Quote to note

It is better to know some of the questions than all of the answers.

— James Thurber

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Whole genome sequencing

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"When people say the genome is so much more complicated than we thought, you have to step back and say, 'How simple did you think it would be?'"
—Eric Landers, 2010[1]

The buzzword these days in medicine and biomedical science is "personalized medicine," also referred to as "individualized medicine." What exactly is personalized or individualized medicine and haven't clinicians always been providing this kind of medical care? While researchers have been able to sequence genes since the 1970s, the days of single-gene sequencing have given way to whole genome sequencing (WGS). Thus, personalized medicine has taken on a new meaning: using an individual's genomic sequencing to tailor health care for that person based on his or her genetic make-up.

Genomic-based personalized medicine will likely contribute to improved management of individual health and medical care. However, as with most technologies and scientific findings, there are considerations beyond the technical that require attention. I will describe what it means to have one's whole genome sequenced and why one might pursue this option. I will also focus on some of the troubling issues of what to do with the information learned from WGS.

All organisms have a set of chromosomes in their cells. Strands of DNA make up these chromosomes, and within these strands are regions of DNA that code for proteins. DNA is made of molecules called nucleotide bases, linked in pairs, specifically four different kinds. Their order determines where and what genes are located within an organism's DNA. The portions of the DNA that actually code for proteins are referred to as exons and all the exons in an individual's set of DNA are referred to as the exome.

Similarly, a genome refers to all of an individual's DNA—the portions that code for proteins and the portions that don't. Sequencing DNA simply means determining the order of its nucleotide base pairs. WGS and whole exome sequencing (WES) determine the order of all the nucleotide bases of an individual's genome, or exome (essentially a subset of the genome). The social, ethical and policy considerations are very similar for WGS and WES.

What kinds of people might seek to have WGS performed for clinical purposes? Generally healthy people who want to know what kind of genetic health risks they have inherited from their parents might seek WGS, believing that this information would facilitate early preventive steps, planning for the future and/or reproductive decision making. We might call these people the "worried well" or the "simply curious."

Other people who seek WGS might include, for example, a patient with a resistant malignancy who hopes that the information from sequencing both the genome of the tumor and the normal germline genome might lead to identifying a specific mutation(s) unique to the tumor, which could then suggest a specific therapy.

Someone with a puzzling set of undiagnosed symptoms and physical findings

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might also want to have his or her whole genome sequenced, as well as that of two family members who are not sick. This might lead to the discovery of a rare variant associated with an already described condition or a rare condition never before identified. In 2010, researchers at the Medical College of Wisconsin used WES to diagnosis a young boy, identifying a new mutation causing XLP, a rare immune disorder, and a novel cause of inflammatory bowel disease.[2,3]

The crux of the social, ethical and policy discussions associated with genomic sequencing research is the decision about what genetic results should be returned to the subject.[4–7] These are not new questions. The amount of information generated from WGS complicates things by bringing to the forefront the discussion of incidental findings and return of results. While the usual intention may be to focus on the medical condition at hand, clinicians will be faced with the fact that other types of genetic information with both established and unclear medical implications will be identified, thus raising the issue of how and when, if ever, to share that information with the patient and even the patient's family.

In nonresearch settings, when an individual has sought WGS for health care and is paying for the service, is the clinician obligated to reveal all available information, even if some of that information falls into the category of "variant of unknown significance" (VUS)? A VUS is essentially an unusual change or variation in the DNA sequence for which there is no confirmed information concerning its biological significance. Many individuals think they want to learn about their genetic risks but do not anticipate the psychosocial consequences of hearing they carry a genetic variant that, for example, puts them at a higher risk for a condition that has minimal if any clinical actionability or was not expected.[8] Our ability to analyze and interpret the data from WGS is limited, which leads to some level of uncertainty.[9] Much of the clinical information that can be gained from WGS can mean more, not less, uncertainty.

What about information that falls into the category of "medium-risk results" or "high-risk results" that might have clinical validity but lack clinical utility?[9] Interpretation limitations also may result in false positives.[10] These are the kinds of genetic results that have the potential to create significant psychological distress for individuals and their family. Information obtained from WGS could be overwhelming for the average person. For example, telling a patient he has an APOE4 allele, a genetic variant associated with significant risk for developing Alzheimer's disease, generates angst and problems more complex than simply telling someone her cholesterol is high. There are ways to lower cholesterol but there is no way to prevent Alzheimer's disease. Clearly, the informed consent process and the discussions leading up to the patient making decisions about what findings he/she wants to learn and whether he/she wants those shared with family members will be critical.

