American Medical Association Journal of Ethics

June 2012, Volume 14, Number 6: 437-526. **Psychiatry in a Brave New World**

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FROM THE EDITOR

The Human Condition in the Twenty-First Century

Aldous Huxley imagined a brave new world in which technology had triumphed in all facets of human life. In his dystopic world, the euphoria-inducing drug soma had placated the masses and subdued human emotion. Now, 80 years after the publication of *Brave New World*, the book's themes are more relevant than ever.

I was reminded of this at the most recent annual meeting of the American Psychiatric Association (APA). While psychiatrists from around the world gathered inside the convention hall, "Occupy the APA" protesters stood outside to sound their concern that the association's new DSM-5 (Diagnostic and Statistical Manual), due to be unveiled in 2013, would unduly pathologize the human condition. Furthermore, protestors were worried that medications for treating these "pathologies" would come to suppress the full range of human experience.

Indeed, there is an ever-burgeoning brave new world of psychopharmacology. However, it is not just advances in psychotropic medication that have been taking psychiatry by storm. Advances in digital technology, biotechnology, and genetics are also changing the landscape of psychiatry in the twenty-first century.

This month's issue of *Virtual Mentor* examines the powerful role of rising technologies in psychiatry and how they are shaping our conversations in psychiatric ethics. David H. Brendel, MD, PhD, explores the ethics of reading patients' blogs. Anthony P. Weiss, MD, MBA, comments on using firewall protections to segregate psychiatric information in electronic medical records, and Richard A. DeVaul, MD, discusses treating bereavement with antidepressant medications.

As new technologies are introduced to the field, policy makers struggle to understand what sorts of regulations will be needed to manage unforeseen ethical questions and problems that arise from their use. Daphne C. Ferrer, MD, and Peter M. Yellowlees, MD, highlight this concern using the emergence of telepsychiatry as an example. Dien Ho, PhD, wonders whether the FDA's placing a black-box warning on antidepressants was the best possible policy action, given the absence of sufficient evidence.

Perhaps even more importantly, we must ask how the medical profession should deal with emerging, yet-to-be proven technologies. Martha J. Farah, PhD, and Seth J. Gillihan, PhD, examine the clinical role for brain imaging in the diagnosis of psychiatric disorders, and Aaron D. Besterman, MD, offers his thoughts on a literature review of ethical considerations in psychiatric genetics. Does what we

know about the brain allow us to predict with any accuracy who might become violent? Robert T. M. Phillips, MD, PhD, explains how the courts treat expert predictions of future dangerousness and defines various approaches to making those predictions.

Advances in psychiatry and neuroscience have social as well as medical implications. Using images and language from psychotropic drug ads, Jonathan M. Metzl, MD, PhD, illustrates that pharmaceutical companies exploited social fears and racism in the 1960s and '70s to promote sales of their treatments for psychosis. Nada Gilgorov, PhD, comes closest to Huxley's imagined world when she probes the question of humans' accountability for their actions. Do correlations between specific behaviors and localized patterns of brain activity challenge the belief that we have free will?

Much is said in this issue about how mental conditions get pathologized and often subsequently depathologized. In her op-ed article, Christina Nicolaidis, MD, offers physicians insights from the autism self-advocacy movement, encouraging them to treat each autistic person as an individual. In a medical education article, David Elkin, MD, Erick Hung, MD, and Gilbert Villela, MD, suggest ways to help resident physicians think critically about many of the topics that this month's authors raise.

With a new edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* coming out next spring, the ethical concerns examined in this issue of *Virtual Mentor* will remain topical and controversial.

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ETHICS CASE

Monitoring Blogs: A New Dilemma for Psychiatrists

Commentary by David H. Brendel, MD, PhD

As Dr. Patel, who specializes in treating mood disorders, walks into the waiting room to greet her new patient Jonas, she notices that he is furiously typing away on his laptop. His brow is furrowed in deep concentration.

Jonas was recently hospitalized for mania and psychosis. He was initially brought to the hospital in police custody after claiming to have a bomb in his backpack and assaulting a police officer. At the hospital, he was started on antipsychotic and mood-stabilizing medications and referred to Dr. Patel for outpatient follow-up care.

Even before they settle into Dr. Patel's office, Jonas is eager to tell Dr. Patel how much he has improved since his hospitalization. "I am a thousand times better already!" exclaims Jonas. "I've realized that I'm on a sacred journey of recovery, and so I started a blog to record all the ups and downs. The blog is going to be huge because I already have a ton of followers on Twitter."

After Jonas leaves, Dr. Patel begins to wonder if she should take a look at Jonas's blog. On one hand, she thinks it would allow her get to know Jonas better. On the other hand, she wonders whether she would be crossing patient-doctor boundaries by seeking out the blog. Jonas has not asked her to read it. She thinks to herself, There is no telling what may turn up online.

Commentary

Internet technologies in the twenty-first century have provided countless opportunities and potential pitfalls for professional practice in areas as diverse as medicine, law, politics, business, and academia. These technologies have especially serious implications for psychiatry, where emotional complexities, boundary issues, and privacy concerns are of particular concern in the relationship between clinician and patient. In the course of routine clinical practice, psychiatrists nowadays must grapple with questions about whether to exchange e-mails with patients, to participate in social networking sites such as Facebook, and to perform Internet searches in order to learn information about patients. Each of these uses of Internet technologies in psychiatry has received growing attention in the professional literature [1-3]. The case scenario raises the question of whether clinical psychiatrists ought to read and monitor the websites or blogs of some of their patients.

Blogging is a relatively new Internet phenomenon that has gained immense popularity and influence in recent years. On easily accessible blogging platforms such as Tumblr, virtually any person with Internet access can instantly post text, pictures, and video for the public (or a more restricted audience) to view. Among the millions who engage in this activity are psychiatric patients. In just the past few months, several patients in my own practice have mentioned maintaining or reading blogs.

For one of my patients, a high school student, keeping a blog became a major source of distress. Some of what she wrote on her blog apparently led to emotional bullying by classmates at school, and other posts appeared to be maladaptive responses to that bullying. After an episode of self-injurious behavior that appeared to be fueled by this upset, her parents and I convinced her to discontinue blogging in any form. But simply instructing patients whose blogs cause them distress not to blog is an inadequate clinical approach in certain cases. Some patients will continue to blog, even when doing so exacerbates their distress.

Should psychiatrists monitor their patients' blogs to learn what may be essential clinical information about them? Might it be useful for the psychiatrist to keep an eye on certain blogs and intervene clinically if the patient's written words raise serious safety concerns, as in the case of a patient blogger with a mood or psychotic disorder who is expressing worrisome suicidal or homicidal tendencies? If the psychiatrist does not monitor a known blog and the patient proceeds to act on a suicidal or homicidal plan posted on the blog, could the psychiatrist later be held liable for inaction? In such cases, failure to hospitalize the patient or to give a "Tarasoff" warning to others might be regarded as negligent clinical care and a serious source of medicolegal risk for the psychiatrist [4].

In the intriguing (and quite plausible) case narrative presented above, the psychiatrist faces this very dilemma. The patient, Jonas, has a severe bipolar mood disorder that necessitated a recent psychiatric hospitalization for assault on a police officer and threats of major violence with a bomb. He most likely remains symptomatic, with grandiose, psychotic thinking still present at the time of the initial outpatient visit to Dr. Patel. At this time, Jonas appears to lack insight into his still fragile (and most likely manic) mental state and he seems overly animated about his blogging activity. Given the recent assault and verbal threats that were part of his acute mania and psychosis, Dr. Patel is right to be concerned about what Jonas is writing on his blog. If Jonas makes violent threats on his blog and Dr. Patel fails to learn about those threats or to act to prevent their execution, a disaster could ensue for Jonas—and possibly for others.

Dr. Patel must decide whether to monitor or "mind" Jonas's blog in the coming days and weeks, which means Dr. Patel now needs to grapple with a host of ethical issues around privacy and informed consent. Does Dr. Patel have the right to monitor Jonas's blog without first obtaining his consent to do so? If Dr. Patel begins to monitor his blog without consent, is there an obligation to inform Jonas post hoc about the monitoring and what has been discovered? What information obtained by reading his blog is suitable for entry in Jonas's medical record? At what point might

Dr. Patel involuntarily hospitalize Jonas or give Tarasoff warnings to others based on what Jonas writes on his blog? This case will quickly become incredibly timeconsuming, and precarious, for Dr. Patel.

There are no easy, ready-made answers for the ethical dilemmas raised by this case. Professional guidelines, regulatory requirements, and legal precedents do not yet exist for dealing with these situations. In the meantime, individual clinicians must exercise their best judgment on a case-by-case basis. There is no consensus about whether a patient's blog should be regarded as private (akin to a conventional, handwritten journal) or as public (like anything available on the "information superhighway"). Likewise, there is no consensus as to whether psychiatrists may be medicolegally responsible for knowing about and acting upon material that their patients post on publicly accessible blogs. These issues warrant self-reflection on the part of individual psychiatrists, as well as deliberation (and possibly policy formation) in the broader psychiatric community.

With Internet technology pervading daily life and increasingly affecting the nature of the patient-doctor relationship, psychiatrists cannot avoid engaging these issues. In the course of routine clinical practice, psychiatrists more and more will have to determine whether or not to mind the blogs.

