1 Camden Coalition of Healthcare Providers. Healthcare Hotspotting. 2019; https://hotspotting.camdenhealth.org/.
- 2 Fox W. Segregation Along Highway Lines: How the Kensington Expressway Reshaped Buffalo, New York: History, SUNY University at Buffalo; 2017.
- 3 Ross T. Health Equity: The Path to Inclusive Prosperity in Buffalo. University of Southern California Program for Environmental & Regional Equity, Policy Link; 2017: https://nationalequityatlas.org/sites/default/files/EP\_summarybuffalo-05-05-17.pdf.

Blake Kruger, MPH, received his BS in chemistry at Louisiana State University Agricultural & Mechanical College. After working extensively in research capacities, be completed his MPH at Dartmouth College's Geisel School of Medicine. As a medical student at the Jacobs School of Medicine & Biomedical Sciences, University at Buffalo, Blake aspires to deliver informed and consensual care, in an interdisciplinary fashion, serving the indigent and underrepresented while championing innovative, patient-centered care.

Shannon Coleman completed her BS public health at American University as a member of an accelerated public health scholars program. Three years of involvement with Community of Hope, a non-profit focused on improving healthcare and housing conditions in Washington, D.C. led Shannon to pursue a career in culturally competent primary care. Currently studying medicine at the Jacobs School of Medicine & Biomedical Sciences, University at Buffalo, Shannon aspires to serve low-income Buffalo residents to reduce health disparities and bolster community strength from within.

Sangrok Oh, DO, was born in South Korea and educated in England. Dr. Oh's worldly interests in family medicine grew from volunteering in rural Ghana and Haiti as a medical student, where he learned that fostering strong physician-patient relationships and health education is crucial to improving the overall health of a community. Dr. Oh practices full-spectrum family medicine at in the UBMD Family Medicine office on Sheridan Drive, and also cares for patients at Millard Fillmore Suburban Hospital in Williamsville, New York.

# The Last Visit

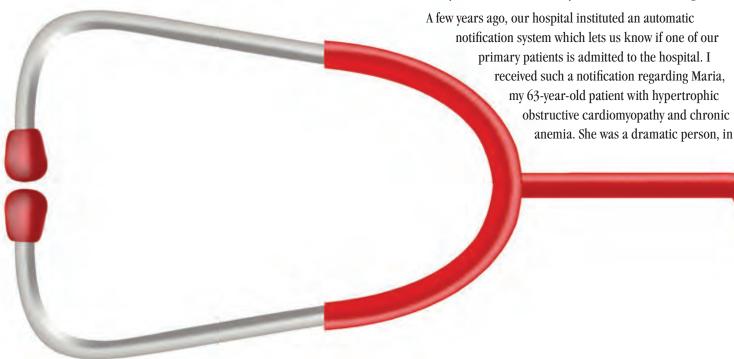
By Marion Richman, MD

In July, a new class of PGY 1s began their journey toward becoming family doctors at our residency program in a large urban academic tertiary care center. I jokingly say that I am now PGY 23 since I was in the first residency class of the same program so many years ago and now practice there as an attending. Being a PGY 23 means that some of the babies I delivered now have babies of their own. It also means that some of my patients who were in their prime when I began caring for them are now facing complications of their chronic diseases or developing new age-related conditions. In the last few months three of my longtime patients became precipitously ill. All of them had been living with chronic diseases but were managing reasonably well for years, with good quality of life. Specialists in the fields of oncology, pulmonology and critical care played a key role in their care as they became sicker. I began to reflect on my role as their primary doctor in this situation.

The "specialty" of family medicine has its roots in general practice. The "GP" took care of the community in small towns where settlers set up their homesteads in the US of the 1800s. Most of the care was done via home visits with the doctor arriving by horse and buggy. There were no antibiotics, no MRSA, no EMR, no radiology, and no specialists. If you were the GP, you were essentially "it" as far as births, deaths and broken bones were concerned. I believe that this version of "doctoring" still embodies the essence of today's family doctor.

The scope of medicine has certainly changed radically. There are specialties that are extremely specific such as pediatric neurooncology - invaluable if you should need them and hopefully you never will. Some specialties have become worthy of cult TV show status. Devotees (my teen daughter included) binge watch "Grey's Anatomy" which glorifies the specialty of surgery and many of us were rivetted by the aptly titled series "ER." As a child I too was mesmerized by a doctor TV show called "Marcus Welby." If you are not of the generation who got up to slowly turn dials on their black and white televisions, you may not be familiar with Dr. Welby. He was, actually a "family practitioner" who had a practice full of longtime patients whose families he knew well. I remember very little about the actual medical cases but his bedside manner and meaningful relationships with his patients impressed me. Although I did not set out to become my own version of Marcus Welby, I have nevertheless done exactly that! (So maybe TV is not all bad).

In the large tertiary care center where I practice, it would not be unusual for a patient's last weeks and days to come and go with the excellent care of the "house staff" alone. We are extremely busy with our scheduled clinical duties; many have research or academic commitments and we have our lives outside of this profession to deal with. Burnout is a buzzword these days — we are not looking for extra time-consuming activities. Furthermore, the idea of walking into a hospital ward, ICU or home that you do not usually frequent and where you do not have a clearly defined role is daunting.



contrast to her small and round stature. Our visits always included a lot of laughter and some bawdy jokes (on her part). I could see her jowly cheeks shake as she made declarations about life, her other doctors and her family. I saw via our EMR that she was admitted to the ICU and intubated. She had a respiratory infection, human metapneumovirus. She had been managing well with a home attendant and a rollator walker the last time we met which was a few months ago. The next time I checked our EMR, she was being discharged to the floor for comfort care/hospice. To be honest, I could not imagine this extremely animated woman in any other way than her laughing jovial self I had known for years. I wondered what I might possibly say to her family who were likely sitting there by her side. I did have a meeting to attend right near the main hospital, so I really had no reason not to go, except the ambivalent feeling in the pit of my stomach – wanting to be available at this last opportunity to visit her and yet not quite knowing what my role was, what I might say to her or her family that would offer comfort or meaning....

