Welcome to the Health IT Theme Issue
This month, we offer a smattering of columns based on health IT. From the power of the “wiki” and its capacity to reform how we update the electronic health record (EHR) to the impact of personal devices on medical education and professionalism, we know this month’s content will help you think about the changing culture of health IT, as well as cautions about letting it flourish unconstrained in our clinical practices, as expressed in Ann Nattinger’s column on the EHR. Enjoy!

SIGN OF THE TIMES

Make Your Problem List Wiki Wiki
Neeraj H. Tayal, MD; Robert Murden, MD; and Sarah Jonaus, MD

Dr. Tayal is assistant professor, Dr. Murden is clinical professor, and Dr. Jonaus is assistant professor at The Ohio State University Wexner Medical Center in Columbus, OH.

A wiki (/wik-ee/) is a technology that allows a community of online collaborators to add and edit the content of a webpage using a simple user-friendly interface. The content of a wiki is posted immediately without further review. Wikipedia, “the free encyclopedia,” is created and maintained using wiki technology. Its success as a knowledge management tool is hard to overstate with more than 4,062,639 current articles. In contrast, medical professionals generally regard Wikipedia with skepticism. We are accustomed to scholarly peer-reviewed literature in which the author and his or her credentials are clearly identified. That skepticism should be balanced, however, by the reality that bits of information from different vantage points accumulated in one place will paint a more diverse, accurate, and current account of the subject.

Wiki for medical care? Really? The current generation of learners is, and should be, castigated for using sites like Wikipedia as a medical reference. Yet, we boldly suggest that the wiki approach can effectively be applied to electronic medical documentation.

We know that in order to make optimal medical decisions, physicians must understand the unique disease experience of a patient. This includes the patient’s risks factors, early manifestations of illness, and evaluation establishing the diagnosis, treatments, and responses. We also need to know what information was provided to the patient, including his/her decisions and preferences. Without this patient-centered understanding, we are prone to management errors. Unfortunately, the vast amount of data in a modern-day medical record, whether paper or electronic, promotes information overload that results in losing the forest for the trees. Furthermore, key elements of a patient history must be quickly ascertained before meeting with a patient and making management decision.

Traditionally, we have captured these key elements as narratives in our progress notes. These progress notes have served us well over the past 40 years but are proving inadequate in a shared medical ecosystem. In a paper chart, progress notes disappear from sight as they form deeper and deeper sediment layers. In electronic record systems, they vanish into giant spreadsheets with hundreds of rows. As a consequence, many clinicians fail to look back more than a couple of notes in the record.

continued on page 13
iPod, iPad, iPhone: iPatient?
Tanu S. Pandey, MD, MPH

Dr. Pandey is assistant professor of medicine at Rush University Medical Center and co-program director of the Preventive Medicine Fellowship in the Division of General Internal Medicine at John H. Stroger Jr. Hospital of Cook County in Chicago.

Listen to the patient, he is telling you the diagnosis.

—Sir William Osler, MD

And if you listen more, he will tell you the treatment. The art of history taking and physical examination is a vital and fundamental aspect of clinical care. Well-trained doctors depend predominantly on these clinical skills to make decisions and deliver optimal medical care. Educational programs in US medical schools and across the globe emphasize early initiation into clinical training, mostly in the second or third year of medical school, and require one year of mandatory rotating internship prior to specialty training. In 1998, a Clinical Skills Assessment section was added to the qualifying United States Medical Licensing Examinations to assess the ability of foreign medical graduates to gather and interpret clinical patient data and communicate effectively in English. This has since been replaced by the Step 2 Clinical Skills examination that uses standardized patients to test all examinees on their ability to collect pertinent medical information from patients, perform physical examinations, and communicate their findings to patients and colleagues. The goal of this integrated clinical encounter is to ensure that appropriate emphasis is given to clinical sciences and basic patient-centered skills as the foundation for the safe and effective practice of medicine.

In recent times, state-of-the-art electronic mobile devices have literally brought real-time medical information to the fingertips of health care providers. These handheld devices or “smartphones” are increasingly being used by medical professionals and have been shown to be useful tools in the day-to-day practice of evidence-based medicine. Traditionally, physicians as a group have been slow to adopt information technology, including electronic medical records. However, when it comes to mobile devices there has been a significant increase in their use by physicians from 25% in 2004 to more than 50% in 2010.

These devices are available at reasonable prices and have easy learning curves—both attractive features for resident physicians in training programs. There is little debate over the fact that portable computation improves point of care practice, medical decision making, effective clinical communication, cost, patient education, and overall coordination of care. However, the relevance and suitability of such devices in the training process of medical students and residents is questionable and may even negatively impact the problem-based learning format that has historically been an integral part of educational programs in the United States. “Bring your own device (BYOD)” is a business strategy in the technology world that is increasingly being used by companies to boost employee productivity, morale, and convenience by allowing them to use their own devices, perhaps at the risk of potentially continued on page 12
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ccording to the US government’s Office for the National Coordinator for Health Information Technology, “health information technology (health IT) makes it possible for health care providers to better manage patient care through secure use and sharing of health information.” As general internists, we may be uniquely positioned to recognize both the opportunities and the pitfalls of health IT.