In the case scenario presented above, I would advise Dr. Patel to inform Jonas that monitoring his blog is essential, at least until he is clinically stable and not an imminent safety risk to himself or others. This and ensuing discussions about the blog should be documented in the medical record, and appropriate third parties should be warned if Jonas appears to present a serious and imminent threat. Perhaps Dr. Patel's informing Jonas about monitoring his blog will lead to fruitful discussions between them that will help to ensure safety and promote Jonas's best interest.

In general, it may not be realistic to mind patients' blogs in this manner, in part because it's so time-consuming and unlikely to be billable clinical work. What's more, ethical concerns around patient privacy and consent issues will give many psychiatrists pause or inhibit them from seeking out their patients' blogs.

We may, however, be damned if we do and damned if don't. The human costs and the medicolegal risks of failure to mind the blogs of potentially violent patients like Jonas could turn out to be unacceptably high. Given this fact, at least in certain special cases, minding the blogs is an essential new role for the twenty-first century psychiatrist.

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ETHICS CASE

Special Protections for Mental Health Treatment Notes

Commentary by Anthony P. Weiss, MD, MBA

Dr. Kessler is a psychiatrist at Parks Medical Associates, a large multispecialty medical practice with more than 60 physicians. Dr. Kessler has had an interest in health information technology since he was an undergraduate majoring in computer science. Over the past year, he has been managing his group's transition from paper charts to an electronic medical record (EMR) system. He believes that the system will produce more efficient and coordinated patient care by giving clinicians seamless access to patient medical records, thereby leading to better patient health outcomes and overall cost savings for the practice.

Given the sensitive nature of psychiatry visits, Dr. Kessler proposes the use of a firewall as an additional safeguard to ensure the confidentiality of patients' mental health records. This firewall prevents employees who are not mental health clinicians from accessing psychiatry notes.

When Dr. Kessler presents this proposal at a meeting with senior members of the practice, several physicians raise their concerns. Dr. Liu, an internist, asks, "How will I be able to monitor my patients' depression or alcohol treatment if I can't read the psychiatrist's notes?" Dr. O'Leary, a gynecologist, wonders, "Aren't we perpetuating the stigma surrounding mental illness by creating special protections?"

Commentary

The development of electronic methods for documenting and sharing medical information in the health record has raised a number of new ethical challenges and given new life to some old ones. This case highlights an important issue: how to handle the documentation of mental health care so that patient wishes for confidentiality are balanced with the need for interdisciplinary communication and care coordination.

For the purposes of this discussion I will put aside many of the other complexities associated with the privacy and confidentiality of mental health information, such as situations where clinicians are obligated to breach confidentiality to protect the safety of the patient or other members of society (e.g., homicidal threats, evidence of child abuse or neglect, statements of imminent suicidal intent) and other situations in which the notes are barred from view by anyone but the author (i.e., psychotherapy process notes). I will confine the discussion to the sharing of information within a specific practice, inasmuch as state laws differ in their restrictions on the communication of mental health information to an outside entity. This latter point is

becoming increasingly difficult to ignore as the boundaries of information access become blurred with the advent of health information exchanges.

Even with these issues conveniently out of the way, the matter at hand is ethically challenging. On one hand we have the important emphasis on confidentiality, the expectation that information provided by a patient to his or her physician will not be shared without the patient's permission. The ethical basis for confidentiality is said to be the principle of respect for patient autonomy. One could also argue that confidentiality is critical for beneficence, since, without a guarantee of confidentiality, the patient will be reticent about sharing important information, and the physician's capacity to accurately diagnose and treat him or her would be compromised. For example, a patient who lacks trust in the confidentiality of the physician encounter may not disclose that his or her symptoms of anxiety began after a sexual assault, thus impeding the physician's ability to diagnose and effectively treat posttraumatic stress disorder.

As described in the case, societal stigma related to mental illness plays an important role in this discussion. Stigma and shame about mental health diagnoses often inhibits patients from disclosing relevant information to their physicians or seeking help from mental health specialists. And when they do share this type of information, patients desire greater levels of confidentiality. Paradoxically however, the methods used to ensure this confidentiality ("hiding" notes) could perpetuate the stigma associated with these conditions, as it suggests that this "shameful" information, somehow distinct from medical care, should be kept in a corner. Thus, a cycle of stigma is continued.

There may also be important safety risks associated with cordoning off the mental health aspects of the care provided. The principle of respect for autonomy may need to be balanced by the principle of nonmaleficence. A psychiatric consultation that elicits important risk factors for suicide may be of great value to a primary care physician's determination of risk when considering prescribing varenicline or in a neurologist's prescribing an anticonvulsant—medications that may exacerbate risks of self-harm in a vulnerable person. Furthermore, some psychotropic medications, such as the atypical antipsychotics, raise the risk of metabolic syndrome and require close medical monitoring and care coordination. When there is a culture of secrecy around everything pertaining to mental health, and psychiatry notes are not viewable, collaborative activities between physicians become far more difficult.

Two solutions to this situation attempt to take a middle road. One approach leaves the decision to suppress mental health notes to the patient—akin to an informed consent process. Although patient-centered and thoughtful, this resolution can cause problems if the patient wishes to suppress the note but the psychiatrist believes the information should be viewable due to concerns about harm to the patient from poor care coordination.

A second approach allows some information to be viewable to all (e.g., psychotropic medications in the medications list) but the remaining content of the psychiatric note is secured behind a "firewall." This has the benefit of protecting the information that may be of greatest concern to the patient, but often creates a guessing game for clinicians who, based on the few clues available in the record, attempt to deduce the diagnosis. This approach also requires authorizing a growing number of clinicians (especially those working in emergency settings) to be able to "break the glass" to read the otherwise suppressed notes. In the end there may be a false sense of security, as ultimately several hundred clinicians within the organization may have legitimate access to a note that the patient believes is confidential. Furthermore, it doesn't address the mental health content and diagnoses contained within the notes of non-mental-health professionals. This is important since the vast majority of psychiatric care is actually provided by primary care physicians, rather than psychiatrists.

There are no easy answers, and the field will need to find its way, as physicians work with patients to develop documentation approaches that are acceptable to all. Evolving technology within electronic medical record systems, which allow greater flexibility in selecting heightened security for discrete portions of a note, are a helpful advance. Open discussion with patients about the process employed, including the various people who may legitimately need to see the notes to provide them with optimal care, is now a critical part of an initial visit. In addition, physicians need to use greater care in drafting notes, realizing they may be writing for a broader audience, including the patient.

With the national push toward electronic data collection and ultimately data sharing, the general concerns about patient privacy and confidentiality of the medical record are likely to remain front and center for the foreseeable future. Whether the need for psychiatric exceptionalism persists is less certain, but technology may be the stimulus to encourage long overdue discussions within the mental health community (patients and clinicians) about how best to retain trust while not perpetuating stigma and inadvertently promoting poor quality care.

Further Reading

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Anthony P. Weiss, MD, MBA, is an assistant professor in psychiatry at Harvard Medical School in Boston, chair of clinical policy and records, quality chair for psychiatry at Massachusetts General Hospital, and chair of the Mental Health Privacy and Confidentiality Subcommittee at Partners Healthcare.

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ETHICS CASE 3

Treating Bereavement

Commentary by Richard A. DeVaul, MD

On the examining table, Mrs. Greene looked much older than her 41 years. There were dark bags under her eyes, and her hair was tied back in a bun. She was seeing her primary care physician, Dr. Samuel, for a routine physical exam.

"Do you have any pain?" Dr. Samuel asked as he pressed on the patient's belly.

Abruptly, Mrs. Greene sat up. Tears were overflowing her eyes.

"Dr. Samuel, I'm in a lot of pain," she admitted. "Since my daughter died, I wake up in the middle of the night thinking I hear her calling out my name. Am I going crazy?"

Mrs. Greene's 8-year-old daughter had died from leukemia about 7 months before, and since then Mrs. Greene had had trouble falling asleep and staying asleep. She had lost 10 pounds. She was on a leave of absence from her job as an accountant because she couldn't concentrate on her work.

Dr. Samuel handed her a box of tissues. "My heart goes out to you," he replied. "I can't imagine what it's like for you to lose your child. The grief you're going through must be terrible."

"It is terrible," murmured Mrs. Greene. "It's been going on for months now. Shouldn't it have stopped by now? Can't you prescribe me a pill to take away this pain?"

"Would you be interested in grief counseling?" asked Dr. Samuel.

"I went to a group once, but I couldn't stand it. All those sad people just made me feel worse," Mrs. Greene explained. "Can't you just give me something to stop the pain?"

Dr. Samuel recognized that Mrs. Greene had some symptoms of depression, but he was reluctant to diagnose her with major depressive disorder, given that the loss of her daughter was still fairly recent. Furthermore, he was unsure whether medication was warranted at this point. As terrible as it is, grief is a natural human condition, he mused.

Commentary

The case of Mrs. Greene raises many key issues in the management of acute grief. Bereavement is all too common but is seldom identified or accorded significance in explaining a patient's medical condition. Good for Dr. Samuel for allowing Mrs. Greene to express her emotional concerns and for realizing how important her loss is to her medical presentation.

While uncomplicated grief and clinical depression share characteristics such as crying spells, withdrawn behavior, depressed mood, acute dysphoria, and disturbances of eating and sleeping, they have distinct and very different patterns of clinical presentation. Clinical depression is continuous, involving a constant depressed mood for at least 2 weeks without relief. Grief, on the other hand, is characterized by episodes of intense dysphoria brought on by memories of the deceased. These "ambush episodes" alternate with intervals of relative relief with a decrease in despair and social dysfunction.

