

Joy in the Practice of Sleep Medicine

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The Mission of the American Academy of Sleep Medicine: The AASM improves sleep health and promotes high quality patient centered care through advocacy, education, strategic research, and practice standards.

It was a great honor to begin service as the 29th President of the American Academy of Sleep Medicine earlier this month at the SLEEP 2014 meeting in Minneapolis. There, I had the pleasure of joining with current and past leaders in sleep medicine to honor Dr. Thomas Roth for his years of contribution to the science and practice of sleep medicine. But foremost, I had the great privilege to meet with colleagues, mentors, and collaborators, new and old. Relationships are key in professional satisfaction, and so often serve as gateways to insight.

JOY

One sunny evening I shared a sidewalk dinner on the Nicollet Mall with a recent alumnae of our fellowship program who had started her practice in sleep medicine in a modest-sized midwestern community. She relayed some of the challenges and frustrations she was experiencing as she learned how to practice sleep medicine in the non-integrated practice world. Don [fictitious name] entered her office tired, frustrated, almost angry, and seeking help. Ten years previously, he had been tested for and found to have obstructive sleep apnea (OSA). He had never had the opportunity to hear the details of his test findings or to ask questions, nor did he recall ever receiving much follow-up care or assistance after a positive airway pressure (PAP) machine with a one-size-fits-none mask had arrived at his door without a person to explain what to do with it. After some initial struggles and failure to get assistance from the remotely—really remotely—positioned durable medical equipment (DME) provider, his primary care provider suggested a different DME provider some miles away, who was unable to help him because they did not have the reports needed for insurance purposes. After Don obtained copies of the needed paperwork, they offered some instruction but—unfortunately, did not have much variety to offer in terms of interfaces. Don couldn't recall ever being told about heated humidity settings. Don abandoned his efforts and was untreated these past 8 years. He had suffered at work, in his family, and in his social life from sleepiness and other effects of untreated sleep apnea. He had hypertension and developed atrial fibrillation 5 years ago. My colleague explained how Don entered her office resolute

to not use “C-crap” and demanded another therapy. After first tracking down the old study results, she patiently explained them along with many treatment options (PAP, oral appliances, oral pressure therapy, surgical approaches), and explained the potential benefits, likelihood of success, risks, and costs of each kind of therapy. Don asked to know more about PAP. She asked Don if he would be willing to see what some newer or different PAP interfaces might feel like. She spent time letting him try some different masks, and saw what she described as “a light go on” in Don as he understood that there could be some options for him. He expressed willingness to try PAP again. She next worked through his insurance issues, and then coordinated things to get him a new PAP machine and supplies—ones that Don liked. This took several phone calls and many signatures, often for duplicate paperwork. Four weeks later he returned to her office. She was ready for a challenging visit—the kind associated with a patient who is struggling to succeed or who has decided against being helped. Instead she found a large midwestern man with a huge smile on his face who hugged her, proclaiming, “Thanks for giving my life back to me.”

Joy. There was great joy in my colleague's eyes as she related how it made her feel to reach in and change someone's life for the better. She was enthused about how practicing her chosen field was impacting so many patients' lives for the better on a daily basis. She was excited about Don.

I relate. I know you do, too. I've been practicing sleep medicine for 20 years. I love it. In some sense, there has never been a better time to be a patient in need of sleep care. Our field offers highly trained sleep specialists, other well-trained professionals who help deliver sleep care, many accurate means of diagnosing sleep diseases, and a wide variety of effective therapies. We can and do make a difference in patient's lives.

However, there was a long distance between Don's first sleep study and my colleagues joy in seeing him cared for. Too long. That is why I feel more than ever that the mission of the American Academy of Sleep Medicine is exactly the right mission. If we succeed in this mission, patients will benefit, society will benefit, and we will have joy in our work.

THE COSTS

So, what is in the way? Don was fortunate to have a well trained and dedicated professional who spent lots of time working through a highly fragmented and poorly coordinated system. This system failed Don. Years later, possibly with preventable harm, Don re-entered the system through the office

of a sleep specialist. Only through significant persistence and expertise did Don receive a treatment program that is working. And, my colleague paid for the system inefficiencies with her time, frustration, and quite literally, her income. She experienced joy, but at too high a cost.

Fighting the many areas of waste in a poorly designed health-care system is not sustainable. More importantly, working in a system with such wastes disrespects persons of any level of training—physician, advanced practice registered nurse, physician assistant, registered nurse, clinical assistant, respiratory therapists, sleep technologists, secretaries, whomever. Over time, such bad systems deprive our patients of high value healthcare and rob us of joy.¹ This is particularly concerning at this tender time for sleep medicine. We will need to take action to improve the systems we work in, or risk missing an opportunity to make a huge difference.