Biobanks collect samples on large numbers of people from multiple research projects and serve as a repository for future research. Studies indicate that research participants expect that research results, even incidental findings of unknown significance, will be returned to them. A significant number of biobanks have not explicitly addressed the question of returning information to contributors. Wolf et al argue that researchers should explicitly address this issue.[7]

An important question is whether biobank samples should irretrievably be stripped of any patient identifiers which would, of course, make the return of results to contributors impossible. A derivative question is what kinds of incidental information should be returned to individuals by biobanks. For example, should a contributor be notified that a study of pancreatic cancer incidentally reveals that a person is at high risk for colon cancer?

Researchers argue that returning information to individuals is burdensome to the biobank and involves a diversion of scarce resources. They add there is no agreement on what information should be returned. Researchers probably do not have an obligation to return genetic research findings of unknown significance and in fact should not return that kind of information. It is argued that researchers have a fiduciary duty to return information of clinical importance. The challenge is that there are varying views of what "clinical importance" means. Suggested criteria for the return of information include: 1) the genetic information has substantial and established health implications for the research participant. Some would offer back information related to "life-threatening or grave" conditions, while others more liberally would advocate the return of information related to conditions that pose a "substantial risk of a serious health condition"; 2) the genetic finding is actionable with interventions that can avoid or ameliorate the relevant disease and benefit the contributor; and 3) the genetic information is relevant to reproductive decision making. Because of the continued acquisition of new genetic knowledge, specific recommendations likely will change over time. It has been suggested that a roster of returnable findings be kept and updated.[7]

What I fear about WGS is that it is being translated too quickly, and that it is being prematurely framed as a tried-and-tested clinical tool. As others have noted, there is no doubt that WGS will have a significant role in improving health outcomes and medical care.[6] We must be careful that our abilities to interpret and use the data are not being prematurely framed as accepted clinical tools, giving the impression that we know and understand more about the human genome than we actually do. We must also ensure that such knowledge can be usefully incorporated into therapeutic or preventive clinical interventions. There is still much to be learned and we must be cautious in ushering WGS into standard clinical practice. ❑

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Ask the ethicist:

Should a physician honor a medically inappropriate request for CPR based on religious beliefs?

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Question: A 79-year-old woman with metastatic bladder cancer was admitted to the ICU for respiratory failure, renal failure and sepsis. She was intubated and on four vasopressor drugs to support her blood pressure. She was not a candidate for dialysis. Because of her poor prognosis for survival, her niece (lawful health care proxy) was asked for permission for a DNR order. Although the niece was told that it was unlikely that the patient could survive CPR and would never leave the hospital, she refused to permit a DNR order banning chest compressions and electrical defibrillation. The niece produced an advance directive in which the patient had indicated that she wanted aggressive treatment even in a hopeless situation. Apparently this wish was based on her religious beliefs in Orthodox Judaism. The proxy expressed that a person should be treated "until God is ready to take her" and that not resuscitating the patient would be "like killing her before her time." The proxy said that she did not necessarily fully agree with these religious views but felt it was her duty to do what her aunt wanted, noting, "God takes you when He wants." The physician spoke with the patient's rabbi, who said, "Life is precious, even a few minutes." What should the physician do?

Response: The question posed here is, "What should the physician do?" But another question must first be addressed, namely, "What should the physician know?" Before the doctor can decide how to proceed, he or she should be aware of the Jewish view of this situation. First, in Jewish thought, life is sacred and possesses infinite value, without exception. Thus, traditional Judaism prohibits euthanasia and the withholding or withdrawal of treatment, as every moment of life is precious.

Second, a *gosses*, a patient for whom death is expected in a very short time, must not be placed in a position wherein death is hindered; such a person's death process should not be delayed.

Third, applying the appropriate *halachah*, Jewish law, in an end-of-life case is not normally the problem. The difficulty arises in making a separate determination about the moment that the death process has begun, when there is no prospect for continued life. As indicated above, Judaism is clear that life is not to be taken before its time. It is also clear that impeding the death process once it has begun is forbidden. The same texts may be used to support lenient and strict rulings. This dilemma is a regular feature of Jewish end-of-life decision making. Within the sphere of the general duty to care for the sick and the infirm, there needs to be consideration of which in each case is the greater duty—on the one hand, to save a life; on the other hand, to not prolong the dying process.