When I think back over the past couple of decades, it is truly amazing how much clinical practice has been affected by health IT. The transition from paper to electronic medical records has greatly improved the availability of information to the numerous members of different health care teams (e.g. inpatient, emergency, and ambulatory teams). Having always practiced in large multispecialty settings, I can remember clinic days when only 50% to 60% of the patient’s paper medical records arrived at the clinic prior to the appointment time. This led to many opportunities for exercising the provider’s memory—but also many opportunities for mistakes. The situation was not much better on the inpatient side, with the chronic problem there being the inability to find the chart in reasonable temporal proximity to one’s visit to the bedside—leading to numerous unnecessary return trips to the wards.

So when our institution decided to commit to an electronic medical record some time ago, my initial thoughts focused on how wonderful it would be to almost always be able to have access to the notes, lab results, imaging reports, and myriad other pieces of data needed to care for my patients. I did not comprehend for some time the many other ways that health IT would provide opportunities for improved care. For example, I now have access to all my patients’ immunizations if administered anywhere in the state of Wisconsin and can see glimmers of a future when I will be able to see the entire care record for episodes of care taking place anywhere in the country.

Similarly, health IT has opened patient records to the patient. My institution has a patient portal that permits patients to view their problem lists, medical/family/social history information, medications, allergies, selected test results, and immunizations—almost anything other than notes. Former SGIM President Tom Delbanco is actively studying the consequences of permitting patients routine access to their medical notes,’ which I suspect will become standard practice.

Less anticipated benefits have been the changes in workflow attributable to the health IT system. While careful scrutiny of exactly who does what and in what order may be a painful process to undergo, I am convinced that this process can increase the efficiency of the care we provide. An unanticipated benefit for those of us residing in Wisconsin has been the fact that the large EMR firm Epic is located here, and its growth has led to a kind of full employment plan for many college graduates in this state.

I have to say that my initial expectations of health IT were so low that those expectations have largely been met, even exceeded. The patient data I need (at least data from my own institution) is almost always available, I can use the chart while other team members also use it, and the ability to have access to data while covering for other colleagues has been wonderful. The challenges now have to do with pitfalls that were typically not anticipated in the past and the greater expectations that have developed now that we are gaining a clearer vision of what may be possible in the future.

For example, we now understand the incredible temptation to import material gathered or created during prior clinical encounters into a current encounter. The ability to do this is sometimes a benefit to the patient. However, this temptation is leading not only to poor communication (viarambling “cut and paste” continued on page 11
There are multiple surveys that report physician compensation and production each year. Each has slightly different survey techniques. For instance, the American Medical Group Association (AMGA) 2012 Medical Group Compensation and Financial Survey provides data on compensation from 225 medical groups representing 55,800 providers and 124 specialties. The 2012 Medscape physician compensation study surveyed 24,216 US physicians across 25 specialty areas between February 1-17, 2012.

Changes seen in the 2012 reports include a 4% to 5% increase in median compensation for primary care physicians based on both the Medical Group Management Association (MGMA) Physician Compensation and Production Survey: 2012 Report and AMGA 2012 Medical Group Compensation and Financial Survey. Other medical specialties averaged an increase of 2.8%, and surgical specialties averaged around 3.4%. This is likely secondary to the increased focus on preventive care and health care reform. However, based on the 2012 Medscape physician compensation survey, 54% of primary care physicians felt that they weren’t being fairly compensated. Similarly, a QuintiaMD study of physician well-being in July 2012, which included approximately 5,700 physicians, showed that 26% of primary care physicians reported poor financial health, 43% had trouble covering costs, and 18% had their salary reduced over the last one to two years. Reasons for the financial difficulties include decreased reimbursements and increased costs. Without primary care physicians, it will be difficult to fulfill primary care-centric models such as the patient-centered medical home and to accommodate new patients brought in by the Affordable Care Act (ACA).

In response to this, insurance companies such as WellPoint, the nation’s second largest insurer, began paying bonuses to primary care physicians in their networks. The MGMA Academic Practice Compensation and Production Survey for Faculty and Management: 2012 Report, which is based on 2011 data from more than 20,000 faculty physicians and non-physician providers across all specialties, found that physician compensation in academic settings continues to trail that of physicians in private practice. For instance, anesthesiologists earned $326,000 in median compensation in academic settings and $407,292 in private practice.

In addition to salaries, many physicians qualify for bonuses and incentives based on performance. In a 2011 Today’s Hospitalist Compensation and Career Survey, 70% of hospitalists reported having some form of bonus and incentive program. On average, hospitalists reported that 18% of their annual income (or $45,000 per year) came from bonuses and incentives. Measures used to calculate bonuses and incentives include meeting productivity standards, improving quality and/or core measures, and participating on committees. Factors associated with higher bonuses include working in a local hospitalist group, having high volumes, and living in a higher-paying geographic area. (Southwest averaged $77,000, while Northeast averaged $33,000 in bonuses.)