Grief is a painful experience that can be lonely as well as scary. Unusual experiences like hearing or seeing the deceased are normal in grief, as are receiving "signs" or messages from them. Similarly, most people underestimate the length of normal grief. While variable, several years may be required to deal with a significant loss. Often patients, friends, and family are impatient to move on rather than continue to work through the loss, but a healthy conclusion requires processing the grief. Unresolved and complicated grief is associated with ongoing personal and medical risks. Dr. Samuel should inquire how Mrs. Greene is doing with her grief at every appointment.

Clinical depression, a syndrome seen in response to a variety of social stresses and medical illnesses, often complicates normal grief, as it appears to have in Mrs. Greene's case. Loss can vary in intensity, but one of the most difficult to confront is the death of a child. It is not surprising that Mrs. Greene is depressed. Her persistent sleep disturbance, inability to work, and weight loss strongly suggest clinical depression. Dr. Samuel could substantiate this impression by: (1) asking the patient if she is depressed (patients know, and a "yes" is greater than 90 percent accurate) and, more importantly, (2) by determining whether her symptoms have been constant or episodic.

Regardless, it is imperative to ask Mrs. Greene about suicidal thoughts and plans. Suicide is a risk throughout the course of depression and occasionally in acute grief when the patient may feel an urge to join the deceased. Simply asking the patient if he or she has thought about suicide will identify a current risk (which may prompt a psychiatric referral). It is also an opportunity to educate the patient about the risk of such thoughts and the importance of calling the physician if they occur.

Dr. Samuel expresses reluctance to diagnose Mrs. Greene with major depressive disorder. The real priority is to identify a depressive syndrome and evaluate suicide risk. Treatment of depression secondary to grief is always indicated. Only if the

patient has a previous history of depressive episodes (or prior diagnosis of major depressive disorder) would a recurrent depressive illness be suspected.

I use antidepressants for patients struggling with grief as well as for those with secondary depression. I think the SSRIs in particular help with the stress of grieving as well as the symptoms of anxiety and depression commonly seen. If Mrs. Greene becomes so depressed that she is unable to care for herself or is acutely suicidal, hospitalization could be indicated. If a patient is very suicidal, ECT can be effective because it treats the depressed mood first and other symptoms such as lack of energy and sleep disturbance last. The opposite is true for antidepressants. This is why the first few weeks of drug treatment may increase the risk of suicide in some patients who still feel suicidal but now have the energy to act on those feelings. It's imperative to warn patients of this risk and monitor the initial weeks of drug treatment carefully.

Individual and group grief therapy can be helpful. Therapy offers structure and support for processing the loss. However it's important to identify people with experience in grief counseling because many therapists are unfamiliar with it. Hospice grief services are usually available to the general community and are a good source for counseling and referral to other community resources.

Dr. Samuel can help the family and Mrs. Greene understand both grief and depression through a brief discussion and by answering questions. Some points to touch on include the length of time it takes to grieve, its episodic nature, and the importance of embracing it. Both grief and depression are typically self-limiting processes, and the purpose of interventions is to shorten their courses. Suicidal thoughts are often experienced in the course of both and should be reported to a physician immediately. It's worth mentioning that special dates, holidays, and anniversaries will be "hard times" in grief, and planning special activities to celebrate the deceased can help make these times more manageable. Many patients express the concern that grieving will mean letting the deceased go and are reassured to learn that grieving actually allows them to become closer to the deceased.

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Richard A. DeVaul, MD, is retired from the Texas A&M Health Science Center, where he was a professor of psychiatry and family medicine. He has a long history of teaching, research, and clinical experience with grief and bereavement.

Related in VM

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MEDICAL EDUCATION

Resources for Teaching Neuroethics

David Elkin, MD, Erick Hung, MD, and Gilbert Villela, MD

Many of the ethical dilemmas that physicians confront are the result of the research and technological innovation of the last half century. Perhaps the most challenging ethical controversies that will result from scientific advances are expected in the field of brain science. News headlines from recent years demonstrate that this has already begun to happen: "More Students Turning Illegally to 'Smart' Drugs" [1] and "A Definitive fMRI Test For Narcissism" [2].

The rapidly evolving field of neuroethics—ethical issues involving neurologic and psychiatric conditions—is concerned with the great promise of newer technologies as well as the ethical questions that they will pose about autonomy, privacy, the definition of "normal," and the nature of individuality.

The promise and danger of cognitive and emotional enhancement are now being considered. Listed below are some ethically controversial interventions that are either currently possible or are likely feasible in the near-future:

- The use of stimulants (obtained either illegally or through physicians) by significant numbers of college students for the purposes of enhancing concentration;
- Possible pharmaceutical advances of the future that may allow users to select their mood states for the day—perhaps increasing confidence on the day of an important interview or test;
- The use of electrodes placed in the brain to treat depression via deep brain stimulation;
- The use of microelectrodes to allow "locked-in syndrome" patients to control a computer cursor;
- The use of fMRI for "lie detection" in unwilling subjects;
- The detection of Alzheimer disease decades prior to the appearance of clinical symptoms;
- Genetic testing that may someday allow for correlations with personality traits; and
- Possible future advances in stem-cell technology that would allow for the regeneration of damaged brains—the person receiving those treatments would not be the "same" person as before the disease or accident.

Educators should consider the specific dilemmas that arise in assessing and treating brain conditions and the special aspects of brain function that set controversies in neuroethics apart from those involving any other organ system. It is the brain that

determines individuality and makes persons unique. Repairing damaged brain cells with stem cells is a very different proposition than fixing, for example, vascular tissue; replacing brain cells might lead identity to be altered. Similarly, the possibility of enhancing intelligence or mood beyond the normal range could change the social perception of what constitutes a normal or desirable state. If mental states or personality disorders are traced to specific DNA sequences, rapid genome sequencing may lead to a significant loss of privacy.

How will our society view these advances, and what role will physicians play in their implementation? Can scientists determine research agendas, or must society and social norms play a governing role? Considerations of autonomy, social pressure, access to care (another important issue in costly new treatment options) and the possibilities of neuroenhancement make for exciting discussion as trainees explore the social implications of potentially revolutionary innovations in medical care. We recommend several books, articles, and web sites that discuss these issues [3-9].

Critical Thinking and Psychiatry and Neurology Ethics

Critical thinking is reflective consideration leading to reasoned judgments. It can be characterized as a set of skills and habits of mind:

- Reflection: considering one's own emotional reactions and thought processes;
- Avoidance of common cognitive traps like confirmation bias and groupthink (pressure—conscious or unconscious, external or internal—to go along with others' opinions);
- Awareness of strong emotional reactions that can influence decision-making;
- Humility: an awareness and appreciation for one's limitations and knowledge gaps; and
- Tolerance for ambiguity: being able to hold disparate and even contradictory
 perspectives without immediate resolution, even constructing arguments for
 and against different points.

Critical thinking is often fostered through the Socratic method, in which instructors use questions to prompt reflection among students, empowering them as thinkers, and model open-mindedness and humility. We recommend several books on critical thinking in medicine and more generally [10-12].

The application of critical thinking to ethics offers numerous advantages and highlights the importance of techniques useful in teaching. Having trainees reflect on their process of ethical reasoning encourages practices that will be useful in the future. Highlighting the dangers of groupthink in ethical dilemmas, and the influence of emotions on supposedly rational analysis, offers important insights for trainees about psychological mechanisms that can influence ethical analysis. Asking trainees to explore their values explicitly, often as their idealism comes into conflict with real-life dilemmas, encourages self-knowledge and stresses the importance that each individual brings to such study.

Trainees can be asked to examine the basis for their beliefs by posing questions like: Where do you believe ethical authority originates? Do you believe in a religious or spiritual basis for morality or does society make rules that we must all follow? Can a decision be right or wrong on its own, or do individuals decide? How might beliefs that arise from these different bases conflict? How should conflicting beliefs and values be treated in a democracy?

The ability to tolerate ambiguity is key to discussions of ethical dilemmas. It is instructive for trainees to ponder how they will act under conditions of uncertainty. Many students and residents feel a strong desire to achieve closure on dilemmas by the end of a class or seminar, often prematurely.

Pedagogical Strategies

Studies demonstrate the limited effectiveness of uninterrupted lectures. Most participants will be excited about discussing ethical issues; it is an instructor's responsibility and charge to build on that enthusiasm, employing different pedagogical approaches such as didactic or informational presentations, Socratic discussion, case presentation and discussion, and other media including articles, advertisements [13], documentaries [14], film clips (see below), and nonacademic web sites [15, 16]. The University of Pennsylvania Center for Neuroscience and Society has online resources teachers may find useful in designing curricula and choosing assignments [17, 18].

The following scenarios can serve as the basis for small-group discussions:

- A college student comes to you asking for a prescription for stimulants. His screen for ADD is largely negative, but he is insistent that he needs more "focus," concentration, and energy. Would you prescribe stimulants for him?
- A woman has a history of severe depression which has not responded to antidepressants, adjunctive agents such as antipsychotics, and ECT. She undergoes deep brain stimulation and experiences significant reduction in her symptoms. In calibrating the stimulation, clinicians believe that they have found the optimal results with one pattern of electrode firing. However the patient reports that she gets more relief from a slightly different pattern, which the clinicians feel places her in a hypomanic state. The patient insists that she should be the one to determine the final settings for the electrodes. How do you respond?
- A woman with a strong family history of early-onset Alzheimer disease asks for genetic testing and analysis of cerebrospinal fluid to determine her precise risk of developing the disease. The patient argues that she can use the information to reduce her risk factors. You counter that she can reduce her risk factors through diet, minimizing other conditions such as diabetes and hypertension, and increasing exercise. Due to the novelty of these tests, you are uncertain how to balance autonomy (the patient's wish for the test) and beneficence (seeking the best outcome for the patient) and your desire to do the least harm (i.e., protect the patient from the emotional impact of the test). How do you proceed?