With these three points in mind, it would seem that first, the physician should engage in clarification and verification of the diagnosis and any available treatment options and their prognoses. Jewish medical ethical literature also encourages the physician to ensure that these data are based on expert medical opinion. There is always the possibility of error and uncertainty as well as a sudden change in a patient's condition. In many cases, and it may well be the case here, the direction is clear and the diagnosis/prognosis is self-evident. However, in cases where there is doubt, Judaism would clearly favor the position of extending life.

The next point is that Jewish legal and ethical experts have affirmed the permissibility of withholding CPR and mechanical ventilation in the case of terminal illness. There are differences among rabbinic authorities concerning the withdrawal of mechanical ventilation if the doctors believe the situation is hopeless. Once the machinery is in place, it is questionable whether it can be removed.

The final point is that there are sources within Jewish writings that indicate sanctity of life presumes a minimum quality of life. Rabbinic authorities arguing from these sources claim it is not valid to "fight to the last breath." There is, for example, a tale found in the great corpus of Jewish law and lore, the Talmud, concerning a rabbi who is shown his place in Paradise by the Angel of Death. He asks to hold the Angel's sword, as it frightens him. With sword in hand, the rabbi jumps into his appointed place and refuses to leave. When the Angel of Death pleads for the return of his sword, the rabbi refuses in order to banish Death forever. God intercedes and instructs the rabbi to return the sword, since "mortals have need of it." From this tale, some rabbis have inferred that there is a time to die; there is a time when living becomes too burdensome.

How should the physician proceed once he or she is aware of the aforementioned points? If the patient is truly in a condition where it is doubtful she would survive CPR and likely never be discharged from the hospital, what can the doctor do? Regarding the proxy, he or she can ask both parties the same question: "Would the patient want CPR in her current state, understanding the risks and benefits?" To the rabbi, it may be suggested that, just as the doctor sought out expert opinion on the diagnosis/prognosis, it might be well to call in a consult, someone seen as more expert and knowledgeable on these matters. Often, this is just what occurs. Nevertheless, it would appear that, if the niece and the rabbi are insistent, the DNR should not be ordered. However, assuming the physician believes that CPR will ultimately be futile, he or she should seek periodic reevaluation with the niece and rabbi as to which is more appropriate, CPR or a DNR. They should also be assured that, even with a DNR, supportive care and pain relief will aways be provided.

Outcome: The proxy said she would feel extremely guilty if she did not honor her aunt's wishes,

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The legal column:

The transformation of defining disability: An overview of the Americans with Disabilities Act

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> "Every man, woman and child with a disability can now pass through once-closed doors into a bright new era of equality, independence and freedom."
> —President George H. W. Bush[1]

In 1990, President George H. W. Bush signed the Americans with Disabilities Act (ADA) into law. Congress intended to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." However, a trend in Supreme Court decisions and other cases limited protections by restricting the definition of "disability." Congress amended the Law in 2008 to reestablish the focus of analysis, not on whether the claimant's impairments meet the definition of disability, but whether the institution or entity's actions constitute discrimination.

Two Supreme Court decisions highlight the restriction placed on the intent of the ADA. First, in *Sutton v. United Airlines, Inc.*, the Supreme Court held that mitigating or corrective measures should be considered when determining whether an individual's impairment constituted "disability" under the ADA. Here, the Court reviewed a claim made by twin sisters after United Airlines denied their applications for pilot positions because they suffered from myopia and did not meet vision requirements. The Court found that because the sisters were able to function with the use of corrective measures (eyeglasses or contacts), the sisters were not disabled. Second, in *Toyota Motor Manufacturing, Kentucky, Inc., v. Williams*, the Court found that to meet the definition of "disability," an individual's impairment must prevent or severely restrict an individual from "doing activities that are of central importance to most people's daily lives."[2] Using this framework, the court found that the claimant, Ella Williams, was not disabled under the ADA because her impairment (carpal tunnel) did not interfere with activities central to most people's daily lives, even if the impairment interfered with the manual tasks associated with her position.