Yet does money equate with happiness? The 2012 results for the Medscape Physician Lifestyle Report show that on a Likert scale, with 1 being very unhappy and 5 being very happy, internists ranked themselves as 3.88, which was tied with gastroenterologists and neurologists in the least-happy group. Only 45% of internists felt that they were fairly compensated according to the Medscape Internist Compensation Report: 2012 results. Of these, 61% felt that they would choose medicine again as a career, but only 25% would choose the same specialty. In contrast, 71% of dermatologists surveyed on the Medscape Dermatologist Compensation survey felt that they were fairly compensated, and 69% said they would choose the same specialty. These factors contribute to dermatologists being some of the “happiest physicians on the block.”

In conclusion, although increases in salaries and bonuses were seen for internal medicine this year, a large number of internists feel undercompensated—especially with increasing overhead costs and decreasing reimbursement. A physician’s financial health plays a large role in overall job satisfaction, but other factors such as personal family time, respect among colleagues, and lessening the burden of administrative work play important roles as well. Because general internal medicine and family medicine physicians are essential to health care reform policies as outlined in the ACA, care needs to be taken to improve the overall satisfaction of physicians.

Suggested Reading

continued on page 15
Ensuring robust and sustained appropriations for the Title VII workforce training and diversity programs is a critical advocacy activity of SGIM’s Health Policy Committee. While most SGIM members are not direct Title VII grantees, many of us are products of such training programs. Since the 1960s, Title VII legislation has catalyzed the growth of the generalist workforce and helped establish many divisions of general internal medicine (GIM), primary care clerkships, residencies, and GIM fellowship programs. These Health Resources and Services Administration (HRSA) programs are unique in their focus on training a workforce to address health care disparities and the health care needs of medically underserved communities, both urban and rural.

HRSA’s Bureau of Health Professions (BHPr) oversees grant programs of potential interest to SGIM members, including pipeline and diversity programs (Centers of Excellence, Health Careers Opportunity Program, Area Health Education Centers) and seven primary care training grants in: 1) predoctoral training, 2) residency training, 3) physician faculty development, 4) academic administrative units (research infrastructure grants), 5) physician assistant training, 6) interdisciplinary and intraprofessional joint degrees, and 7) National Research Service Awards (NRSAs).

During the 1960s and 1970s, HRSA Title VII programs addressed the shortage of health care professionals by funding the expansion of medical schools and student loan programs. In the 1980s, the focus shifted to building the infrastructure for academic primary care in divisions of GIM, general pediatrics, and departments of family medicine and providing funding for generalist research training. In the 1990s, HRSA responded to growing concerns about health care inequities by focusing Title VII programs on the care of vulnerable populations. New grant scoring mechanisms were implemented for training grants. The Primary Care Funding Priority added points to the final grant score if the applicant met specific targets for placement of graduates in primary care careers. The Medically Underserved Community Preference moved submissions to the top of the list of approved grant applications if specific targets for placement of graduates in medically underserved communities were achieved. All grant applicants were required to propose innovative curricula designed to prepare trainees to care effectively for segments of the medically underserved community.

Moving Forward
With the enactment of the Affordable Care Act in 2010, Title VII was reauthorized. The new authorization eliminated a funding preference for family medicine, earmarked 15% of the funding for physician assistant education, expanded the funding cycle from three to five years, and increased the funds authorized to be appropriated to $150 million per year. The expansion of the grant funding cycle, along with flat funding, has resulted in less frequent competitions (Table 1).

The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) advises and makes recommendations to the secretary of Health and Human Services concerning policy and program development for the HRSA BHPr. Their ninth report recently submitted to the secretary and to Congress highlights improvements in primary care education, faculty development, and workforce capacity due to Title VII Section 747 grant programs despite significant reductions in funding over several years. The committee suggests as areas of emphasis for future Title VII grant guidance: interprofessional training in the patient-centered home model, skills to address population-based health, and increased funding for faculty development.

Table 1. Title VII Grant Cycles, 2011-2012

<table>
<thead>
<tr>
<th>Program</th>
<th>Reviewed/ funded</th>
<th>Current grants</th>
<th>$ in first funding year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic Administrative Units</td>
<td>2011: 39/19</td>
<td>34</td>
<td>$2.9 million</td>
</tr>
<tr>
<td>Pre-doctoral Training</td>
<td>2011: 45/21</td>
<td>41</td>
<td>$3.8 million</td>
</tr>
<tr>
<td>Inter-professional Joint Graduate Degree Program</td>
<td>2012: 32/10</td>
<td>13</td>
<td>$2.5 million</td>
</tr>
<tr>
<td>Residency Training</td>
<td>2011: 77/30</td>
<td>58</td>
<td>$5.8 million</td>
</tr>
<tr>
<td>Physician Faculty Development</td>
<td>2011: 69/23</td>
<td>33</td>
<td>$4.4 million</td>
</tr>
<tr>
<td>Physician Assistant Training</td>
<td>2012: 19/12</td>
<td>39</td>
<td>$2.3 million</td>
</tr>
</tbody>
</table>

Source: Shannon Bolon, MD, MPH, Branch Chief, Division of Medicine and Dentistry, Primary Care Medical Education Branch, ACTPCMD meeting, July 2012.
The Society of General Internal Medicine is pleased to announce its new logo and website at www.sgim.org. Over the past year, SGIM has been working to redefine itself as the premier society for academic general internists. We think our new touch-points logo represents the future of the field and the connections that academic physicians can make through membership in the Society.