At times like these one often wishes someone would tell you exactly what to do and how to behave. Many religions have very useful customs surrounding transitions in the life cycle such as births and deaths. Jewish custom dictates a period of mourning after the death in the immediate family. It is called "Shiva" which literally means seven. It lasts 7 days and there are guidelines for how a person should mourn and how visitors can offer solace. In the instructive book To Be a Jew by Rabbi Hayim Halevi Donin, the section on "Comforting the Mourner" offers this guidance: "Upon entering the house of a mourner one does not extend greetings. Since words cannot adequately express the depth of sympathy a comforter wishes to

convey and what is said is often shallow, it is best to say nothing." Similarly, when visiting an extremely ill patient, I often feel that words are extraneous, it is more important to share space and time. Maria was alone, unconscious and

unarousable

when I

authorization form: "vanilla."

Angelica called me from the ER one

arrived. The openings of the nasal cannula were just to the left of her nostrils blowing their puff of air at her still round cheeks. A jacket lay on the chair near her bed and the neighboring patient in her room had a visitor. I nodded to the neighbor's visitor who told me the family had gone home to rest. I did not have to speak to anyone or even look her in the eye- she would not open them. Somehow, I had not anticipated this scenario and took a moment to consider how to proceed. Eventually, I just pulled the chair close to her bed and sat with my hand on her arm for a while. I spoke to her a little, though I'm not sure she heard me. The next day, I checked the EMR and read that she had died earlier that morning. I felt flooded with relief and gratitude that I had been able to see her one last time. I resolved to visit any and all my critically ill patients!

Angelica already had a diagnosis of breast cancer when she became

my patient more than 10 years ago. It had started in her 40s and now she was in her early 50s. She had a few other difficult diagnoses as well including idiopathic intracranial hypertension. The VP shunt had left her blind in one eye. Angelica had bone, liver and brain metastases for the last year but appeared to be managing with a variety of chemotherapies which seemed to change with great speed as her cancer outwitted them. She was demanding and persistent, often arriving at my office without a scheduled appointment when she thought she needed something. I had recently become much more involved in her care when her diabetes became uncontrolled due to oral steroids she was given by her radiation oncologist prior to her brain irradiation. If you happened to see her on the subway, you probably wouldn't have even known that she was sick at all. This spring however, her situation had changed. The brain metastases had reached her optic nerve and she became completely blind. Her son had become her primary care giver and would call me frequently, as did she. Both spoke Spanish, very quickly and I had to exert myself a bit to keep up with them, especially on the phone. When I last saw her in my office, her appetite was low. I was trying to get her insurance to pay for liquid nutritional supplements. She told me emphatically that she only wanted vanilla. I wrote it on the prior

morning — she was there because was having trouble walking. The inpatient oncology team quickly discerned that she had leptomeningeal disease. All her doctors were in contact via email and we conferred about the situation. I wondered if she might want to finally stop fighting. She had seemed resigned when I last saw her, just after she'd become blind. A note from ophthalmology stated that she would not likely recover her sight. Her oncologist offered that there were still chemotherapies that she could try.

Angelica was discharged to home hospice shortly after her admission. I believe she made the right choice and yet I felt defeated knowing that this tenacious woman was finally giving up. I called and spoke with her son. He spoke slowly now. She did not want to speak with me at all. They lived very close to my office and I asked if I could visit but Angelica declined. I said that I would check in with them the following week. When I got to work on Monday, I had received the rejection from Angelica's insurance for her vanilla nutritional supplement. I called her number and her son told me she had died over the weekend. There was a distinct sense of relief in his voice.

It's difficult for me to tease out exactly what I felt. She was a patient who was often challenging, did not follow my recommendations and was not always easy to deal with. I admired her commitment to this exhausting battle and mourned her loss of desire to live. It was frankly a relief to me when she did not want me to visit, but nevertheless her death left me floored.

It seems to me that despite our best efforts- writing birth plans and advanced directives, these life passages rarely go according to our plans. As a doctor, I want to heal and comfort my patients whenever possible. Somewhere in the overlapping circles of the Venn Diagram that is my life I am a mother, a daughter, a spouse and a friend. Elements of these relationships exist between me and my patients and yet the edges of that circle are wavy. This lack of clear borders, defined path and frankly lack of control is difficult to navigate at best.

Susanna was an extremely vital, intelligent woman in her 70s. She and her sister had been my patients since I was an intern. Susanna was formally diagnosed with idiopathic pulmonary fibrosis a few years ago and it affected her quality of life but did not seem to threaten the length of her life until recently. This past year she'd had a few hospitalizations with respiratory infections, each time requiring more support. This last time, she had a brief ICU stay and then was moved to a step-down unit. I wasn't sure what to expect when I went to see her one rainy afternoon. I had watched a dear patient die of lung cancer years ago and hoped this would not be similar. As I went to the nursing station to confirm that she was in her room, I saw her sister in the family waiting area. I went over to them and was surrounded by her family, each one greeting me warmly with hugs

and kind words. We walked to her room together and I was relieved to see that she was as I had always known her to be - alert, intelligent and clear eyed. I felt very connected to her and to her family and was so grateful for their warmth. I realized that I was grieving too. This visit helped me come to terms with the losses I have recently had. I felt that my relationship with Susanna was complete and whole. I knew this would be our last visit and it was okay.