• As a military physician, you are ordered by your superiors to use an fMRI as a lie-detector test on a prisoner. Advances have permitted increased accuracy and the cooperation of the subject is not a limiting factor. Information from the prisoner could save thousands from a terrorist attack, but its contradiction of your oath as a physician gives you pause. How can you act against the patient's wishes and still maintain your professional integrity?

Films that promote critical thinking about topics in brain-science-related ethics include:

- *Limitless*: Bradley Cooper portrays a man who receives a supply of cognition-enhancing pills; his experience of increased memory, concentration, and insight is especially well-depicted in early scenes, along with the temptation and hubris that might accompany medications that affect not only intelligence but personality.
- Endless Sunshine of the Spotless Mind: Jim Carrey's character, Joel, is dismayed to learn that his ex-girlfriend Clementine has elected to undergo a procedure that erases all memories of their relationship. In his despair he decides to undergo the process to erase his memories of their relationship as well; it is only when he has partially completed the treatment that he decides that the painful memories are worth having.
- *Charly*: Cliff Robertson won an Oscar for his portrayal of a man whose intelligence is boosted from subnormal to "genius" level in a scientific breakthrough that is both miraculous and tragic; based on the award-winning novel *Flowers for Algernon* by Daniel Keyes.

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THE CODE SAYS

The AMA Code of Medical Ethics' Opinion on Confidentiality of Patient Disclosure and Circumstances under Which It May Be Breached

Opinion 5.05 - Confidentiality

The information disclosed to a physician by a patient should be held in confidence. The patient should feel free to make a full disclosure of information to the physician in order that the physician may most effectively provide needed services. The patient should be able to make this disclosure with the knowledge that the physician will respect the confidential nature of the communication. The physician should not reveal confidential information without the express consent of the patient, subject to certain exceptions which are ethically justified because of overriding considerations.

When a patient threatens to inflict serious physical harm to another person or to himself or herself and there is a reasonable probability that the patient may carry out the threat, the physician should take reasonable precautions for the protection of the intended victim, which may include notification of law enforcement authorities.

When the disclosure of confidential information is required by law or court order, physicians generally should notify the patient. Physicians should disclose the minimal information required by law, advocate for the protection of confidential information and, if appropriate, seek a change in the law.

Issued December 1983. Updated based on the report "Opinion E-5.05, 'Confidentiality,' Amendment," adopted November 2006.

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American Medical Association Journal of Ethics June 2012, Volume 14, Number 6: 460-463.

JOURNAL DISCUSSION

The Ethics of Genetic Testing in Psychiatry

Aaron D. Besterman, MD

Hoop JG. Ethical considerations in psychiatric genetics. *Harv Rev Psychiatry*. 2008;16(6):322-338.

Before the Nazi regime focused its efforts on the extermination of European Jewry, one of its early eugenics directives aimed at cleansing the gene pool of psychiatric disease. Thousands of mentally ill patients were either sterilized against their will or murdered as part of the German Racial Hygiene Movement. Shamefully, this movement was largely fueled by the research and ideologies of early psychiatric geneticists, such as Ernst Rudin [1].

Similar efforts were undertaken in the United States to prevent the reproduction of those deemed mentally insufficient. This practice was famously upheld by the Supreme Court in *Buck v. Bell* in 1927, with Justice Oliver Holmes Jr. concluding his argument by declaring that "Three generations of imbeciles are enough" in reference to the plaintiff Carrie Buck, her mother, and her daughter [2].

Given a past marred by such ethically deplorable behavior, it is vital for current medical professionals to have a thorough understanding of the ethical issues involved in psychiatric genetics and a structured framework with which to evaluate new psychiatric genetic tests. In "Ethical Considerations in Psychiatric Genetics," Jinger Hoop provides a succinct introduction to this topic with practical suggestions on how to assess the ethical acceptability of psychiatric genetic tests.

Summary of "Ethical Considerations in Psychiatric Genetics"

In her review article, Dr. Hoop touches on four broad ethical issues in psychiatric genetics: (1) the use of genetic testing to predict future health outcomes, (2) the psychosocial consequences of genetic testing, (3) the effect of genetic testing on family members and communities, and (4) the ethics of the use of emerging genetic technologies [3].

She begins by describing how the landscape of clinical psychiatric genetics has changed from one focused on rare, monogenic disorders such as Huntington's disease (HD) to one that will be dedicated increasingly to common, polygenic diseases, such as schizophrenia. In HD, the ethical debate concerns the risks and benefits of providing a patient with precise information about his or her medical future—if you have the HD gene, you will get the disease if you live until its onset, typically middle age. If little can be done to prevent the onset or mitigate the effects of the disease being tested for, is it ethical to test for the disease at all?

In contrast, hundreds or thousands of genes each confer a small increase in risk for developing schizophrenia. Testing a patient for such genes provides only an estimate of his or her increased risk for developing schizophrenia (e.g. 3 percent, when risk is 1 percent in the general population) with much uncertainty remaining. Hoop highlights the difficulty patients are likely to have in interpreting such results. Some patients may think they are completely free of risk if they test negative for a risk gene, while others may believe that they are destined to develop a disease if they test positive, when really they may have only a slightly greater-than-average risk.

Hoop identifies psychological consequences, insurance and employment discrimination, and social stigmatization as the three main psychosocial risks of psychiatric genetic testing. While genetic testing in general certainly has psychological consequences, the consequences of genetic testing for psychiatric disorders may be more profound. Many view the psyche as an inextricable component of one's being. Thus, being told of a genetic "defect" in one's psyche may be particularly distressing. The findings of several studies Hoop cites are consistent with this theory; they suggest that "learning one has a 'good' or 'bad' [psychiatric] genotype may have a more profound psychological impact than learning one's absolute risk of illness"[4].

Another potential hazard of genetic testing in psychiatry is that employers, insurers, and the general public may discriminate against individuals based on their psychiatric genotypes. Hoop discusses a case of three young men who lost their jobs because their employer discovered that they had first-degree relatives with schizophrenia [4]. There is a risk that similar discrimination could occur based on one's genotype, a risk that may be more likely to happen with mental than with physical disease. In hopes of limiting such discrimination, the United States Congress enacted the Genetic Information and Nondiscrimination Act of 2008 [5].

Genetic information can also have serious implications for relatives of a person being tested and for those who come from a similar ethnic background. For example, if a grandparent developed Alzheimer's disease, his or her grandchild (of adult age) may wish to get tested for disease-related genes to determine the risk for developing Alzheimer's. If the grandchild's parent does not want to know his or her risk, an ethical dilemma arises in which the parent's right to not to know must be weighed against the child's right to know.

Similarly, ethical conflicts may arise during population-based genetic testing in reproductively isolated groups, such as the Amish or Ashkenazi Jews. Testing can have great public health benefits by identifying severe genetic conditions that are present in these groups. But this benefit must be carefully weighed against the risk that finding a genetic predisposition for illness, especially mental illness, could reinforce preexisting stigmas and provide a false basis for discrimination and bigotry.

At the time of Hoop's writing, many candidate genes had been identified, but virtually no genes had been conclusively linked to psychiatric disease, with the exception of APOE for Alzheimer's disease. Without a definitive link between gene and disease, genetic testing may be highly unethical. With significant advancements in the field, however, direct-to-consumer or physician-requested genetic testing will certainly play a future role in the management of psychiatric illness. It will fall to the clinician to interpret the results and advise patients on how to proceed. Unfortunately, data from the most recent studies published (up to 2008) [6] indicate that the vast majority of psychiatrists are insufficiently trained in genetics to provide this service and that there are too few genetic counselors to fill in the gaps.

Hoop then applies Burke et al.'s framework for categorizing ethical considerations of genetic tests to psychiatric testing specifically. According to Burke's frameworks, the primary ethical consideration in psychiatric genetic testing is nonmaleficence, doing no harm, as few effective treatments can be provided based on test results and tests have low predictive power. Hoop proposes an expanded framework that includes additional factors, such as psychosocial risk, the level of stigma of the condition, and the newness of the test to provide a more robust evaluation of whether genetic tests for psychiatric disorders are ethical.

Lastly, Hoop emphasizes the importance of designing "prospective evaluations of the outcomes of psychiatric genetic counseling and testing...[to] complement empirical ethics research methods"[7]. She argues that the knowledge gained from such studies will help prevent genetic discrimination and improve public trust in psychiatric genetic research and testing.

Discussion

Hoop's piece stands out in the field of bioethics not only as a review of important ethical issues in psychiatric genetics but also as a source of a novel, structured framework for evaluating the ethical nuances of new psychiatric genetic tests. This is a particularly timely contribution to the field, as our knowledge about the genetic underpinnings of mental illness has been advancing at a furious pace. For example, many genomic deletions and duplications have been detected in patients with autism spectrum disorders [8]. This has led to recent guideline changes recommending chromosomal microarray analysis as part of an initial work-up for children who display autistic-type behaviors [9]. Similar advances have been made in schizophrenia, with strong evidence for associations with *vasoactive intestinal peptide receptor 2* (VIPR2), *neurexin 1* (NRXN1), and *transcription factor 4* (TCF4) [10].