Aside from the new logo and color scheme, the most tangible element of our new brand is the completely re-envisioned SGIM website. Built with our members needs in mind, this site is full of ways to connect to each other. Networking is the cornerstone of the new website, which is fully integrated into social media outlets like Facebook, Twitter, LinkedIn, and YouTube. There are online areas in which people can discuss the latest Forum articles; learn about the work being done in SGIM committees, task forces, and workgroups; and find out about innovations in education, research, and clinical practice. The Association of Chiefs and Leaders in General Internal Medicine (ACLGIM) has a new look and website as well and can now be found at www.aclgim.org. Here you’ll find information about the Association, including links to ACLGIM meetings, publications, and tools for ACLGIM members.

One of the most exciting parts of the new website is GIM Connect (http://connect.sgim.org). Available to SGIM and ACLGIM members only, GIM Connect is a portal filled with opportunities for information exchange. It is a great way to collaborate, document share, and interact with your peers in real time.

Over the next few months, members will continue to see innovations popping up on the website, including the brand new www.jgim.org microsite and the newly designed directories for fellowship, residency, and public health training (a collaborative effort with the Association of American Medical Colleges, George Washington University, and the Centers for Disease Control and Prevention). We plan to invigorate the clinical practice area and add more resources in the advocacy section as well.

We’re proud of the work we’ve accomplished over the past year and are pleased to be able to present this new look and new site to you. We’d love to hear your feedback. Feel free to contact SGIM through Francine Jetton, Director of Communications, at jettonf@sgim.org with comments or questions.

It’s an exciting time to be an SGIM member. Welcome to the new SGIM!
What’s New at SGIM?

The Society of General Internal Medicine (SGIM) is excited to announce the launch of our newly designed, easy to navigate website, located at www.sgim.org.

In addition to our new logo, this member-centric website will proudly present GIM Connect – SGIM’s new collaborative online environment.

This new platform is the premier route for our members to interact with one another through file sharing, discussion boards, blogs, etc. The website also features exciting new areas in research, education and clinical practice as well as information on advocacy and SGIM’s award winning career center.
Clinical Study Start-Ups—Best Practices
Kimberly Irvine, CIP, CIM

Ms. Irvine is vice president of Operations and Regulatory at BRANY, the Biomedical Research Alliance of New York (www.brany.com), which is a consortium of several academic medical centers and offers services to clinical investigators, research sites, sponsors and clinical research organizations.

The increase over the last decade in the cost of running clinical trials is well documented. Phase III clinical trial costs account for 90% of the cost of drug development. Several issues have contributed to this increase and the disproportionate costs of late-stage clinical trials in the drug development process. One of these issues is the duration of clinical trials. A Tufts University study showed that the average length of a clinical trial increased by 70% between 1999 and 2005.

While the reasons for this are many and varied, delays in study start-ups are a significant contributor. A 2011 industry study showed that clinical trial delays were primarily due to contract and budget negotiations. Other frequent factors leading to delays were patient recruitment, protocol amendments, legal review, and review of consent forms.

Both parties—the study sponsor as well as the investigator—can play a role in streamlining the start-up and therefore expediting the process. This article addresses how study investigators can prepare for the start-up of a study so it runs on time.

There are benefits to both physician and patient participation in clinical trials. Physicians gain greater awareness of new therapies and are able to provide them to their patients. Their practice becomes attractive to patients who are seeking the latest treatments. Additionally, investigators have opportunities to meet, collaborate, and network with leaders in the field.

The relationship between an investigator and a sponsor is important not only to ensure good science but also to prevent miscommunications and conflicts. We recommend several strategies to strengthen the sponsor-investigator relationship.

Dedicate an employee to staff the study. Larger multi-specialty medical groups and hospitals may have specially trained study coordinators. Working under the direction of the investigator, these specialized staff act as a single point of contact among the principals—the sponsor, the institutional review board (IRB), and the department, among others. Even if you do not have the resources to hire or retain a clinical research coordinator or research nurse, it is important to identify one employee as the point person to facilitate the administrative tasks critical to starting and running clinical trials. A coordinator can help the physician to prepare the regulatory documents for the IRB review, prepare a budget, maintain documentation and study-specific forms, and track source documents.

Another benefit to having a dedicated employee working on clinical trials is in responding to sponsors’ monitoring visits and inspections by regulatory agencies. At least one person should be intimately familiar with all the study documentation and materials.

If you expect to participate in several clinical trials, it may be beneficial to invest in special training and education for your staff member. Training courses can familiarize your employee with fundamentals of clinical research, federal guidelines, ethics, and clinical trial budgeting.