What can we do? I believe there are distinct roles for both the Academy and for sleep specialists to play.

THE ROLE OF THE ACADEMY

One of the most pressing issues we face is clarifying the role of a sleep specialist in a future outlined in broad strokes by the Patient Protection and Affordable Care Act.² This act is encompassed in its consolidated form in 955 pages, divided into 10 TITLES, referencing primary care 156 times. Reference to specialty care (11 times) or specialists (21 times) is comparatively scant, and reference to sleep is 0, but sleep medicine is not alone in seeking to understand the best way to contribute in an ACA era.³⁻¹⁰ The chief goals of the ACA are to extend health care insurance coverage to millions of Americans and improve the value of care by improving outcomes and reducing wastes and costs. Several models of care are under evaluation as means of reaching these goals. One of the most prominent models of care promoted by current policy is the Accountable Care Organization (ACO), a group of health care providers who have agreed to accept responsibility for the health care of a defined population and to meet predetermined quality benchmarks. In December of 2013, the Centers for Medicare and Medicaid Services announced the addition of 123 Medicare Shared Savings Program ACOs to those already in existence, making a total of 366 ACOs, serving over 18.2 million lives.^{11,12} ACOs are becoming a dominant model for care delivery, although 46% of healthcare executives do not have plans to implement an ACO in the future.¹³ Similar to the ACO, the goals of the patient-centered medical home (PCMH) are to move from rewarding volume of care to rewarding value of care.^{14,15} In both models, details of the relationships between primary and specialty care, and the required infrastructure needs to be worked out at local levels.

How the Academy Can Help

I believe the Academy can help patients a) by helping sleep medicine specialists and their care teams practice better sleep medicine, b) by providing tools to assist in the conversion from volume based to value based incentives for care, c) by partnering with and educating primary care providers and integrated care organizations so that patients receive appropriate testing and care for sleep diseases, d) by being a resource to and influencer

of our legislators who help form health policy that affects sleep patients and physicians, e) by helping to promote sleep research that will produce the diagnostic and management methods of the future, and f) by developing future leaders who can help influence sleep health for our fellow citizens.

These goals will not be accomplished during my tenure, or the tenures of my immediate successors. However, we have begun the work required to meet these goals. Many of the details of our plan were detailed in my report presented at the SLEEP 2014 meeting.¹⁶ A summary follows.

Develop Clinical Care Standards. We may be sure that clinical guidelines will play an increasingly important role in this new era of ACOs and PCMHs. Because sleep specialists are critical to efficient diagnosis and effective management of common sleep complaints and diseases, evidence based guidelines will be particularly useful as specialists inform local practices of how to maximize outcomes while reducing costs. We are not only updating several key guidelines; we are working on new or enhanced key guidelines such as Diagnostic Testing for Adult OSA, Actigraphy, PAP Therapy, and Pharmacologic Treatment of Adult Primary Chronic Insomnia. We continue improvement to accreditation standards so they serve our patients and those delivering care.

Develop Quality Metrics. All of the models of care developing in the ACA era feature the need to measure quality. The Academy has been at work since last June developing sleep-specific quality metrics that will help practitioners measure, improve, and demonstrate the quality they provide. Patients will benefit as we together learn the most effective ways to improve the quality of their care.¹⁷ In nearly every instance studied, improving the quality of care reduces the costs of care as well, making the value proposition even brighter for sleep medicine. We will begin to develop programs to help our membership develop their capacity to lead improvement and change.

Advance Infrastructure And Role Definitions In New Models Of Care. The AASM additionally seeks to reduce the fragmentation and delays often experienced by our patients while managing sleep diseases. Reducing fragmentation requires better definition of the roles and responsibilities in relationships between primary and specialty sleep care, as well as improved electronic infrastructure. One way to help accelerate that change for some will be to enroll with Welltronic, an investment of the Academy that seeks to provide a more integrated and assisted way for sleep centers and specialists to interact with payors, PCPs, and patients.¹⁸

Prepare for Care in the Connected and Contextual Age. When properly aligned, sleep specialists and AASM accredited centers can positively influence outcomes.¹⁹ However, there is a large segment of our population who has limited access to a sleep specialist. Accordingly, the Academy has started efforts to develop policies and best practices to standardize and appropriately promote telehealth sleep services.²⁰ We have also undertaken efforts to develop recommendations for standardized sleep diseases and sleep medicine specific discrete data fields that EMRs should provide to best serve patients.

Strengthen and Expand the Team. We can also improve the level of care for sleep diseases delivered by primary care physicians, advance practice registered nurses, physician assistants, and registered nurses through helping to develop

or deliver appropriate educational programs.²¹ In this way we strengthen the whole sleep care team.