Many more genes involved in psychiatric disease are likely to emerge in the near future, with the thousand-dollar genome, once a distant dream, now at our fingertips [11]. Furthermore, some genetically informed pharmacotherapies are now in development, from mGluR5 antagonists for fragile-X syndrome to PI3K inhibitors for schizophrenia [12, 13] With such advances, nonmaleficence will no longer be the prevailing ethical principle dictating psychiatric genetic testing. Instead, as Hoop

proposes, justice, respect for autonomy, psychosocial risk and stigma of disease will all have to be strongly considered before pursuing genetic testing for psychiatric illness.

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STATE OF THE ART AND SCIENCE

Diagnostic Brain Imaging in Psychiatry: Current Uses and Future Prospects Martha J. Farah, PhD, and Seth J. Gillihan, PhD

Psychiatric Diagnosis and Brain Imaging

The biological revolution in psychiatry, which started in the 1960s, has so thoroughly transformed the field that the phrase "biological psychiatry" now seems redundant. A huge literature exists on the biological correlates of psychiatric illness, including thousands of published research studies using functional neuroimaging methods such as SPECT, PET, and fMRI. In addition, most psychiatric treatment is biological in that it directly affects the brain through medication, stimulation, or surgery. Even "talking therapies" are now understood to change the brain in ways that have been visualized by neuroimaging [1].

Diagnoses in psychiatry, however, are based entirely on behavioral, not biological, criteria [2]. Depression is diagnosed by asking patients how they feel and whether their sleeping, eating, and other behaviors have changed. Attention deficit hyperactivity disorder (ADHD) is diagnosed by asking the patient, family members, and others about the patient's tendency to get distracted, act impulsively, and so on. For these and all other psychiatric illnesses described by the Diagnostic and Statistical Manual of the American Psychiatric Association, findings from brain imaging do not appear among the diagnostic criteria. Aside from its use to rule out potential physical causes of a patient's condition, for example a brain tumor, neuroimaging is not used in the process of psychiatric diagnosis.

In this article we review the current status of brain imaging for psychiatric diagnosis. Among the questions to be addressed are: why has diagnostic neuroimaging not yet found a place in psychiatric practice? What are its near-term and longer-term prospects? What obstacles block the use of such methods? The answers to these questions involve the nature of imaging studies and of psychiatric diagnosis.

Sensitivity, specificity and standardization in psychiatric brain imaging. The vast majority of psychiatric neuroimaging studies aggregate data from groups of subjects for analysis, whereas diagnosis must be made for individuals, not groups. Structural and functional studies reveal a high degree of variability within groups of healthy and ill subjects, often with considerable overlap between the distributions of the two groups [3]. In the language of diagnostic tests, imaging studies are generally not highly *sensitive* to the difference between illness and health.

Another current limitation concerns the *specificity* of candidate diagnostic markers from imaging. Most psychiatric imaging studies involve subjects from only two

categories—patients from a single diagnostic category and people without any psychiatric diagnosis. The most that can be learned from such a study is how brain activation in those with a particular disorder differs from brain activation in those without a disorder. The dilemma faced by a diagnosing clinician, on the other hand, is rarely "Does this person have disorder X or is she healthy?" Rather, it is typically "Does this person have disorder X, Y, or Z?" The pattern that distinguishes people with disorder X from healthy people may not be unique to X but shared with a whole alphabet of other disorders.

Indeed, there is considerable similarity in the abnormalities noted in brain activation across different diagnoses. A meta-analysis of neuroimaging studies of anxiety disorders reported common areas of activation (amygdala, insula) across posttraumatic stress disorder, social phobia, and specific phobia—suggesting that neuroimaging has yet to reveal patterns of neural activity that are unique to specific anxiety disorders [4]. Abnormalities of amygdala activation also have been reported consistently in neuroimaging studies of depression [5], bipolar disorder [6], schizophrenia (a disorder primarily of thought rather than of mood) [7], and psychopathy (which shares features with the DSM diagnosis of antisocial personality disorder) [8].

More sophisticated methods of image analysis may hold promise for discerning the underlying differences among the many disorders that feature similar regional abnormalities, including the "usual suspects," limbic hyperactivity and prefrontal hypoactivity. In addition, new multivariate statistical approaches to image analysis make it possible to discover spatial and temporal patterns that correspond to performance of specific tasks and specific diagnoses [9]. These methods have only begun to be applied to clinical disorders but show promise for increasing the specificity of brain imaging markers for psychiatric illness [10, 11].

Standardization is relevant in light of the many ways in which protocols differ from study to study, particularly among functional imaging studies. The patterns of activation obtained in studies of psychiatric patients depend strongly on the tasks performed by the subjects and the statistical comparisons examined by the researchers afterwards. Although the results of psychiatric imaging research are often summarized by stating that certain regions are under- or overactive or more or less functionally connected, such summaries are fundamentally incomplete unless they include information about what task evoked the activation in question: were the patients resting, processing emotional stimuli, trying not to process emotional stimuli, or engaged in effortful cognition? The fact that any imaging study's conclusions are relative to the tasks performed adds further complexity to the problem of seeking consistently discriminating patterns of activation for healthy and ill subjects.

Reliability and validity of current diagnostic categories. Other reasons why progress toward diagnostic imaging in psychiatry has been slow stem from the nature of the diagnostic categories themselves. The categories of the DSM are intended to be both

reliable and valid. That is, they are intended to be usable in consistent ways by any appropriately trained clinician, so that different diagnosticians arrive at the same diagnosis for each patient (reliability) and to correspond to the true categories of psychiatric illness found in the population, that is, to reflect the underlying psychological and biological commonalities and differences among different disorders (validity). Good, or at least improved, reliability was one of the signal achievements of the DSM-III, and was carried over to DSM-IV. Unfortunately, validity continues to be more difficult to achieve.

As an illustration of how far from being necessarily valid our current diagnostic categories are, consider the criteria for one of the more common serious psychiatric conditions, major depressive disorder. According to the *DSM-IV-TR*, patients must report either depressed mood or anhedonia and at least four of eight additional symptoms. It is therefore possible for two patients who do not share a single symptom to both receive a diagnosis of major depressive disorder. There are also commonalities of symptoms between categories. For example, impulsivity, emotional lability, and difficulty with concentration each occurs in more than one disorder. To the extent that our psychiatric categories do not correspond to "natural kinds," we should probably not expect correspondence with brain physiology as revealed by imaging. Taken together, the fact that (a) different exemplars of a category can share no symptoms and (b) exemplars of two different categories may share common symptoms raises questions about the validity of the current diagnostic categories.

The Present and Future of Diagnostic Brain Imaging in Psychiatry

A defiant minority now use brain imaging for psychiatric diagnosis. Despite the challenges just reviewed, a small number of psychiatrists offer diagnostic neuroimaging to patients in their clinics. The imaging method used is single photon emission computed tomography (SPECT), which measures regional cerebral blood flow by detecting a gamma-emitting tracer in the blood. The best known of these clinics are the four Amen Clinics, founded by the psychiatrist and self-help author Daniel Amen. Others include the Clements Clinic, Cerescan, Pathfinder Brain SPECT, and Dr. Spect Scan. The use of brain imaging appears to be a selling point for these clinics; their websites generally feature brain images prominently and the names of the last three leave no doubt about the emphasis they place on imaging.

These clinics promise to diagnose and treat a wide range of psychiatric disorders in children and adults based on patient history and examination along with the results of SPECT scans. The Amen Clinics use a system of diagnosis that does not correspond to the standard diagnostic categories defined by the American Psychiatric Association's *Diagnostic and Statistical Manual*. For example, anxiety and depression are combined into a single superordinate category and then divided into 7 subtypes with names such as "temporal lobe anxiety and depression" and "overfocused anxiety and depression" [12]. Attention deficit hyperactivity disorder is also reconceptualized as having 6 subtypes, with names such as "limbic ADD" and "ring of fire ADD" [13].

The Amen Clinics website states that they have performed almost 50,000 scans [14], a huge number that, combined with associated clinical data including outcomes, could provide important evidence on the value of SPECT scanning in diagnosis and the efficacy of Amen's approach to psychiatric care. Unfortunately, no such studies have been reported. The lack of empirical validation has led many to condemn the use of diagnostic SPECT as premature and unproven [15-18].

Why do people pay for an unproven, even dubious, diagnostic test? Brain imaging has a high-tech allure that suggests advanced medical care. People may assume that the treatments available at these clinics, as well as the diagnostic methods, are cutting-edge. In addition, there is a strong allure to the idea that imaging can give visual proof that psychological problems have a physical cause. The Amen Clinics cite several ways in which patients and their families may find this evidence helpful, including the reduction of stigma and guilt [14]. Of course, these considerations do not address the question of whether diagnosis is improved by the use of SPECT scans.

Diagnostic neuroimaging: prospects for the near-term and longer-term future. Few believe that brain imaging will play a role in psychiatric diagnosis any time soon. The forthcoming DSM-5, expected in May of 2013, will include reference to a variety of biomarkers for psychiatric disease, including those visible by brain imaging, but their role is expected to be in the validation of the categories themselves rather than in the criteria for diagnosing an individual patient [19].

In the long term, there is reason for optimism concerning the contribution of brain imaging to psychiatric diagnosis. This may happen first for differential diagnosis, particularly for diagnostic distinctions that are difficult to make on the basis of behavioral observations alone. In such cases potentially distinctive patterns of brain activation identified through imaging will be especially useful. For example, Brotman et al. have studied the patterns of brain activation evoked in the performing of various tasks with pictures of faces and found differences between the neural responses of children diagnosed with severe mood dysregulation and those with ADHD or bipolar disorder [20]. They and others [21] suggest that this finding could provide the basis for the future development of diagnostic imaging.