Understand the process. In addition to an IRB review, the protocol may also need to undergo additional reviews by other committees. For example, some institutions have specialty-specific committees in oncology or surgery. While the IRB’s focus is on protecting the rights and ensuring the welfare of research subjects, other committees may consider additional issues such as the feasibility of the study or biohazard material safety. Additionally, there may be a conflict of interest committee to ensure possible or perceived conflicts are appropriately addressed and managed.

Create a template workflow approach. If you plan to participate in more than one clinical trial, you should consider developing a checklist of policies and procedures as well as expected timelines. You can then re-purpose this template across all your trials to ensure consistency and to avoid skipping any steps. Workflow can be managed through simple paper-based checklists or project management software. There are also Clinical Trials Management Systems (CTMS) specifically designed to track clinical trials.

Whichever system you choose, it should be detailed enough to allow for tracking of activities, timelines, and assignment of tasks.

Understand the timelines. Your workflow should include all the dates and deadlines for meetings. According to the Association for the Accreditation of Human Research Protection Programs (AAHRPP), the mean time from submission of a research protocol to approval is 45.2 days.

Consult with your colleagues. Before agreeing to participate in a trial, you may want to discuss it with others in your department. Your department chair may have questions, or there may be concerns about whether you have a large enough patient population to meet recruitment goals.

Develop a patient-participant recruitment plan. The holy grail of successful clinical trials is the recruitment and retention of participants. Clinical trial enrollment rates are dropping, and up to 20% of research sites never enroll a single patient. 

continued on page 10
Tired of Feeling Sleepy

Barry G. Fields, MD (presenter) and Ilene M. Rosen, MD, MSCE (discussant, in italic)

Morning Report is edited by Michael Landry, MD, and Deepa Bhatnagar, MD. Dr. Fields is a sleep medicine fellow and Dr. Rosen is an associate professor of clinical medicine, in the Division of Sleep Medicine, Perelman School of Medicine, University of Pennsylvania Medical Center.

An otherwise healthy 25-year-old woman presents to her primary care physician concerned that she is tired all the time, “dragging through the day.” She first had trouble staying awake at school around age 14 and has experienced worsening of her symptoms since then. She occasionally naps off while driving and often falls asleep during work breaks. Her medical history only includes seasonal allergies, and she takes an oral contraceptive. She works as a research assistant, denies smoking or illicit drug use, and rarely consumes alcohol. Nobody in her family experiences similar symptoms. Her Epworth Sleepiness Scale score is 17/24.

Feeling “tired” can be interpreted various ways, making it important to distinguish fatigue from sleepiness during initial evaluation. While fatigue can result from prolonged physical or mental exertion, excessive daytime sleepiness (EDS) refers to the tendency to fall asleep; fatigue can improve with short work breaks or rest without sleep, whereas sedentary conditions often exacerbate true EDS. A commonly used subjective sleepiness measurement tool is the Epworth Sleepiness Scale (ESS). This self-administered questionnaire records sleepiness on a scale from 0 to 24, with a score greater than 10 representing sleepiness and a score greater than 15 suggesting pathological sleepiness. Given the patient’s history and the results of her ESS, she appears to be pathologically sleepy.

The differential diagnosis for EDS is quite broad. Common non-sleep disorder etiologies include medication effects, hypothyroidism, and mood disorders such as depression. Illicit drug use should also be considered. Basic laboratory work-up (e.g. chemistries, complete blood count [CBC], thyroid function tests [TFTs], and urine toxicology screen [Utox]) along with a depression screen can rule out many of these diagnoses. In addition to laboratory testing, a detailed sleep history should be obtained to evaluate for sleep disorders leading to EDS such as:

- Disorders of sleep quantity: sleep deprivation (“insufficient sleep syndrome,” poor sleep hygiene)
- Disorders of sleep quality: sleep apnea, restless leg syndrome (RLS)
- Disorders of circadian rhythm: advanced sleep phase, delayed sleep phase, jet lag
- Primary disorders of hypersomnolence: narcolepsy, idiopathic hypersomnia

The patient sleeps between about 8:30 pm and 6:30 am nightly; she has a similar sleep schedule on both weekdays and weekends. There are frequent, temporarily refreshing two-hour daytime naps on weekends. Our patient reports no recent travel. She does not snore and never awakens choking or gasping. The patient denies nighttime lower extremity dysesthesias (aches, pains, crawling sensations) as can be seen in RLS. Her depression screen is negative. On physical examination, her vital signs include a pulse of 76 beats/minute, blood pressure of 120/68 mmHg, and BMI of 21.5 kg/m². There are no signs of macroglossia (enlarged tongue), retro/micrognathia (recessed/small mandible), enlarged tonsils, or low-lying soft palate to suggest that the upper airway could obstruct during sleep. The rest of her examination, including neurologic assessment, is also normal.

Her chemistry panel, CBC, thyroid function tests, and urine toxicology screen are all within normal limits. The patient reports ongoing sleepiness and anxiety over what could be wrong with her.

Since the most common sleep and non-sleep-related disorders are unlikely to be contributing to our patient’s symptoms, there is now increased likelihood of a primary hypersomnolence disorder such as narcolepsy or idiopathic hypersomnia.