In the Marcus Welby TV series that had inspired me as a child, there were not many fancy treatments. The Bipap that Susanna had on and the chemo and radiation that prolonged Angelica's life were not yet part of the routine armamentarium that doctors used to treat their patients at that time. I do however, remember a lot of meaningful glances and heartfelt exchanges between Dr. Welby and his patients and their families. While much of medicine has become complicated, this aspect has not changed. It was so comforting to know Dr. Welby would always be there with a firm grasp and a guiding word no matter what was happening. Patients and family members often feel abandoned by their doctors at the end of life. Back et al (https:// www.ncbi.nlm.nih.gov/pmc/articles/PMC2918275/) identified two important elements in the professional value of non-abandonment: "providing continuity of both expertise and the patient-clinician relationship and facilitating closure of an important therapeutic relationship." I believe that closure of a long-term relationship is important to us as doctors too. We grieve these losses, especially after knowing a patient and their family for many years.

These final visits do not always go as planned- the patient may not be conscious; you may be rejected or not know what to say and yet I feel that they can play a vital role for our patients and for us. As family doctors, a large part of the care we offer is in the form of a lasting relationship. We age with our patients, witness each other's lives and hear each other's stories. If you are in a mental, emotional and physical state that allows you to visit a patient for the last time, I strongly recommend that you go and hear the end of their story. Don't plan your words too much, just showing up speaks for itself.

After one completes the long road from medical school to residency, they become an "attending." As a PGY 23, I have been an "attending" for 20 years yet I have always found the word to be odd. Is it a noun? A gerund? It certainly comes from the root "to attend." If you look this word up in a dictionary (they still exist), the first definition you find is "to be present." I believe this is still one of the most important things we can offer our patients.

**Marion Richman, MD** is a family doctor at Columbia University Medical Center in Washington Heights, New York City. She trained in the first residency class of the Columbia Presbyterian Family Medicine Residency Program where she is now an attending physician and faculty member.



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# Sundowning

### By Emily Chase

Does an interaction with a patient need to be remembered in order to have meaning? Does a conversation need to be retained beyond its time in order to have significance? Or could that conversation simply happen and in that temporary existence have importance in itself?

These are the questions that circle in my mind as I sit at the edge of a plastic chair in a white-walled hospital room in the middle of the night. The phone had rung minutes earlier in the residents' office—a nurse concerned about a patient sundowning and asking for permission to use restraints. Sundowning is a term used to describe the increased confusion that can occur in older patients with dementia during the nighttime. The resident had agreed to the use of restraints, but after hanging up the phone, had clicked her tongue against the roof of her mouth with a sense of sadness and explained that she didn't like to use restraints against patients unless she absolutely had too. This patient was a sweet elderly woman, and the resident had asked if we, the medical students, could go to floor five, talk to her, and help to calm and orient her to the environment of the hospital.

This was how we found ourselves, a group of three exhausted and excited medical students, facing this woman at 12 am. We peek our heads into the door of room 513, and there she was, a woman with a wrinkled face and hair the color of sunlight thrashing

against the hand restraints holding her to the bed. "Help!" She croaks this word over and over into the hallway, the P of one "help" tumbling over the H of another until there is no space between them, cycling together into one human groan.

We tiptoe into the room hesitantly. The woman's gray eyes focus on us, these three shadowy figures in the dark. One of the students leans down and asks, "Would it be okay if we join you?" She breaks out of her shouting and blinks, her eyes clouded. "I feel helpless," she croaks. "People keep coming in and out of the room and I don't know what is going on..." She reaches up her hands to adjust her hair, and her scarred veiny wrists strain against the ropes tying her to the bed. "You were pulling out your tubes earlier," one of the other students explains. "Don't you remember?" She nods, slowly, the fog blinking out of her eyes until the three figures become real, become students, and the details of our faces sharpen into focus. "I love your hair," she exclaims to me, and we chuckle and she grins, and the air lightens. It feels for a moment as if the confusion has dissipated.

"Are you happy?" The woman reaches out as far as she can to hold to my hand. "I'm okay," I swallow. "But, are you *happy?*", she asks again with a particular urgency in her voice. And for a moment there, I think this elderly woman possesses some special wisdom to see into another's heart as she continues, her voice



hesitant. "Is there someone special in your life?" Those eyes, which I had so easily dismissed as confused, now hold such insight, such sensitivity.

The crinkles around her eyes brighten. "I love your hair," she says again. "Thanks," I smile. Then she laughs and smiles and looks at me intently, as if she knows me, as if she cares deeply about me, and asks the same question again. "Are you happy?" "Sometimes," I say.

"Is there someone special in your life?", she asks, her eyes still as bright and curious as one minute before. And it begins to sink in—she has forgotten what we had told her previously. The conversation is on a loop, running over itself like a record.

"I love your hair. Are you happy? Is there someone special in your life?" she begs. We answer and she responds with the same words over and over again. I begin to wonder if our conversation was doing anything important, or if she would again become just as agitated and confused after we left. Would she lay back in bed just as unhappy as before? Would our interaction have any impact? Would we leave an impression?

What is this life, of things disappearing? This entire hour of conversation— I know it's still supposed to mean something. But sometimes, I don't understand what I'm supposed to do with these tiny moments that are not connected to something else, that don't build, that don't become bigger, that only sink deeper and deeper into themselves.

But watching her face brighten, in those small moments, there is a feeling within me declaring, softly at first and then more loudly, that there must be a value to this interaction. Every small transience mirrors a larger transience. If one conversation an elderly woman would soon forget lacked value, was one life we would soon leave also not valuable?