In 2008, Congress amended the ADA to reestablish a broad scope of protections. Congress explicitly rejected prior case law that limited protections by narrowly defining disability.[3] The Amended Americans with Disabilities Act (ADAAA) reestablished a lower threshold for determining whether impairment substantially interferes with a major life activity. Consistent with rejecting the finding in *Toyota Motor Manufacturing*, the amended law includes a nonexhaustive list of "major life activities," including caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating and working. For example, the Act includes detailed protections for people who use a wheelchair. A major life activity also includes the operation of a major bodily function, such as digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine and reproductive functions. Thus, an impairment (e.g., cancer) that interferes with a bodily function (e.g., limiting cell growth) may be sufficient without demonstration that the individual is limited in his or her daily activities.

Additionally, the ADAAA explicitly rejects the finding of *United Airlines*. In doing so, the ADAAA no longer permits the consideration of mitigating measure such as prosthetic limbs, hearing aids and oxygen therapy in determining whether a person is disabled. However, the ADAAA does provide an exception for eyeglasses and contact lenses, which may be considered when assessing whether impaired vision constitutes a disability.

A final amendment addresses the permanency of impairment. Episodic conditions or those in remission may still constitute a disability if, when active, the condition "would substantially limit a major life activity." Additionally, transitory impairments, defined as those lasting less than six months, may not constitute "disability." The Law, however, does not indicate whether a presymptomatic condition, which has not yet caused symptoms, may qualify as a disability. The potential for presymptomatic and asymptomatic diagnosis (e.g., preclinical Alzheimer's) may challenge future interpretations of the ADAAA. Specifically, courts may need to consider whether protections should extend to individuals who are not yet impaired, but may be in the near future.

Discrimination under the ADAAA

The ADAAA prohibits discrimination on the basis of disability by private entities, employers with 15 or more employees a day for at least 20 weeks a year, and state and local government. The United States Government, Indian Tribes and bona fide private membership clubs are exempt under the Law. An individual is protected under the ADAAA for employment purposes so long as she is impaired within the meaning of "disability" and is qualified to perform "essential functions" of the job with or without accommodation.[4] The essential functions of the job are largely determined by the employer. Factors include the employer's description of the position used in advertising or interviewing applicants for the job. Under the ADAAA:

- An entity cannot discriminate against a qualified disabled individual "in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training and other terms, conditions, and privileges of employment";
- An entity must provide "reasonable accommodations" to the "known physical or mental limitations of an otherwise qualified individual," unless the accommodation would cause an undue burden to the entity

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Ethics and the humanities:

On assisted suicide
A review of the film Mar Adentro (The Sea Inside), *directed by Alejandro Amenábar, 2004*

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The death of Ramón Sampedro on January 12, 1998, made national headlines in Spain. The news of his assisted suicide spread rapidly across Europe, the United States and Australia, where euthanasia and assisted suicide remain topics of frequent debate. (Recall the rejection of assisted suicide by Massachusetts voters in November 2012.) Rendered quadriplegic at age 25 by a disastrous dive into the ocean that had been the source of his livelihood as a ship's mechanic, Sampedro had spent much of his 28 years since seeking a way to end his suffering. With the help of the Spanish Association for the Right to Die with Dignity (RDD), his case had been argued before Spain's lower and higher courts, presented to the European Commission on Human Rights in Strasbourg and profiled on television in Spain and abroad. Sampedro was caught in the legal vacuum of procedural barriers and prohibitions that even prevented him from speaking on his own behalf in court, and his request for the right to die was consistently denied. Finally, in a plan carefully choreographed to involve 11 friends so that no one individual could legally be held responsible, Sampedro took his own life by drinking potassium cyanide through a straw, videotaping for posterity the entire scenario.

Alejandro Amenábar's internationally acclaimed film *Mar Adentro* tells the story of Ramón Sampedro, his family, the women who loved him despite his physical limitations, and his quest to die. We meet a man of sharp intellect and quick wit, with a ready smile; a man who loves literature and music, who designs gadgets like the "personal computer" he can manipulate with a blade held in his mouth and the mouth-operated device that allows him to answer the phone. We observe his confinement to bed in a second-floor room with a view of the surrounding hills and watch as all his physical and bodily needs are attended to by his older brother, José; devoted sister-in-law, Manuela; and nephew, Javier. We learn that he can smell the sea he loves on a morning breeze and can transport himself there in his imagination. Ramón seems to have so much to live for that we are confounded by his rejection of a wheelchair: "Accepting a wheelchair would be like accepting the crumbs of what used to be my freedom" and his insistence that "life like this has no dignity."