Narcolepsy is a lifelong condition that often develops in adolescence and early adulthood. It is characterized by an inability to maintain wakefulness due to abnormal intrusions of rapid eye movement (REM) sleep (or features of REM sleep). REM sleep is an active stage of sleep where brain activity is similar to that of wakefulness or very light non-REM sleep; there is also an active paralysis of all skeletal muscles (known as REM muscle atonia) with the exception of the ocular muscles, the cricothyroid muscles, and the stapedius muscle. The patient should be queried for features comprising its classic tetrad (not all need be present for a diagnosis of narcolepsy):  

1. EDS
2. Cataplexy (sudden bilateral loss of skeletal muscle tone often elicited by strong emotion)
3. Hypnagogic hallucinations (sensory experiences upon transitioning between wakefulness and sleep that appear real)
4. Sleep paralysis (sensation of complete skeletal muscle paralysis when transitioning between sleep and wakefulness)

EDS in the setting of cataplexy is considered pathognomonic for narcolepsy. However, cataplexy may not be seen at all or may occur several years after the onset of signif—continued on page 10
RESEARCHERS’ CORNER continued from page 8

Be prepared to engage your colleagues to discuss clinical trial opportunities with their patients, and leverage other marketing and outreach activities in your community. These may include community lectures, traditional advertising, flyers, letters to colleagues in the community, and listing trials on your website. Be aware that some of these activities require IRB review as well as sponsor approval.

being awarded a study is just the beginning of the process. Having a clearly defined process for starting the study will improve relationships with the sponsors, making your site more likely to be included in future studies.

References

MORNING REPORT continued from page 9

cant sleepiness. The other REM-related phenomena may be seen in idiopathic forms of hypersomnia or, more commonly, in patients with significant acute or chronic sleep deprivation. Prevalence of narcolepsy among individuals of European ancestry (such as our patient) is 0.02% to 0.05%, although prevalence rates up to 0.16% have been reported in East Asian populations; possession of the human leukocyte antigen (HLA) DQB1*0602 predisposes patients to the loss of hypothalamic hypocretin neurons seen in some cases of narcolepsy.4 Idiopathic hypersomnia, in comparison, is characterized by EDS despite adequate or, more commonly, significantly increased sleep amounts. REM sleep-related phenomena (items 2-4 above) are less commonly seen than in narcolepsy, and post-awakening confusion (“sleep drunkenness”) is common in this population.

On obtaining a more detailed history, the patient states that when laughing intensely or suddenly angered, her jaw feels weak and her body feels “heavy” as if she might “crumble.” Additionally, she describes monthly episodes where she awakens from a dream completely paralyzed for almost one minute. Less frequently, she has awakened from sleep to observe a “ghost” or “life-sized action figure” standing near her bed. The patient was referred to sleep medicine for further evaluation of possible narcolepsy.

The patient’s weakness with strong emotion is suggestive of cataplexy. Although pathognomonic for narcolepsy, cataplexy can be difficult to assess; a cataplectic episode need not involve complete physical collapse but may include more subtle features such as jaw dropping and head nodding.

With a strong suspicion for narcolepsy, a Multiple Sleep Latency Test (MSLT) should be obtained. The MSLT complements the subjective ESS as an objective measure of pathological sleepiness and is considered the gold standard used to diagnose narcolepsy.

After undergoing in-laboratory overnight polysomnography (PSG), which demonstrated normal sleep quality and quantity in the absence of sleep-disordered breathing, the patient remained in the sleep laboratory through the next afternoon. She was given five opportunities to nap and fell asleep each time after an average of 6.9 minutes (a mean sleep onset latency of less than 8 minutes is consistent with narcolepsy). Additionally, REM sleep was observed on two naps within 15 minutes of falling asleep. The presence of two sleep-onset REM periods (SOREMPs) is reasonably specific for the diagnosis of narcolepsy (Figure 1).

The patient was diagnosed as having narcolepsy with cataplexy, and modafinil was prescribed. She has experienced considerable improvement in her EDS without noticeable side effects. There has been no change in her cataplexy.

Figure 1. Patient’s MSLT Report

continued on page 14
notes) but also the inflation of billing levels and allegations of fraud. An-
other example of an unanticipated pitfall is the fact that alerts for possible errors have become so common that they are sometimes ignored, leading to suboptimal care.

Brad Crotty, SGIM Council associate member representative, is developing a plan for an SGIM Health Information Technology Task Force. As envisioned, this group would help the Society’s members conduct research related to IT; improve their clinical use of IT; better engage patients in IT; and examine health disparities, professionalism, and education related to the role of health IT. Please contact Brad at crotty@post.harvard.edu if you have ideas or would like to be involved.

When thinking about the potential uses of health IT, we need to be careful not to be a slave to the technology. Rather, we should determine what we wish to accomplish in order to improve health and then use the technology only as needed to help accomplish the aim. For example, Tom Delbanco’s goal of increasing transparency in health care may be accomplished in part by the availability of electronic records, but the electronic records are not what drives that goal. This point is also made in the excellent management book Good to Great by Jim Collins. In describing empirically based research on the characteristics of companies that outperformed their peers, Collins observed, “The idea that technological change is the principal cause in the decline of once-great companies (or the perpetual mediocrity of others) is not supported by the evidence. Certainly, a company can’t remain a laggard and hope to be great, but technology by itself is never a primary root cause of either greatness or decline.” We must continue to be driven by our vision for better health and better health care outcomes rather than by the availability of alluring technology, including health IT.