Diagnostic imaging in psychiatry could emerge from basic research on psychopathology, as in the example just cited. Alternatively, the relatively atheoretical multivariate statistical approach mentioned earlier could provide the first candidate neural signatures of psychiatric disorders. By whatever method the candidate neural signatures are identified, large-scale validation trials will be needed before they can enter routine clinical use. This process promises to be lengthy and expensive and could easily fill the interval between two or more editions of the DSM.

Coevolution of diagnostic methods and diagnostic categories. Whether the path to imaging-based diagnosis involves translation of newly discovered mechanisms of

pathophysiology, brute-force number crunching, or both, we cannot assume that it will preserve current nosology. Indeed, given the overlap of imaging findings between diagnostic categories and the heterogeneity within categories mentioned earlier, it seems likely the widespread incorporation of imaging into diagnostic criteria will force our nosology to change. If the mismatch between imaging markers and diagnostic categories is not drastic, the *DSM* categories may change incrementally, for example by revisions of individual diagnostic criteria for specific disorders. However, if brain imaging reveals a radically different pattern of "natural kinds," and if these kinds are proven to have clinical utility (e.g., enabling better treatment decisions), then imaging may prompt a radical reconceptualization of psychiatric diagnosis and entirely new diagnostic categories may emerge.

There are, however, strong arguments for conservatism. The current system of diagnostic categories is valuable in part simply because we have used it for so long and therefore much of our clinical knowledge is defined in relation to this system. *DSM* diagnoses have so far changed in a gradual and piecemeal manner through multiple editions of the manual, with most disorders retaining their defining criteria and a only minority being subdivided, merged, added, and eliminated in the light of new research findings. In keeping with this approach, the future influence of brain imaging on psychiatric diagnosis is likely to be more evolutionary than revolutionary.

An attempt to reconcile the need for consistency with the promise of more neurobiologically based classifications can be found in the Research Domain Criteria (RDoC) for psychiatry research proposed by the U.S. National Institute of Mental Health. This is "a long-term framework for research... [with] classifications based on genomics and neuroscience as well as clinical observation, with the goal of improving treatment outcomes" [22]. The RDoC system, still under construction at the time of writing [23], is meant to be used, in parallel with DSM categories, for research that may ultimately lead to more valid diagnostic categories, which might also be more consistent with the use of imaging as a diagnostic test.

Conclusions

Brain imaging will probably enter clinical use in other roles before it serves as a diagnostic laboratory test. For example, imaging has already guided clinical researchers in the development of new therapies [24] and in the customization of therapy for individual patients [25]; it shows promise as a predictor of vulnerability [26] and treatment response [27] and has even been used as a therapy itself [28].

While some physicians insist that they are able to use brain imaging now for psychiatric diagnosis, there is currently no reliable evidence supporting this view. On the contrary, there are many reasons to doubt that imaging will play a role in psychiatric diagnosis in the near future. As argued here, much psychiatric imaging research remains to be done to achieve sensitivity, specificity, and standardization of imaging protocols.

In addition, the nature of current psychiatric diagnosis may not even correspond to the categories of brain dysfunction that imaging reveals. Finally, the practical value of maintaining continuity in diagnostic classifications requires a cautious and incremental approach to redrawing diagnostic classifications on the basis of imaging research.

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HEALTH LAW

Predicting the Risk of Future Dangerousness

Robert T. M. Phillips, MD, PhD

School shootings, workplace meltdowns, domestic violence, bullying, criminal behavior, predatory sexual misconduct, the list goes on, and the central question remains: why did they do it and, more importantly, will they do it again? Forensic psychiatrists are increasingly called upon to evaluate what seems to be an evergrowing number of persons exhibiting violent and aggressive behaviors for the purpose of assessing the risk of future danger.

Clinical evaluation for predictions of future dangerousness, have become integral to the function of the legal system. Such assessments are essential to involuntary civil commitment hearings, capital sentencing proceedings, bail and parole determinations, sexually violent predator assessments, and sex offender registration [1].

Predictions of future dangerousness have undergone much scrutiny over the past 20 years with considerable focus on the accuracy and reliability of such attestations by experts. This is understandable since the result of such courtroom testimony may lead to commitment to or retention in a psychiatric hospital (civil) or detention in a correctional facility (criminal) due to dangerousness or, alternatively, release back to the community.

Denial of a person's liberty—whether by civil or criminal proceedings—is a serious matter. The ability of the government to abridge individual freedom arises from one of two powers codified in the United States Constitution [2]. First, the government is responsible for protecting its citizenry from the harmful acts of others. This is known as its "police power." The primary goal of "police" civil commitment is protection of others rather than the patient.

Second and more benevolently, the government is responsible for the care of a disabled citizen much as a parent is responsible for the care of a child. This principle is known as "*parens patriae*." Here the primary goal is to care for an individual deemed unable to care for him- or herself.

The denial of liberty requires adherence to the strictest applicable standards of law. Consequently, civil commitment laws may be justified under either of these governmental powers as long as they meet the respective requirements to "police" or to "parent" [3]. State statutes rewritten in the past two decades have placed less

attention on the principles of parens patriae and more on the police powers of the state.

When considering the admissibility of expert predictions of future dangerousness, courts have traditionally applied the test for scientific evidence articulated in Daubert v. Merrell Dow Pharmaceuticals, Inc [4]. This 1993 decision of the U.S. Supreme Court changed the standard for admissibility of expert testimony which until then relied on the Frye test or the general-acceptance test [5]. Frye admissibility was based on the expert's credentials, experience, skill, and reputation with the expectation that any faults in the expert's conclusions would be exposed through cross-examination.

Under *Daubert*, a trial judge has a "gatekeeping" duty to rigorously scrutinize evidence to determine whether it meets the requirements of Federal Rule of Evidence 702. This rule states that

a witness who is qualified as an expert by knowledge, skill, experience, training, or education may testify in the form of an opinion or otherwise if (a) the expert's scientific, technical, or other specialized knowledge will assist the trier of fact to understand the evidence or to determine a fact in issue, . . . (b) the testimony is based upon sufficient facts or data, (c) the testimony is the product of reliable principles and methods, and (d) the witness has applied the principles and methods reliably to the facts of the case [6].

In 1999, the U.S. Supreme Court in Kumho Tire Co., Ltd. v. Carmichael held that the gatekeeping obligation imposed upon trial judges by Daubert applies to scientific testimony as well as to expert opinion testimony [7].

A consequence if not a driving force of the pendulum swing away from benevolence and toward the protection of others has been increased attention to an individual's dangerousness, with the operative presumption that dangerousness is often the result of a mental illness. But dangerousness is not always the result of mental illness. Individuals who commit violent or aggressive acts often do so for reasons unrelated to mental illness. The contract killer, for example, who murders to receive payment for services rendered and the aspiring gang member whose right of passage requires taking the life of another do so with full knowledge of the nature and consequence of their actions. Their motivation is the benefit derived by the act unencumbered by any impairment of mental capacity.

Research, in fact, confirms the error in associating dangerousness with mental illness, showing that "the vast majority of people who are violent do not suffer from mental illnesses [8]. The absolute risk of violence among the mentally ill as a group is still very small and...only a small proportion of the violence in our society can be attributed to persons who are mentally ill" [4]. Violence is not a diagnosis nor is it a disease [9]. Potential to do harm is not a symptom or a sign of mental illness, rather it must be the central consideration when assessing future dangerousness.

In reality, no one can predict future dangerousness precisely and with absolute certainty. Assessments of future dangerousness therefore may be more accurately described as the identification of factors associated with potential dangerous behavior by a given individual. In making such an assessment, the clinician should be able to articulate measures necessary to a management plan that minimizes the identified future risks. Hospital emergency rooms, outpatient departments, general psychiatric in-patient wards and day hospitals all demand their own particular clinical justifications [10].

Clinicians are often unaware that they make predictions about future dangerousness every day. For example, any physician who has made a decision about whether to release a disruptive patient from the emergency room, commit a patient to hospital for psychiatric evaluation or treatment against his or her will, or to release a patient from hospital after such treatment [11] has made an implicit prediction about future dangerousness. So have nurses who determine what level of staffing and supervision is necessary on a given ward or social workers who investigate child abuse and neglect allegations [12].

In the provision of patient care, psychiatrists and psychologists must make predictions about future dangerousness. The legal duty of a psychiatrist or psychotherapist to warn an identifiable victim of a patient's serious threat of harm has been well recognized in U.S. jurisprudence and clinical practice since the *Tarasoff* case of 1976 [12]. In this famous court case, a psychologist was held to have a duty to warn the woman whom his patient had confessed an intention to murder, which he later acted on.

An individualized assessment of the risk of future dangerousness requires the acquisition of considerable data from which conclusions may be drawn. Understanding the context, opportunity, frequency, intensity, and severity of past dangerous behavior; identification of circumstances and stimuli that trigger dangerous behavior such as substance abuse or intoxication, paranoid psychosis, work conflicts, economic problems, interpersonal relationship difficulties, or loss of loved one (real or imagined), and recidivism are some examples of information essential to a competent and reliable risk assessment.

Views of a clinician's ability to predict who will be dangerous in the future have become polarized along a methodological lines. Approaches have been broadly categorized into three groups: actuarial, clinical, and structural clinical judgment.