Advocate for sleep health and sleep specialty care. The AASM will advance its efforts to advocate for healthcare policies that promote care of sleep diseases and sleep health. Academy efforts helped bring about bipartisan support to our Seniors Sleep Campaign, a budget neutral bill that adds an OSA questionnaire to the “Welcome to Medicare” preventive visit.²² We have extended our new partnership with the CDC in the National Sleep Health Awareness Project, which raises awareness of the sleep medicine specialty and brings increased recognition to “healthy sleep” as a key to population health and public safety.²³ These are examples of the enhanced visibility that sleep is gaining in public health awareness.

Promote Research. Research expands options for patients with sleep diseases. The Academy made a decision earlier this year to fund \$10 million in research over the next 5 years primarily earmarked for sleep related healthcare delivery research, training of younger sleep researchers, and seed money for newer innovations in treatment or humanitarian projects via the American Sleep Medicine Foundation.

THE ROLE OF SLEEP SPECIALISTS

Realizing the unique training and expertise of sleep specialists, the relatively superficial training in sleep medicine afforded our primary care providers, and the vast numbers of Americans with sleep complaints, it is clear that sleep specialists should play a vital role in helping ACOs and PCMHs determine how to achieve the best outcomes while being responsible with resources.

How Sleep Specialists Can Help

Seek leadership positions. Sleep specialists should look for leadership opportunities in integrated models of care, and promote the specialists’ role in appropriately caring for sleep patients. Look for opportunities to interact consultatively with local industries to inform their sleep and fatigue policies. If sleep specialists do not assume these roles and do not become involved in consultative relationships with local practice groups and guide them in evidence based approaches to sleep care, sleep specialists will be marginalized by ACOs, PCMHs, and others involved in care model development. Patients will suffer, and the joy of practice will diminish.

Help demonstrate and develop local evidence-based policies. Keeping the best possible care of patients in the forefront, sleep specialists will need to expand their focus from test interpretation to a greater emphasis on demonstrating expertise in the longitudinal care of sleep patients. Sleep specialists are uniquely qualified to assist in the development of local policies and plans to assure that the right tests and treatments are applied in order maximize clinical results and reduce wastes. This means promoting both avoidance of overutilization of certain tests, such as polysomnography or multiple sleep latency testing, and assuring that needed tests are available when indicated.

Measure and Improve Quality and Costs. We should anticipate that integrated health care organizations of whatever construct will expect participation in “shared risk,” i.e., that we will benefit when costs and outcomes are favorable, but will

bear some of the costs of suboptimal outcomes. In one model of shared risk care, the Alternative Quality Contract, primary care providers demonstrated a shift in their referral patterns toward specialists who maintained quality data and effectively shared these with PCPs.²⁴ Individual sleep specialist practices must learn to collect quality metrics and use them to continuously improve the care they deliver. Additionally, we should take measures to understand unit costs and find ways to trim away excesses. Only in this way will a sleep practice be prepared to enter into risk-sharing arrangements.

Tell your patient’s stories. During the Sleep 2014 meeting I had the honor to introduce Congressman Erik Paulsen, who serves Minnesota’s Third Congressional District, as our speaker at the AASM Political Action Committee breakfast. He led with an impressive and fact-filled story about a patient in his district. What impressed me most was something he said during the question and answer period—something that might have escaped my notice except for my dinner conversation with my colleague. He explained that our legislators need to hear the patient stories. The Academy provides Congressional leaders with information and research that support good sleep medicine policies. That data can be useful in changing minds. But our leaders need patient stories in order to change hearts. Only changed minds and hearts aligned together bring change. Sleep specialists know the stories. Sleep specialists can relate their patient’s stories of frustration and missed opportunities for care. They can also relate the stories where specialists make the difference. I urge you to collect these important stories and to relate them to your representatives via letters, phone calls, and conversations.

Mentor the next generation. Most of us entered our profession because of patients, because of the joy in the practice of medicine.²⁵ Others who conveyed that joy to us likely influenced our career decisions heavily. Sleep specialists must convey that joy to high school, medical students, and residents as they consider their futures. We know that sleep medicine is a very satisfying profession, but they don’t know that. Tell them. Show them. Look for opportunities to mentor. Most of our future colleagues are making decisions earlier in their careers than we did, so reach out and see what you can do to convey your enthusiasm.

JOY REVISITED

We have great accomplishment behind us, and great opportunity before us. The Academy and other specialty societies have important roles to play. We have stepped into our role. Individual sleep specialists and those they work with have an important role as well. Martin Luther King, Jr. once said, “Our lives begin to end the day we become silent about things that matter.” Joy matters. Speak loudly with your actions. Go take care of a patient, and watch for the joy. Know that we can increase it by working together to improve our systems of care, by increasing the quality of what we bring to our patients, and by continuing to nurture our exciting field of sleep medicine.

CITATION

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