References
promising data security. In health care, there is no such formal strategy, but the use of personal mobile devices at work is fast becoming an integral component of delivery of care and medical education. In a recent study published in the British Medical Journal that examined the use of mobile devices in medical education by trainees and faculty, concern was expressed over the problems associated with their widespread use, including superficial learning, inappropriate use, distraction in the classroom and during clinical care, access to ambiguous learning resources, and breach of privacy. Participants also expressed concern over possible compromise of professional behavior due to the fact that almost always a single device is used for both personal and professional purposes without any specific guidelines about how to maintain boundaries. Moreover, the majority anticipated that these devices were going to become more integrated into daily practice and learning and might even replace textbooks.

My concern as a faculty member in an academic medical center is all of the above but predominantly the impact on the overall learning process for the trainees. There are several observations that I have made during my day-to-day work that I would like to share. Residents seem to spend less time with patients and more time in front of their electronic devices. They often place the burden of organizing, and easy to internalize can be a problem. Instead of learning the old way by reading text books to formalize basic concepts of medicine, students and residents skim over easily available sources online on their devices and move on to the next thing on their agenda. This is detrimental for retention of knowledge and application into clinical practice. The information available on the Internet is vast and of varying quality. This can become a challenge for students and teachers both, as they struggle to understand how to effectively manage this. It has been recommended for years that medical schools and academic centers meet the challenges associated with technological advancement by developing clear strategies and guidelines that can enhance the quality of medical education.

Sir William Osler (1849-1919), a pioneer of clinical medicine, insisted that his students learn from seeing and talking to his patients. He implemented the clinical clerkship for third- and fourth-year students and spearheaded bedside teaching rounds with them. He declared, “To study the phenomenon of disease without books is to sail an uncharted sea, while to study books without patients is not to go to sea at all.” He also proclaimed that “the primary work of a professor of medicine in a medical school is in the wards, teaching his pupils how to deal with patients and their diseases.”

Alas, the science of this scholarly activity seems to be dying in this modern world of technology-savvy trainees. Educational programs in medical schools across the United States are working on initiating the introduction to clinical medicine earlier than before by providing better structure for teaching clinical skills. Universities and academic medical centers with resident training programs should enhance the continuum of clinical training by understanding the inroads made by technology into medical practice and education. Clear guidelines should be set for the use of mobile devices within training programs to standardize instructional formats and avoid compromise of medical education and patient care. Mobile devices can be tremendous assets in current times, but barriers to optimal use must be recognized also.

I end with another quote from Sir Osler:

I desire no other epitaph...than the statement that I taught medical students in the wards, as I regard this as by far the most useful and important work I have been called upon to do.
SIGN OF THE TIMES
continued from page 1

The problem in both the paper and electronic record includes information storage based on the source of information and the narrative that is buried in notes that are rarely if ever read. Progress notes are stored in the “notes” tab, labs in the “lab” tab, and X-rays in the “imaging” tab. This results in the navigation of six to seven screens as we struggle to reconstruct the patient’s story; furthermore, this exercise is performed at each encounter. We believe there is a better way. Let’s take a fresh look at our documentation process with the new documentation tools available in an electronic medical record. With some creativity and courage, something much better than the traditional progress note can be developed.

Two electronic medical record tools to explore in more depth are the shared problem list and the “wiki” functionality that accompanies the problem list. Ironically, we can look to the originator of the SOAP note, Lawrence Weed, for guidance. In his visionary writings of more than 40 years ago, Dr. Weed described standards for what should exist in a problem list. He wrote that the list should include both active and inactive problems and information on a patient’s social and psychiatric status. The list should be concise and practical. Problem list entries that are the result of one parent condition should be consolidated to keep the list concise (e.g. advanced cirrhosis in place of ascites, edema, encephalopathy). Dr. Weed also described including signs and symptoms of disease on the list but stated that these should be refined as conditions are better understood (e.g. “chest pain” changed to coronary artery disease after heart catheterization confirms stenosis). If a community of health care providers chooses to manage a problem list using this shared approach, our efficiency and ability to coordinate care will be greatly enhanced. Dr. Weed’s vision also included a common approach to managing the details associated with each problem. Unfortunately, his ideas have not yet been completely realized.3

We now have a new opportunity. Electronic medical records can be configured to provide wiki functionality. Simply defined, a wiki is a software application that allows a community of users to freely create and edit the content of a shared web page. It has been a profoundly successful tool on the Internet to maintain up-to-date and informative web content, with Wikipedia being the most well-known application. Topics and their associated content are constantly under scrutiny with additions and edits being made as new knowledge is gained. Could we use the same conceptual ideas in the medical chart to manage a patient’s medical story? Many electronic medical records allow the creation of a problem list-associated free-text field, allowing users in a community to document additional details of each problem. In an ideal system it would allow easy editing and even include the ability to link to other documents in the record and import images such as ECG strips, X-rays, pathology images, and photographs. An ideal overview for each problem would synthesize content from all the various sources of the chart and allow users to quickly understand the condition in a patient-centered manner.4