Or put another way, if our short and transient lives are to be meaningful, then this brief encounter must also be meaningful. For the value is not just in the length of the moment or the remembrance, but in the beauty of the moment itself. Our meaning is not measured by our invincibility or long-lastingness. Perhaps it is even the fragile and forgetful nature of our lives that makes the moments we do have special.

I think of time, which passes by beyond our control, and I think of the memories I still hold onto and the memories I have forgotten. All those unremembered times from my childhood—I cannot imagine a world in which they do not still have some importance. They existed, they happened, and this has to be enough.

Being with a patient, in that moment, is enough. Patients with dementia often forget their conversations with their providers, but that does not undercut the value of those interactions. Learning to appreciate conversations with patients with memory difficulties is crucial to us as family medicine physicians, as we are often the first line of providers for our older patients. Grappling with learning how to connect with these patients and to be able to value those connections is vital to treating and caring for our geriatric population.

But still, I wish she could remember. And still, I wish the moment would carry onward. In some small way I feel like her, locked inside a life too small for all the things she wants it to contain. "I feel helpless," she says and fights against her constraints. I can't prove for certain it means something, me standing with her and answering her over and over, us creating and erasing our own personal spiral of conversation. And still, I hold her hand.

**Emily Chase** is a medical student at Albert Einstein College of Medicine, currently pursuing a master's degree in bioethics between her third and fourth year.

SEXUAL TRAUMA AND CHRONIC PELVIC PAIN: JUST ASK

By Chelsea Daniels and Orlando Sola, MD, MPH

Virginia¹ presented to our clinic for her first time complaining that her leg felt like broken glass that could shatter at any moment. She was 21 years old, a soon-to-be college senior, an avid hiker, a vegan; but all of this had been dwarfed for the past two years because of what she described as an insidious, persistent left-sided body pain. It all started in her left hip, then her left knee, then back to the hip, then down to the ankle. And before she knew it, this pain spanned the left side of her body from head to toe. She had seen neurologists and physiatrists, orthopods and rheumatologists, all of whom were befuddled — every piece of laboratory and imaging data came back clean, leaving Virginia feeling helpless in the face of her chronic pain.

As she told me her story, I found myself clinging to one detail in particular: the pain first appeared in her hip. And it was a pain so severe, she said, that putting weight on this hip became a painstaking effort with every step. I knew of a few studies that detailed a correlation between victims of sexual violence and the later development of pelvic pain in some form, so I asked Virginia to reflect back to two years ago when this pain first began. Could she think of any form of physical, emotional, or sexual trauma that she may have survived, I wondered? Without hesitation, she divulged that she had been raped that very same semester, a connection she herself had never made, nor had the multitude of specialists following her case.

While there is limited research on the physiology underlying this phenomenon, there is compelling evidence suggesting that Virginia is not alone. A retrospective chart review at the University of New Mexico Hospital in 2013 revealed that of the nearly 1300 women studied, 17% had survived sexual violence; and among these women, "chronic pelvic pain" was "significantly associated with a history of sexual abuse." Another study based out of a pelvic pain clinic at the University of North Carolina, Chapel Hill demonstrated that 46% of patients with pelvic pain endorsed a history of sexual or physical trauma. Data like this seem to suggest that providers have identified the issue and implemented a solution—though I fear that in many cases, only the former tends to be true.

However, since the start of the #MeToo movement in the fall of 2017, the tides appear to be turning—#MeToo has revolutionized the way that we, as a society, discuss and confront the lived sexual trauma of and violence against women. In doing so, we have taken several important steps forward: perpetrators are increasingly being held accountable — 201 in the first year of the movement, to be exact.<sup>4</sup> Women are feeling more and more empowered to speak out. And structural sexism is gradually moving to the forefront of our collective consciousness. While meeting Virginia and hearing her story caused me to reevaluate the medical community's relationship to the often

missed, or worse—ignored, sexual violence that our patients experience, I remain steadfast in my belief that there is immense hope, yet, still progress to be made and that family physicians are uniquely situated to lead the charge.

Both AAFP and ACOG acknowledge the direct link between chronic pelvic pain and sexual trauma, and the impact that chronic pelvic pain

can have on a survivor's life. In 2010, AAFP listed chronic pelvic and back pain, in addition to fibromyalgia, as well-documented sequelae of sexual violence.5 And just earlier this year, ACOG went so far as to recommend that providers "[pay] particular attention to those [survivors] who report chronic pelvic pain," citing this as a primary responsibility of the clinician in order to provide comprehensive "traumainformed care."6 These two academic bodies are also unanimous in their assertion that it is the physician's duty to talk to their patients about sexual assault, and each has published committee options and editorials with specific suggestions for the best way to navigate these delicate encounters, such as "[using] the patient's exact words" when discussing the episode, and diligently avoiding overly legalized or medicalized jargon.5

If this evidence linking sexual violence to chronic pelvic pain is widely accepted, and there are a multitude of resources at our disposal for how to talk to our patients about lived trauma, where are we going astray? Where is the foothold for providers to better serve and reach patients who have survived sexual trauma, namely those suffering from pain, like Virginia? First things first: simply ask. Sensitively. Gently. Supportively. With a listening ear. Ask if she is a survivor. Ask how she is feeling. Ask about symptoms of pelvic pain. Gather this information as you would any other in a comprehensive past medical and social history. Women want to be asked: in fact, a

study from the University of Texas showed that 95% of women find "discussions of sexual violence by their [healthcare providers] to be helpful and nonintrusive," while only 6% "expressed" any "discomfort with being screened." This is important—too important to miss.