Actuarial approaches attempt to assess individual risk using information derived from group data rather than from an individualized assessment of dangerousness. Its accuracy in predicting rare events is low because its prediction is limited to those who are similar to the population from which the actuarial data were drawn. No clinical input is required to calculate the risk score mathematically, only translation of relevant material from the records. Proponents contend that actuarially derived decisions should replace existing clinical approaches because the former are devoid

of clinician bias. Others argue, however, that risk assessment based solely upon actuarial methods raises concerns about public safety, compliance with peeraccepted standards of practice, inconsistency with evidence-based medical practice, and exposure to liability [13].

Advocates of actuarial approaches contend that clinical approaches provide individualized and contextualized assessments based upon nothing more than a psychiatrist's intuition, experience, and clinical orientation. They worry that selection and measurement of risk factors could be vulnerable to individual bias and poor interrater reliability. Yet clinical approaches reportedly achieve better-thanchance levels of accuracy [14]. Clinical prediction is described as "anecdotal" or "informal" by detractors, who conclude that it should be considered a less efficient, unsystematic version of the mathematical approach.

Structured professional judgment approaches assemble estimates of risk by reviewing and scoring a set list of empirically validated risk factors known to be associated with violence. In this approach, structure is imposed on which risk factors should be considered and how they should be measured. The weighing of their importance into an assigned level of risk is said to be the result of clinical judgment.

Amidst this debate there seems to be less focus on improving the science of dangerousness prediction and more attention to discipline-specific scope of practice posturing. The purpose of assessing dangerousness is to determine whether an individual poses a risk of endangering self or others now or in the near future and to identify what interventions are necessary to minimize that risk. Whether that means intensifying supervision, altering medications or therapies, hospitalization, institutional confinement, or the notification or protection of potential victims, clinicians will continue to be relied upon to make such determinations and recommendations in medical and legal venues [11].

I believe there can be no substitution for a competent and reliable comprehensive clinical psychiatric risk assessment that is rooted in evidence-based practice standards for medical evaluation and that considers all relevant clinical and historical information including data from standardized risk assessment tools. Anything less would not be worth the risk.

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POLICY FORUM

Telepsychiatry: Licensing and Professional Boundary ConcernsDaphne C. Ferrer, MD, and Peter M. Yellowlees, MBBS, MD

Doctor X in state A holds group therapy sessions via telepsychiatry with eight patients in five states. A patient in state B develops romantic feelings towards Doctor X and begins to contact him outside of the group sessions. Dr. X reciprocates, and the two begin exchanging explicit e-mails. When Dr. X ends the relationship, the patient reports this as a case of sexual misconduct to the medical board of state B.

This case illustrates two major issues for developing policy: the legal rationale behind the need for a national licensure system and ethical responses to online boundary violations. In this discussion, we examine current trends in physician licensure and look into online professionalism as it applies to the case above.

As a branch of telemedicine, telepsychiatry is a means of providing mental health care and information across distances through a specifically defined form of videoconferencing. Since most mental health diagnostic and treatment information is obtained audiovisually, telemedicine seems especially practical for psychiatry. Telepsychiatry can be practiced synchronously, which involves real-time, interactive two-way video transmission to a remote area, or asynchronously in a "store-and-forward" mode, in which clinical information is collected, stored, and forwarded electronically through e-mail or specific web applications for later review.

Advances in telepsychiatry have proven to offer a comparable and cost-effective alternative to face-to-face consultations [1]. It is an effective means for delivering mental health care to underserved or rural areas and addressing the national shortage of psychiatrists [2].

According to a study by Pakyurek et al., younger children appear to be less inhibited when using telepsychiatry, and children with significant behavior and conduct problems may be more expressive in that venue [3]. They add that children with trust issues following abuse or those with chemical dependency may be more comfortable and willing to share at the telepsychiatry "remove." Similarly, people with severe social anxiety and autism may be more able to engage through a monitor than with an actual therapist in the same setting. Some older children and parents may perceive the telemedicine experience as less stigmatizing than in-person sessions [3]. As reasons for the advantages of telepsychiatry over face-to-face consultations in these instances, Pakyurek et al. list the novelty of the experience, the ability of the technology to be directive, the psychological and physical distance, and the authenticity of the family interaction [3].

Deciding whether telepsychiatry satisfies the standard of care is difficult. Some may argue that the lack of physical presence falls short of the standard of care, so is it unethical to treat patients using this method? Physicians have an ethical duty to provide the best standard of care whenever possible, and telepsychiatry may be the best *available* standard of care for certain populations of patients.

Current Trends in Physician Licensure

Is there a license that allows Dr. X to see patients in different states through telepsychiatry? The U.S. Constitution delegates to each state the power to adopt laws to protect the health, safety, and general welfare of citizens [4]. It is under this "police" power that the authority for licensing physicians is delegated to each state's board of medical examiners. According to the Federation of State Medical Boards (FSMB), in 2010, 77 percent of physicians had only one active license to practice medicine granted by a state medical or osteopathic board, 17 percent had active licenses in two jurisdictions, and 6 percent had active licenses in three or more jurisdictions [5]. With the advent of telepsychiatry, it is anticipated that more psychiatrists will wish to be licensed in more than one jurisdiction to increase accessibility to mental health care across state lines and address the national shortage. With per-state licensure registration fees averaging \$339 [4], however, practicing across state lines can become costly.

Currently Doctor X would need to obtain four separate state licenses to practice telepsychiatry in addition to his license in state B. Aside from the expense, the current process is time-consuming; physicians must apply for licenses and acquire continuing medical education credits, the requirements for which vary among states. However, several promising alternative models for licensing and credentialing currently exist, such as consulting exception, licenses by endorsement, licenses by reciprocity, mutual recognition, license registration, limited licensure, and national licensure [4].

The adoption of a national medical license would allow physicians and patients to realize the benefits of telepsychiatry and telemedicine in general. The biggest hindrance to national licensure is regulatory. Medical licensing boards for the 50 states and the U.S. territories each have rules that govern the ability of physicians to practice medicine and the ability of the board to discipline physicians who violate the rules. State boards such as California's have policies that require those who treat instate patients via telephone or videoconferencing to be located within the state [6].

Statutes exist within the U.S., however, that encourage practice across state borders. In December 2011, in a rare bipartisan move, Republicans and Democrats joined together to address the licensure problem for physicians serving the active military and veterans. The U.S. Department of Veterans Affairs and the U.S. military have eliminated internal barriers and use a process that does not require multiple state licenses. Congressman Glenn Thompson (R-PA) sponsored the 2011 Servicemembers' Telemedicine and E-Health Portability (STEP) Act, which removed the state licensure burden, allowing health care professionals to provide

care to servicemen and women in states in which they are not licensed [7]. In addition, U.S. Senator Tom Udall (D-NM) has been exploring issues related to state licensure and possible options for congressional action. One approach Udall proposes is a tandem state/national license that would allow physicians to provide telehealth services in states that accept the tandem license [8].

Other nations have systems in place whereby a single license allows a physician to practice across borders. Physicians have the right of free circulation as providers of medical services within the 25-nation European Union, provided that the licensing regulations of individual member states permit the free movement of doctors both to establish themselves and to practice their profession in all member states [9]. Similarly, as of July 2010, Australia moved from a state-based system to a single national agency that administrates a registration and accreditation program for all physicians [10]. The American Telemedicine Association (ATA) is the first major association advocating for national physician licensure in the United States [8].

The Online Therapeutic Relationship

Bauer asserts that cybermedicine makes patient-physician relationships more difficult to construct and carry out [11]. In the realm of cyberspace the environment can seem far more casual, and, in this informal setting, physician, patient, or both may develop personal feelings for the other. The ability to consult with one's doctor via e-mail contributes to the informality in which the patient-physician relationship takes place. And, as we grow more reliant on mobile phones, the patient-physician relationship may include the exchange of text messages—a form of communication even more casual and immediate than e-mail. The therapeutic relationship that develops between doctor and patient in synchronous telepsychiatry is a hybrid—both in-person and online.

Like the patient in the case scenario, online patients in general tend to project feelings onto the physician more readily [12], a tendency that intensifies in psychiatry due to the content of information being exchanged. Patients who seek psychiatric care are likely to be undergoing serious personal or life crises and may be experiencing depression, anxiety, or both. These are symptoms that can lead to dependence on the psychiatrist.

It is the responsibility of the psychiatrist to manage the therapeutic process appropriately and not take advantage of the patient's vulnerability and need. It is not uncommon, however, for physicians and patients to develop feelings for one another beyond a therapeutic relationship, and there is a higher likelihood of transference in online relationships because the technology alters perceptions of the relationship [11]. The inequalities of power, the nature of the transference, and individual patient characteristics can all contribute to a patient's vulnerability to sexual exploitation by the physician [13].

Boundary Violations, Online Professionalism, and Current Policy

In a national survey of 48 state medical boards the most common physician violations of online professionalism were inappropriate patient communication online, e.g., classified as sexual misconduct, and use of the Internet for inappropriate practice, e.g., prescribing without an established clinical relationship [14]. Greysen et al. state that competency in professionalism is required for maintenance of licensure and specialty recertification, so regulators and physicians must address professionalism violations in emerging online practices [14].

In 2011, the AMA *Code of Medical Ethics* added an opinion on "Professionalism in the Use of Social Media" to guide physicians in maintaining an ethical online presence. The opinion states that "if they interact with patients on the Internet, physicians must maintain appropriate boundaries of the patient-physician relationship in accordance with professional ethical guidelines just as they would in any other context" [15]. It also states that "to maintain appropriate professional boundaries physicians should consider separating personal and professional content online" [15].