It is when Ramón meets Julia, his pro-bono lawyer, that we learn more about the man and his suffering. Fragile, lovely Julia is herself disabled by Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy (CADASIL), the most common form of hereditary stroke disorder, which will eventually lead to dementia. As she explores Ramón's past, she uncovers the soul of a wayfarer and poet. With Manuela's help, she is privy to his old photographs and writings, offering help in compiling the latter for publication. It is to Julia who has fallen in love with him that Ramón describes the "impossible journey" of trying to reach out and touch another human being, the "dead end of never-ending days and nights" that cause him so much pain. Julia suffers a stroke while at the Sampedro home and when she returns to continue with the book many months later, she vows to Ramón that they will die together when the first copy of the book, aptly named *Letters from Hell*, is in hand.

While Julia empathizes with Ramón, Rosa enters the scene, uninvited, as the proponent for life. A single mother of two small boys, Rosa works in a local fish-processing plant and has a hard life. She has seen Ramón on TV, is inspired by him, and is determined to change his mind about death if she can; this will give *her* life meaning. When Julia backs out of the suicide pact, Rosa reveals the depth of her love for Ramón and eventually agrees to help him die. After all, he told her once that the person who really loves him is the person who will do just that.

This film is rich with wonderfully developed characters whose voices argue for and against the right of all to self-determination. Ramón himself respects the fact that other quadriplegics, like the well-intentioned priest who comes to his house to aggressively articulate the position of the Catholic Church, may find every reason to live. Gené from RDD is an active proponent of Ramón's cause but still looks toward life rather than death, cautioning Julia as she contemplates ending her life that "fear is a very powerful weapon." José is adamantly opposed to the idea of his brother's suicide and forbids any such event in his home while gentle, caring Manuela simply listens to the voices around her, supporting Ramón in his quest but offering no opinion or judgment.

Even if you have seen this marvelous multi-layered film before, it is time to see it again. It humanizes the debate over assisted suicide better than any case-based discussion can. It forces us to consider the challenges of long-term family caregiving and the very nature of love. On second viewing, we realize that some scenes suggest that Ramón's disastrous dive all those years ago was actually an act of suicide then, making his 28 years of "living…[as] an obligation" all the more painful. And the closing scene in which Gené visits Julia only to find her in the depths of dementia with no recollection of Ramón at all fills us with ambiguity, wondering who may have made the better choice after all. ❑

Dialogue:

Does googling, friending and tweeting really make it "medicine 2.0"?

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Psychiatrist Benjamin Silverman (*Lahey Clinic Journal of Medical Ethics,* fall 2012) suggests that the Internet has changed medical practice significantly by connecting patients and physicians to information about health conditions and treatment options, and to one another, outside the context of traditional face-to-face encounters. Using the information resources of the Internet, he observes, "patients and physicians initiate the physician-patient relationship long before the initial in-person visit." Moreover, social media enable both parties to extend their interactions beyond in-person encounters, and even into nonclinical realms, far more readily than in the past. Online accessibility offers the possibility to "deepen and improve medical care," notes Dr. Silverman, but equally may "threaten traditional professional boundaries established to protect the best interests of patients."

Like many observers of the health Internet, Silverman notes that what he terms the "medical encounter 2.0" can pose risks with respect to privacy, reliability/quality of information, and fidelity in the face of dual or ambiguous relationships between patient and physician.[1–6] He is concerned, moreover, that a persistent "technological generational gap"—among clinicians as well as patients—limits the opportunity to reap the possible benefits of the Internet for medicine. In his estimation, overall, the peril still outweighs the promise. Silverman acknowledges that, realistically, physicians cannot avoid engaging the Internet entirely, but urges them to "rely on traditional principles of professional ethics" when they do. Efforts to develop exact guidelines, he concludes, "will ultimately fail to keep up with the ever-changing pace of technology."