And it seems that the next, likely more long-term goal is to reprogram our medically-wired brains to think of sexual violence as a buzzword for a myriad of associated conditions, and likewise, to put sexual violence on our differential for any patient presenting with pain. By way of analogy, when a patient reports a history of smoking, we immediately ask about cough, shortness of breath, and sputum production; and when a patient complains of shortness

of breath, we ask about cough, sputum production, and of course, smoking history. Providers should be encouraged to think about sexual violence in a similar fashion—if a patient reports trauma, reflexively ask about pain; if a patient reports pain, reflexively ask about trauma. The more awareness that clinicians have about these experiences and symptoms, the more specific

Family doctors in particular, as the primary point of medical contact for many women, are perfectly suited to screen for violence by posing these hard questions to patients, listening, providing support, suggesting resources, and hopefully drawing the connection between a patient's complaints and her lived violence. In a single visit with a family physician, topics often run the gamut from gynecologic to musculoskeletal to psychiatric specifically because the family medicine setting is designed for this sort of full-scope encounter, enabling us as providers to connect the dots with our patients. And when in doubt, just remember Virginia, my patient who is living proof of the progress family physicians have the power to make. Virginia was bounced around from specialist to specialist simply because nobody asked about her history of trauma. Now, she has a referral to mental health and is on the path to recovery, all thanks to a simple question.

and effective screening can become.

### SUGGESTIONS FOR TALKING TO PATIENTS WITH PELVIC PAIN ABOUT VIOLENCE:

- 1. Make the questions feel natural and seamless, as any other part of the encounter might.
  - "You mentioned this pain in your hip. Any falls recently? Is it worse in certain positions? How is it affecting your ambulation?...
  - ...I was also hoping to ask you a bit about any sexual trauma or violence you may have survived, either recently or far in the past."
- 2. Normalize the conversation topic as much as possible, so as not to make her feel singled-out or judged.

"This is something that I like to talk to all my patients about. I don't want you to feel at all pressured to talk about this if you don't want to, but I am here for you if you would like to share."

- 3. Show her that you understand how hard this must be, and reassure her that this is a safe space.
  - "I cannot imagine how difficult this might be for you, but I want you to know that this conversation is just between you and me, and that I am here just to listen and be an ally for you."
- 4. Explain to her what you might be thinking, especially if there is a reported history of trauma.
  - "There is actually some data that shows us that many women who survived trauma like you did are now experiencing pain like you are. We don't quite understand why, but it is a documented phenomenon—and I want you to know that you are not alone in this."
- 5. Ask her if she would like to be connected to resources. "Based on what you've shared, I can help connect you to different resources that might help, whenever you feel ready for that step."
- 6. Thank her for her honesty and acknowledge her courage. "Thank you for sharing with me. You are so brave to talk to me about this, and I want to help you however I can."

#### **Endnotes**

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Orlando Sola, MD, MPH grew up in New York and Massachusetts with a family of socially-active individuals. He completed his undergraduate studies at McGill University, attended medical school at Columbia College of Physicians and Surgeons, and obtained his MPH at Johns Hopkins University in Health Policy and Management. Prior to medical school, Orlando was an AmeriCorps intern in East Los Angeles. He completed his residency training in family medicine at the Institute for Family Health—Harlem program, and now works as a core faculty member at SUNY Downstate.

# Restoring a Connection: Re-engaging Family Doctors in the Care of Hospitalized Patients

By John Krisa, MD

Family doctors left the hospital. Your patients desperately need you back.

I finished my family medicine residency almost twenty years ago. After a few years bouncing around as a young locum tenens and urgent care physician, I stumbled into the hospitalist field.

Fifteen plus enthusiastic years as a hospitalist clinician and administrator have led me to a stark realization: the absurd absence of primary care input and influence among hospitalized patients. Allow me to explain my perspective.

After moving to Upstate NY to settle down, my job search ultimately came down to two choices: a traditional family medicine practice and a new hospitalist program. Choosing the latter, I had the benefit of interacting with the docs from the FM practice, as they were one of the few practices that

still covered the hospital. We had a pretty symbiotic relationship that I'd like to believe benefitted all parties. The hospitalists offered a "tuck in" service providing H & Ps and initial orders during off hours while the PCPs rounded daily and discharged their patients. Hospitalists were available for acute issues and routine night calls, thus enhancing PCP REM sleep. All in all, it was a good system. Patients understood that the hospitalists were an adjunct complementary service that augmented the detailed knowledge of their PCP and allowed for immediate bedside evaluation and treatment in the event of an emergency.

As the years passed and the hospitalist model grew, most PCPs completely relinquished hospital duties. The field exploded, going from essentially a handful of hospitalists in 1997 to over 50,000 today.

The departure of family doctors from the hospital was logical. Variable volumes, disruption to office hours, uncompensated travel time and an increasing complexity of patients made this an easy decision for many physicians. Better compensation and lifestyle with less hassles seemed attractive.

But at what cost has this come for their patients, and the healthcare system at large? Foremost, the loss of patient comfort, familiarity and continuity. The hospital is a perplexing and frightening hive of activity that can be an unpredictable emotional roller coaster for overwhelmed patients. As opposed to the close intimacy of a primary care setting, with an identifiable PCP and a small number of ancillary staff, an average hospitalized patient staying for even a few days can see dozens of care team members between physicians, advance practice providers, nurses, techs, transport personnel, food service, case managers and the like. For a longer stay this number may balloon to the hundreds.