The proposed content of a problem list overview could include treating physicians, condition onset, goals of therapy, basis for the diagnosis, status of the condition, resulting disabilities, subjective and objective findings (including treatments with associated responses), next steps in evaluation and treatment, and complications to watch for. As an example, the overview associated with the problem polyarthritis rheumatica in a 65-year-old man might read: “Shoulder and hip pain with morning stiffness developed at age 62. Sedimentation rate at the time was 90, and he experienced a prompt response to prednisone 20 mg. Goal is to wean steroid to lowest tolerated dose. Symptoms have recurred at doses below 7 mg. Current functional status remains good, and condition considered controlled. Monitoring for signs/symptoms of temporal arteritis. Followed primarily by Dr. Smith, Rheumatology.” Not all conditions on a problem list would require all of these proposed elements. However, conditions that have an extended natural history and include various diagnostics and treatments lend themselves particularly well to this approach. We should consider these elements when creating overviews for cancer, heart disease, mental health, and other chronic disease states. It also would work well for conditions that are not fully defined and require a team of individuals to coordinate efforts in establishing a diagnosis and treatment plan (e.g. abdominal pain and weight loss).5

Several barriers would need to be overcome in order to establish this Wiki problem list as the focus of the medical record. There would need to be consensus, extending from clinicians to all levels of academic medicine. The inherent discomfort of allowing multiple users to edit such an important medical document must be overcome. This would include moving away from the notion, taught to us by lawyers in regard to paper records, that documents cannot be deleted but only crossed out and initialed if subsequently found to be in error. It would also include acknowledging that some potential editors may be less conscientious stewards of what is placed in the problem lists than others. One new focus of professionalism could be teaching that great care and responsibility should be applied to editing problem lists so that errors, redundancies, and sloppiness are avoided as much as possible. There might even be required training before users obtain electronic record authority to edit problem lists, and there will undoubtedly be discussions as to which medical providers and staff should be authorized to do this.6

continued on page 15
Medical treatment of narcolepsy is symptomatic. Current first-line therapy for narcolepsy-associated EDS includes wakefulness-promoting agents such as modafinil and armodafinil. Common side effects when starting these medications—nausea and headache—typically resolve within days. Our patient’s oral contraceptive could be less effective while taking either of these medications due to their possible induction of drug metabolizing enzyme CYP3A4; she should be encouraged to use barrier contraception while on modafinil or armodafinil. Patients should stop these medications immediately at the first sign of drug-related rash due to a slight risk of Steven-Johnson Syndrome. Stimulants such amphetamine, dextroamphetamine, and methylphenidate remain effective treatments but carry more burdensome side effects (anxiety and tachycardia as well as hypertension and stroke in older individuals). When present, cataplexy does not respond to stimulant therapy and requires additional specific therapy. Cataplexy can typically be managed easily with REM suppressing medications. Historically, tricyclic antidepressants were used, but selective serotonin uptake inhibitors (SSRIs) are now considered first-line therapy for cataplexy. Patients with refractory cataplexy, daytime sleepiness, and nighttime sleep fragmentation (which can develop in patients with long-standing narcolepsy of more than five years) may benefit from sodium oxybate, which requires specialized patient training and use of a single national pharmacy.

In addition to taking medication, patients with narcolepsy should get at least eight to nine hours of sleep nightly. They should also pay strict attention to proper sleep hygiene (sleeping in a darkened cool room, eliminating bright light within one hour of bedtime, avoiding caffeine six to eight hours before bedtime). Two regularly scheduled 15-minute naps daily are recommended to patients with residual EDS. Further, our patient should not drive until her sleepiness is adequately controlled. Safer driving practices, such as strategic caffeine consumption before driving, pulling over to take a 15-minute nap at the earliest signs of sleepiness, and limiting driving distances without breaks, should also be adhered to strictly. Patients with narcolepsy qualify for benefits under the Americans with Disabilities Act and may be entitled to accommodations including longer time for task completion and longer breaks that allow for 20 to 30 minute naps. Long term, patients with narcolepsy should be queried for development of cataplexy and nighttime sleep fragmentation, which may require additional specific pharmacologic therapy.

Learning Points
- The ESS is a reliable tool for differentiating between fatigue and sleepiness, which is important when formulating an appropriate differential diagnosis and work-up plan.
- Narcolepsy’s classic tetrad includes EDS, cataplexy, hypnagogic hallucinations, and sleep paralysis, though many patients with the disorder do not manifest all of them initially.
- Wakefulness-promoting agents, such as modafinil and armodafinil, have been shown to manage narcolepsy-associated EDS effectively, especially in conjunction with sufficient sleep time and proper sleep hygiene practices.

References

North Carolina—Assistant Professor.

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References continued from page 12


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