Silverman essentially conceives of the Internet as an information-rich adjunct to face-to-face patient-physician relationships, the use of which can sometimes go awry. From such a perspective, concerns about the intersection of medicine and the Internet coalesce around what information is available (its accuracy, quality, source, etc.) and how relationships of information exchange are managed (privacy, transparency, integrity). The ways in which patients and physicians can be challenged are accounted for within familiar standards of professionalism. The salient difference between medicine before the Internet and medicine in the era of Facebook is "the potential size of the community [among whom information is exchanged] and the still-evolving rules of etiquette."[3] From this perspective, physicians have a responsibility first to find ways to constrain the Internet's potential for harm, and only second to enhance the possibility of benefit.

This "classical" view is certainly understandable; bad things do happen online and we don't yet have a great deal of clear evidence about benefits. But does this view take us far enough in thinking about what the Internet and its attendant technologies mean for medicine? I'm inclined to think not, for a couple of reasons.

First, by anchoring itself in reference to face-to-face, in-person encounters between physicians and patients, the classical view tends to downplay the Internet as a *site* of medical practice, not simply an adjunct to practice that takes place elsewhere. Yet a decade ago, for example, Miller and Derse noted that the Internet opens the possibility of establishing new, online-only patient-physician interactions that move beyond providing information into the practice of medicine.[2] In addition to scenarios of the sort Silverman describes, in which patients use the Internet to gather information about their health concerns, look up physicians, or communicate electronically as the first step toward establishing a face-to-face relationship, Miller and Derse reflected on situations in which encounters between patients and their physicians are *always* virtual. Thus, for example, interactions with patients "who are homebound, in rural areas, in prison, or in other settings that limit their access to treatment."[2]

Internet-supported telemedicine[7] applications encompass both scenarios. They can be used to augment in-person visits and to replace in-person visits.[8] The Internet supports a range of medical interventions in which patient and physician are geographically distant from one another and may never meet in person, such as telemental health or robotic telesurgery.[9] And it encompasses destination health Web sites that offer diagnostic and treatment services.

When the Internet is the site of medical care—call this the "extended" view—the challenges go beyond those typically recognized in the classical view. Standards for accountability in the online practice of medicine are still in flux—witness the ongoing debate about licensure for telemedicine.[10] Nor is there yet consensus on questions posed by Miller and Derse a decade ago: Which specific diagnoses and treatments are appropriate for online practice and which require a medical visit or physical examination? How important is face-to-face contact for trust and patient satisfaction? What becomes of expectations for and adherence to the traditional ethical obligation of fidelity when patient and physician never meet?

Second, the classical view doesn't much take into account what *patients* are coming to expect of medicine or how they choose to engage the Internet around health issues. When health care organizations build online resources, patients use them.[11–13] Kaiser Permanente's experience with its patient Web portal "indicates that members find the greatest use in a Web site that facilitates e-connectivity with their health care team, allows them to view key components of their medical records and conduct clinical transactions [such as viewing lab results or scheduling appointments] online, and provides them with information so that they can make knowledgeable decisions about their health."[14]

Patients also connect to one another online, seeking advice and finding support.[4] So much so that the Pew Foundation's Internet and American Life project has coined the term "peer-to-peer healthcare" for the practice.[14] As Hawn observed, "Using social media in health care is about changing the locus of control to the patient."[4]

"Medicine 2.0" goes deeper and wider than just medical encounters in new media. Arguably, it represents a new kind of relationship between physicians and patients who are taking on a new role. We don't yet fully understand that new role, and not every patient wants or has the capacity to become an engaged, sophisticated "e-patient," but the way increasing numbers of individuals are going about being patients is surely driving the evolution of Medicine 2.0 as much as innovations in technology.

In the face of that dynamic, I think Ryan Greysen and colleagues capture the challenge for the medical profession when they conclude:

> [W]e must go farther than curtailing unprofessional behavior and embrace the positive potential for social media: physicians and health care organizations can and should utilize the power of social media to facilitate interactions with patients and the public that increase their confidence in the medical profession. If we fail to engage this technology constructively, we will lose an important opportunity to expand the application of medical professionalism within society.[15] ❑

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[6]Wynia M, Crigger B-J. Googling patients and surrogates: Not for health care professionals. *PM&R* 2011; 3(4): 374.

[7]Telemedicine uses communication networks for delivery of health care services and medical education from one geographical location to another. It is deployed to overcome issues like uneven distribution and shortage of infrastructural and human resources.