Frequent handoffs between hospitalists are common. A five-day stay would not be unusual to include an admitting physician, a subsequent rounding physician soon going off service, a locum or per diem provider covering a weekend day or two, and a full timer starting a new stretch

of shifts. Even with a good sign out process, which is far from guaranteed, each provider largely instinctively starts cold and may take several days to get a solid grasp on the unique circumstances of their patient panel. The hospital environment does not lend itself to depth of connection or communication, especially among itinerant staff simply covering a day or weekend. Even when a patient does not adore their PCP, they can at least

identify them, are satisfied enough to have chosen to maintain the relationship, and expect that the

provider knows them. There are defined rules of engagement.

The wealth of knowledge that comes from a longitudinal relationship goes largely untapped under the current hospitalist-PCP model. Communication between factions is often scarce or nonexistent. The warehouse of the ambulatory EHR is shuttered, denying the acute care team pearls of hard won wisdom gleaned from trial and error and patient-physician collaboration. Whether out of convenience or necessity, too many times hospitalists re-invent the wheel. I know I have.

Despite these shortcomings, hospitalists are not going away. The traditional model of PCPs assuming primary responsibility for the hospital and the office (as well as perhaps a nursing home or three) is not coming back. Patients are sicker, older, and have more social problems. Time and financial pressures are too great for an inefficient model to fail on delivery of necessary care.

What we can strive for and achieve is meaningful primary care participation in the care of their hospitalized patients. Particularly as payment frameworks shift away from fee for service and toward population health with assumption of financial risk, PCPs must find innovative ways to remain engaged across the care continuum. Here are some proposals to facilitate that goal.

### **ED Notification/Communication**

Often PCPs are unaware their patients are in the ED, and they are not included in the disposition decision-making process. With primary care input, unnecessary hospitalizations for ambulatory sensitive conditions (think cellulitis, pneumonia and the like) may be avoided or shortened to an observation stay. If the patient must be admitted, opportunities should be made available for discretionary PCP communication with the patient, family, ED provider/hospitalist, and to forward office records to smooth and streamline the hospitalization process.

### **Social Calls**

Not every situation requires it, but a non-clinical correspondence via telephone, email, or if circumstances allow, face to face, can boost spirits and telegraph where the patient is at in preparation for their return to the office.

### **Tele-visits**

Ideally, these would be reimbursable and perhaps they will be in the future. Imagine scheduling a 15-minute daily encounter to communicate with patients, family, hospitalists, or case managers to assist with care coordination and management. Consider the implications of exponentially improving technology: how distant is the prospect of a holographic virtual visit?

### **Pre-discharge Transition of Care Conference, Part I**

Preventable readmissions are the bane of quality and value based care. Often attributed to substandard communication and a "voltage drop" at time of transition, PCP inclusion in a multidisciplinary meeting at or shortly before discharge could alleviate and eliminate many elements responsible for readmits. In a risk based reimbursement model even an uncompensated care conference may far offset the costly expense of an avoidable readmission or even an ED visit.

### **End of Life Discussions**

Hospitalized patients are vulnerable physically and emotionally. Trust problems may arise when already decompensated patients are asked to make major decisions by unfamiliar and sometimes unwanted providers. The hospitalist model suffers from the basic truth that patients get the provider assigned to them, whether the fit is good or not. PCP awareness of and participation in decisions of large magnitude can help to clarify and appropriately direct care consistent with the patient's wishes and expected outcomes.

### Pre-discharge Transition of Care Conference, Part II

Part I discussed earlier regards discharge home, whether directly or after an interim rehabilitation stay. But what if the patient is going to a long-term care facility, or to hospice? An opportunity for the PCP to share knowledge

opportunity for the PCP to share knowledge with the incoming team and forward records preps the new caregivers and is a courteous and humanistic way to bid a proper farewell to a patient who may not return to your care.

### **Analytics Sharing**

As the technology revolution marches us relentlessly forward into a brave new world, a natural repository for health related data, either directly clinical or related

to social determinants of health, would likely be the ambulatory EHR. Monitors, trackers and wearable devices of every variety will continue to proliferate, disseminate and produce analyzable data with the potential to both prevent and treat illness and disease. The absence of interoperability between EHRs remains a vexing challenge and suggests that a PCP intermediary to provide curated contextual information from the reams of data available will be vital to future best practices.

Too often in medicine we strive for what is common and not what is possible. Of the 3.5 trillion dollars spent on US healthcare in 2017, one third is on hospital care. That number can and should be lower, with the value for each dollar spent appreciably higher. Through dedication, advocacy, and spirit, family physicians can reclaim a prominent role in hospital care and lead us to a better future for patients, hospitals and providers.

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# Vaccine Hesitancy

By Jen Baker-Porazinski, MD

I tried not to glance at my watch as Jonathon's mother apologized for being late to her son's first appointment with me. It took longer than she'd thought to find my rural office, which was two and a half hours from her home. I stared at her incredulously. While many of my patients drove an hour or more to see a specialist, it was unusual to travel that distance for primary care. When I asked her why she chose a doctor so far away she confided that she found my name on an "underground network" on the web of anti-vaccine doctors. Whether I was listed as simply tolerant or entirely against vaccines was unclear. Either way, I was shocked that this network existed and that I, a mother of three fully-vaccinated sons, was on it. Maybe respecting parents' choices was no longer the right thing to do?

I guess it was just a matter of time. The local pediatricians in my town stopped seeing unvaccinated children a few years ago. This decision caused an influx of unvaccinated patients to neighboring primary care offices. Although this hadn't really posed any major problems yet, I wondered how effective a doctor I could be to Jonathon when he lived several hours away? While it may seem convenient to label all parents who don't want vaccinations as ignorant, in reality vaccine-hesitant patients are a heterogeneous group and the large majority are white and highly educated. <sup>1</sup>

What makes intelligent parents make this choice? Some simply don't trust their physician because they lack a solid doctor-patient relationship. Many have concerns about vaccine safety, an idea reinforced on social media. Others are concerned about freedom of choice and believe that the government should stay out of health decisions. But vaccination is a public health issue, not a personal one.

Patients increasingly turn to the Internet for information and advice on health issues. It's no wonder that new parents, born in the era of Google searching and internet browsing, readily access this source for opinions on child rearing. Also, unlike their grandparents (whose local doctor often treated their family for generations) many younger people haven't developed a bond with their family doctor. These patients are more likely to make an appointment for a signature on paperwork than to ask their doctor for guidance.

While the benefits of technology can't be overlooked, at least part of the eroded doctor-patient relationship stems from its widespread use in medicine. With the emergence of complex electronic medical records, doctors spend more time looking at computers than they do at the patients in front of them.<sup>2</sup> It's hard to blame patients for not wanting to initiate a potentially controversial discussion of a sensitive nature with a provider staring at a screen, especially when it involves the welfare of their children. It's easy for busy doctors to put the conversation off for another time.

There are several possible outcomes of this divide between weary doctors and their vaccine-hesitant patients. One is that the doctor may

avoid the discussion altogether, indirectly consenting to a parent's desire to defer or skip a vaccine. Another is that the doctor may dismiss unvaccinated children from their practice (or, as recently reported, parents may dismiss a doctor who treats unvaccinated kids). Although the American Academy of Pediatrics recommends providing health care services to unvaccinated children while continuing to engage parents in the conversation, they don't outright condemn the radical stance of dismissal. The possibility of exposing vulnerable patients in the waiting room too young or sick to be vaccinated is a real concern. But the potential ramifications if more doctors refuse to provide care for unvaccinated children can be devastating, especially in rural and underserved areas. Unvaccinated kids need doctors, too.

I admit there have been times when I wished my administrators would take a similar stand so that I could avoid this sometimes heated and time-consuming conversation altogether. I know I'm not alone. Doctors report increased dissatisfaction in their work when dealing with vaccine resistant parents. In truth, though, I believe that a policy of exclusion may be more harmful than the thoughtful inclusion of unvaccinated children. My opinion was solidified when I began caring for a new patient, Charlie, who traveled an hour to become my patient. He showed up late to an appointment one morning with no medical records (something not uncommon in families that don't vaccinate). In Charlie's case, though, he didn't have records because he *badn't been to see a doctor*. His parents, who'd immigrated from a poor country where vaccines weren't as readily available, were so



afraid they'd be coerced into vaccinating their son that they simply avoided bringing him to a doctor. Now, though, Charlie was about to start school and needed a physical. Although he was almost five years-old, he was unable to communicate beyond pointing and grunting, broken up by occasional high-pitched screams of frustration. He ignored any attempt I made to interact with him, avoided eye contact and pulled away when I tried to examine him. He also ignored the pleas from his desperate parents.

To my relief, Charlie's parents weren't completely in denial about his obvious delay. They knew something was wrong with Charlie, but didn't think that there was anything that a doctor could do about it. His devoted mother cooked vegan meals at home with organic vegetables, judiciously avoiding processed food. They used natural cleaning products. Charlie had never taken any medication. Both parents feared that Charlie's developmental delay would be worsened by vaccinations. His father told me that as a child he had an allergic reaction to vaccines. His mother shared that she had been ill for over a year when she first came to the United States. She was convinced that her symptoms were a result of a vaccine she was given in order to attend college. I suspect that the vague symptoms of fatigue, lack of motivation, and trouble concentrating that she attributed to her vaccination were more likely a result of situational depression from leaving her family and country. Regardless, both parents believed that they were doing the best that they could for Charlie. Their fear about vaccinations prevented him from receiving desperately needed intervention sooner.

The World Health Organization ranked "vaccine hesitancy" as a top 10 health threat to the world this year, alongside major public health concerns like climate change, Ebola and HIV.<sup>3</sup> Most family doctors practicing in the United States today were lucky to be shielded from deadly vaccine-preventable diseases during training. As a medical student, I never had to stand by helplessly and watch a child suffocate from epiglottis. None of my newborn patients ever suffered birth defects from a maternal rubella infection. Smallpox (which contributed to the downfall of the Roman, Aztec and Incan empires) was eradicated when I was still in grade school thanks to focused vaccine efforts by WHO. I never even saw a case of chickenpox until well after residency.

But with increased travel and decreased vaccination rates, we are seeing a sharp rise in vaccine-preventable diseases, especially in our most vulnerable populations. It's no wonder WHO is worried. Despite a global effort to eradicate polio spanning 31 years and costing more than \$16 billion, over 42 cases of polio paralysis were reported in Pakistan and Afghanistan this summer. Most victims were children under the age of 5. The polio outbreak was attributed in large part to false rumors spread on social media about children fainting or dying after vaccination. Parents reportedly locked doors and hid their children from vaccinators. WHO estimates that for each child paralyzed there are 200 others shedding the virus in cramped cities with open sewers.

As we are now painfully aware, though, disease outbreaks don't only occur in foreign countries. In 2010, a recurrence of pertussis

in California killed 10 infants too young to vaccinate.<sup>5</sup> These infants would have been protected by herd immunity if sufficient numbers of the population were vaccinated, prompting the recommendation that pregnant women and their family members receive pertussis boosters. Measles, which had been declared eliminated in the US in 2000, had a resurgence with over 1000 cases reported already this year.<sup>6</sup> Over half of these cases were in New York State, prompting the revocation of religious exemptions. Many New York doctors found themselves scrambling as the new school year began to squeeze unvaccinated children into their already over-packed schedules so that they could attend school.