[8]VHA Office of Telehealth Services. www.telehealth.va.gov/real-time/index.asp. Accessed December 16, 2012.

[9]Robotic surgery is the ability for a doctor to perform surgery on a patient even though the two parties are in different locations.

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Response: In the metaphor of the "medical encounter 2.0," the intersection of the traditional face-to-face physician-patient relationship with Web 2.0–based social networking technologies represents a new version of the medical visit that offers promises and challenges to current standards of practice. The medical encounter is continuously evolving into new versions, with innovative technology, novel medical evidence and growing systems of delivery and payment, among numerous other factors.

Bette-Jane Crigger emphasizes important new versions of the medical encounter in which the Internet (or other virtual spaces) becomes the "site of medical practice, not simply an adjunct to practice that takes place elsewhere" (i.e., telemedicine) and in which patients have the ability to take on "a new role" as "engaged, sophisticated 'e-patients[s]'" who continue to drive medical visits in new directions. As Dr. Crigger points out, such new developments can pose even greater challenges to standards of practice than the questions I initially raised. We both agree that this ongoing patient-driven and technological evolution in the medical encounter is unavoidable and has the potential to improve health care relationships. How and whether this leads to improvements in health care outcomes remains to be seen. In the absence of a scientific evidence base, we must continue to

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> (significant difficulty or expense). Reasonable accommodations may include (1) ensuring that facilities used by employees are accessible; and (2) adapting work environment or structure to better suit the individual's needs (e.g., modified schedules or providing services to assist with job duties). An employer is not required to provide accommodations that interfere with the "essential functions" of the position.

In addition to protections provided for employment purposes, the ADAAA prohibits private entities from discriminating against individuals on the basis of disability related to the "enjoyment of the goods, services, facilities, privileges, advantages, or accommodations" provided to the public by the private entity that owns, leases, or operates a place of public accommodations.[5] Public accommodations, for the purposes of the Law, include health care providers and hospitals.[6] An exception is made when the individual poses a "direct threat to the health or safety of others."

Recent developments and applications

Recent case law has begun to interpret the ADAAA (effective January 1, 2009). Courts have held against applying the amendments retroactively. Therefore, only those claims that stem from actions that occurred after January 1, 2009, are analyzed under the amendments.[7] It may take time before the effects of the amendments on the scope of disability protections are fully known. Courts must now reestablish boundaries for how disability is defined under the amendments and what entity actions constitute "discrimination." Courts may be particularly challenged when addressing whether an impairment substantially interferes with a major bodily function. Given the advancement of medical diagnostic capabilities to diagnosis a disease at earlier stages (e.g., preclinical Alzheimer's), a court may be required to evaluate how much impairment interferes—and when in the disease process an impairment exists. Ultimately, the 2008 amendments make critical revisions to reestablish the purpose of the Law. ❑

***Note:** The author would like to acknowledge Paul Ford, PhD, for his assistance with the article.*

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even though she did not necessarily agree with those wishes. The patient was near death but was not suffering. A DNR order was not written. The patient had a cardiac arrest several hours later and CPR was unsuccessful. After her aunt's death the proxy thanked the health care team for allowing her to respect her aunt's wishes. ❑

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rely on traditional principles of medical ethics and professionalism to guide us through uncharted technological waters.

The medical establishment and its rules (or standards of care) for using new technologies will ultimately fail to keep up with the ever-changing pace of technology and even with our own patients' willingness to adopt new forms of communication. By relying on our basic principles, we can most effectively implement cutting-edge technologies in the newest versions of the medical encounter, keeping ourselves open to innovative advancements while simultaneously protecting our patients from harm. ❑

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[1]Devroy A. In emotion-filled ceremony, Bush signs rights law for disabled Americans. *Washington Post*, July 27, 1990.

[2]534 U.S. 184 (2002).

[3]42 U.S.C.A § 12101 (rejecting the holdings in *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999) and its companion cases).

[4]*Kallail v. Alliant Energy Corporate Services, Inc.*, 2012 U.S. App. Lexis 18557 (N.D. Iowa, May 13, 2012).

[5]42 U.S.C.A § 12182.

[6]*Ragdon v. Sidney Abbott, et al.*, 524 U.S. 624 (1998).

[7]*Jeffries v. Verizon*, 2012 U.S. Dist. LEXIS 135537 (E.D.N.Y., Sept. 21, 2012).

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