The success of widespread vaccine efforts does have a downside, though. It is easy to lose fear of diseases we don't ever see. Outbreaks will continue as long as parents, the large majority of which also haven't witnessed vaccine-preventable diseases in friends and family, believe vaccines are no longer necessary. While the recent measles outbreak may serve as a reminder to some about why we vaccinate, it is unlikely to change the minds of the minority of parents who staunchly oppose vaccination. But I wonder how these same parents will react when there is a vaccine against Lyme disease, which is endemic where I practice. Almost every one of my patients knows someone who had severe health repercussions from tick borne illness, from arrhythmias to meningitis. I suspect that most will eagerly embrace a vaccine for themselves and their family members if one becomes available.

Kicking patients out of medical practices and avoiding difficult vaccine discussions is clearly not an effective way to improve vaccination rates. Fortunately, the real solution to the problem of vaccine refusal is a strongpoint for family doctors - connecting and communicating with our patients. The single most important factor in gaining vaccine acceptance remains one-on-one contact with a caring doctor. Like parents, family doctors want what is best for the children in their practice.

Alison Singer, MBA, developed a model for structuring these difficult conversations that she named CASE (Corroborate, About me, Science, Explain/Advise). "Corroboration" is respectfully acknowledging a parents' concern while trying find common areas of agreement. Doctors need to ask specifically what their patients are worried about and then address these concerns in a non-judgmental way. "About me" directs the doctor to describe what they have done to build their knowledge and expertise. "Science" is a reminder to present the facts. Doctors must counter anti-vaccine social media messages with factual information as we are likely the only medical providers that can provide this balanced information to our patients. "Explain/Advise" is to give recommendations based on science. Doctors must give the clear message that vaccines are safe and effective since many vaccine-hesitant parents are actually seeking guidance. Most parents still trust us to help them to do the right thing.

Doctors can also discuss the unintended positive effects of some vaccines, like broad-based protection against other illnesses. For example, scientists observed that after receiving the measles vaccine, not only do deaths from measles plummet but so do deaths from

### Vaccine Hesitancy, continued

unrelated diseases like pneumonia and diarrhea. This phenomenon has also been seen when live polio and tuberculosis vaccines are introduced into poor regions.<sup>8</sup>

Experts recommend that doctors make assertive recommendations regarding immunizations, and assume that their patients will be vaccinated rather than passively questioning parents about whether they are interested. For parents on the fence, this provides some assurance that we ourselves believe in what we recommend. One study showed that a majority of mothers preferred to receive information before the first vaccine visit so that they could formulate their questions and concerns ahead of time. Doctors practicing in a Montreal hospital found they had significantly improved vaccination rates by proactively discussing vaccines with women after birth, before they even left the hospital. These doctors used motivational interviewing to uncover patients' fears and then respectfully addressed them in the immediate postpartum period. This proactive approach resulted in improved immunization rates at the two month well child visit.

I take pride in the relationships I've fostered in my patients through years of caring for them. They appreciate that, like most family doctors, I treat them with dignity. I share my knowledge, guide and listen to them but ultimately respect their choices. In divided political times, though, where many Americans are concerned about an infringement of their personal rights by "forced vaccination," the conversation has become more volatile. But lately, I worry that my tolerant attitude may be more harmful than helpful.

I recently saw Charlie back in my office. He was a different boy. He held my gaze when I looked at him and didn't scream and flail his arms when I examined him. His speech was still difficult for me to understand, but he was able to communicate with his parents and followed their instructions. Since my last visit Charlie had been receiving intensive intervention at home and at school, including speech, physical and occupational therapy. Charlie's parents were different, too. They appeared more relaxed and beamed with pride at his progress. They repeatedly expressed their gratitude for my assistance in getting him the help he needed.

I wish I could report that at this visit we had a heart-to-heart talk about Charlie's health and that his parents, with their newfound trust in the medical establishment, agreed to vaccinate Charlie. Instead, though, they informed me that they had pulled Charlie from school rather than comply with the stricter New York laws requiring him to get eight different vaccines to attend. This year all New York children must receive the initial dose of each vaccine series within two weeks of the first day of school and provide documentation of follow-up vaccine appointments. Primary care offices are working hard to accommodate these families. Like Charlie's parents, though, some parents would rather quit their jobs, relearn algebra, and hire tutors than allow their children to be vaccinated.

Fortunately, although the percentage of unvaccinated children has increased from 0.3% of 19-35 month olds in 2001 to 1.3% of children born in 2015, most parents do follow vaccination guidelines. <sup>10</sup> I've changed my approach to the rare parent who tells

me outright that they won't immunize their child no matter what. In the past, I wouldn't bother even initiating the conversation. Now, though, I treat the discussion the same as I do smoking cessation. Every doctor knows that they can't convince a patient to quit smoking who's not ready yet. We also know, however, that an open dialogue improves chances of quitting in the future.

More than any pamphlet I can provide on the benefits of immunization or scary facts I might share about the dangerous diseases they prevent, I believe that simply having the conversation is how family doctors will combat vaccine hesitancy. We need to do what we do best - build relationships and gain back our patients' trust, one patient at a time. I will continue to educate parents and will still respect their decisions, but I will no longer avoid the difficult conversation.

I owe it to their kids.

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Jennifer Baker-Porazinski, MD is board certified in family practice,

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integrative medicine and acupuncture. She has worked in rural New York for 19 years where she also serves as a school physician. She is currently writing a memoir about her experiences in becoming a family doctor, the current state of bealthcare in America, and the need to bring humanity back into medicine.



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