In January 2012, the American College of Physicians issued the sixth edition of *The Ethics Manual*, which highlights the updates on the patient-physician relationship in social media and online professionalism. The manual states that "physicians who use online media should be aware of the potential to blur social and professional boundaries" and that "physicians must extend standards for maintaining professional relationships and confidentiality from the clinic to the online setting" [16]. Greysen et al. state that, as state licensing boards monitor physicians for breaches of professionalism, categorizing online professionalism violations separately could be of value to better gauge the extent of this problem [17].

Future Ethical Implications

Solutions to the legal and ethical concerns over licensure and online professional boundary violations in the case scenario remain uncertain. Progress has been made toward adoption of a national licensure system in the United States, but it may take time to gain widespread acceptance.

Legal measures have also been taken to address professional boundary violations online. In Wisconsin, for example, a therapist who becomes aware that another therapist has abused a patient is required, if the patient consents, to report the abuse within 30 days. Minnesota's statute requires reporting even if the patient objects [13]. Patient-therapist sex is a criminal offense in seven U.S. states; in Australia, employers may share liability [13].

As for the ethical challenge of boundary breaches in online professionalism, professional societies have promulgated opinions governing physician behavior online and in social media. Medical schools, however, which oversee the incoming members of the profession and the most frequent users of social media, have not universally formed policies specifically addressing this issue [17]. Greysen et al.

suggest that institutions—from medical schools and residencies to hospitals and group practices—take a proactive stance in setting guidelines and standards for their members [17]. As users of these technologies engage in consensus-oriented dialogue that involves students, patients, educators, clinicians, and administrators, institutional concepts for online professionalism will develop.

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POLICY FORUM

Antidepressants and the FDA's Black-Box Warning: Determining a Rational **Public Policy in the Absence of Sufficient Evidence** Dien Ho, PhD

In October of 2004, the Federal Drug Administration (FDA) issued a "black-box" label warning indicating that the use of certain antidepressants to treat major depressive disorder (MDD) in adolescents may increase the risk of suicidal ideations and behaviors. The warning came shortly after the FDA's British counterpart, the Medicines and Healthcare products Regulatory Agency (MHRA), concluded that selective serotonin reuptake inhibitors (SSRIs) with the exception of fluoxetine (Prozac) should not be used to treat adolescents with major depressive disorders.

The MHRA's 2003 recommendation, based on a report by the Committee on Safety of Medicines' Expert Working Group, states that, with the exception of fluoxetine, SSRIs have not been found efficacious in randomized clinical trials [1]. Moreover, the group also noticed an increased risk of suicidal behaviors among adolescent patients being treated with SSRIs and judged that the balance of risks and benefits did not favor the use of SSRIs for adolescents with MDD. Only fluoxetine showed significant therapeutic benefits; fluvoxamine (Luvox) lacked evidence to warrant any cost-benefit analysis.

The MHRA's investigation into the safety of SSRIs in treating adolescents with major depressive disorder came about serendipitously. In evaluating GlaxoSmithKline's application for approving the use of paroxetine (Paxil) to treat adolescents with obsessive compulsive disorder (OCD) and social anxiety disorder, the MHRA requested all data including unpublished trials from GlaxoSmithKline. An examination of the data showed that rate of suicide attempts was higher among adolescent patients taking paroxetine for MDD than among the placebo-controlled group [2]. The MHRA then launched a broader investigation into the safety of SSRIs and requested all data from pharmaceutical companies. It was this meta-analysis of the newly discovered evidence that led the Expert Working Group to its recommendation [3]. In response to the MHRA's recommendation, the FDA launched its own investigation to determine whether there was an increased risk for suicidality among pediatric patients with MDD being treated with SSRIs [4].

One significant difference between the FDA's study and that of the MHRA was that the FDA conducted an independent reclassification of suicidality. Since the original trials did not explicitly study the connection between SSRIs and suicidal behaviors, the FDA was concerned that the data did not use consistent measurements of suicidality across trials. A group of 10 pediatric suicidologists organized by

Columbia University led an independent and blind reclassification. The conclusion of this meta-analysis using the reclassified data was that the use of all antidepressants increased the risks of suicidality among pediatric patients with MDD [5]. As a result, the FDA issued a black-box warning for the nine antidepressants citalopram (Celexa), fluvoxamine (Luvox), paroxetine (Paxil), fluoxetine (Prozac), sertraline (Zoloft), venlafaxine (Effexor), mirtazapine (Remeron), nefazodone (Serzone), and bupropion (Wellbutrin).

The black box is the most severe warning the FDA can place on a drug short of an outright ban. The boldfaced text appears at the beginning of the package insert accompanying each prescription, warning that antidepressant usage for children and adolescents may increase the risk of suicidality. It also indicates that, with the exceptions of fluoxetine for MDD and OCD and sertraline and fluvoxamine for OCD, antidepressants are not approved for pediatric patients. Black-box warnings also prohibit the dissemination of "reminder ads" (i.e., advertisements that mention the drugs' names but not their indications). Along with a black-box warning, a patient medication guide accompanies each prescription or refill for an antidepressant [6]. The guide warns that a child's or adolescent's suicide risk may increase as a result of taking antidepressants to treat MDD. In May 2006, the FDA expanded the warning to include 36 antidepressants and raised the age of potentially vulnerable patients from 18 to 24 [7].

Evidence

The primary difficulty the FDA confronted was determining what public health policy to adopt in the absence of robust evidence; reliable and consistent data on the effects of antidepressants, especially with regards to suicidality, on pediatric patients with MDD were and continue to be scarce.

Although the FDA's meta-analysis of data supplied by pharmaceutical manufacturers indicates that suicidality risk for the 9 antidepressants in MDD trials were 1.37 (citalopram) to 8.84 (extended-release venlafaxine) times higher than for the placebo, a number of other studies show different results [8]. In an ecologic study comparing suicide rates against antidepressant prescription rates at the county level in the United States, investigators found that higher antidepressant prescription rates correlated with lower suicide rates among children [9]. Another population-based study of suicide risk during the initial phase of antidepressant treatment for 65,103 patients (not restricted to children) did not show an elevated risk of suicide or suicide attempts that led to hospitalization [10]. More recently, a meta-analysis found that the use of fluoxetine to treat pediatric patients with MDD neither increased nor significantly decreased the risk of suicidality [11].

In addition to the unknown cost of increased suicidality risk, there is conflicting evidence about the efficacy of antidepressants in treating pediatric patients with major depressive disorder. The FDA approved fluoxetine for pediatric MDD treatment, and a number of studies offer supporting evidence [12, 13]. Nevertheless, a study on sertraline—a drug not approved by the FDA to treat pediatric

depression—demonstrated that it outperformed placebos in a randomized clinical trial [14].

With limited evidence, the FDA must determine if the therapeutic benefits of antidepressants for treating pediatric MDD outweigh the cost of an apparent elevated risk of suicidality. The dilemma is sharp: doing nothing could expose adolescents and children who are taking antidepressants to a heightened risk of suicidality for possibly meager therapeutic benefits, but premature warning on the danger of antidepressants could also discourage much needed treatment for patients with pediatric major depressive disorder.

Indeed, two recent studies identify some concerns with the FDA's black-box warning on antidepressants. A main goal of instituting the label warning was to ensure greater supervision for pediatric patients during the initial stages of antidepressant treatment. In a postwarning study, investigators discovered that the frequency of contact between patients and clinicians did not increase [15].

More worrisome still is the possibility that the FDA's warning might have led to an unforeseen decline in both depression diagnoses and treatments. In a 2009 study, investigators reported that between 2004 (the year of the emergence of the black-box warning) and 2007, there was a substantial decline in the number of MDD cases diagnosed nationwide, contrary to projections based on historic data [16]. The warning not only possibly affected pediatric cases but had a spillover effect on adult and geriatric cases as well.

The same study also noted that, while the use of antidepressants to treat major depressive disorder had decreased, there had been no corresponding increase in substitute treatments. Patients of all ages with MDD, it appears, are less likely to be diagnosed with the disease and are less likely to receive adequate treatments since the introduction of the black-box warning. Furthermore, a recent examination of teen suicide data from the National Center for Injury and Prevention and Control shows that, contrary to the downward trend prior to 2003, there was a significant increase in mortality due to teen suicide between 2003 and 2005 [17]. Although one cannot confidently draw a causal connection between the introduction of the black-box warning and the increase in teen suicides, the data raise serious concerns about unintended consequences of the FDA warning.

Analysis

One can question the wisdom of the FDA's decision to issue a black-box warning on the basis of limited evidence about both the risk of suicidality and the efficacy of antidepressants in treating MDD. The more substantive policy question is what a regulatory agency ought to do when a pressing policy decision must be made in the absence of quality evidence [18].

In his defense of theism, American philosopher William James argues in *The Will to* Believe that decisions do not always have to be made on the basis of evidence [19].

Indeed, under some circumstances, one would not be irrational to make decisions in the absence of supporting evidence. For James, the circumstances that justify making decisions not based on evidence must satisfy three conditions: they must be living, forced, and momentous. A living decision is one in which either choice or hypothesis contains some appeal, however small. A forced decision is a decision that cannot be avoided. James suggests that the imperative to "choose between going out with your umbrella or without it" is not a forced decision; one can simply avoid making a decision by not going out. A logically exhaustive disjunction such as "either be a theist or not" forces a decision. Finally, a momentous decision is one that entails a significant stake.

The dilemma confronting the FDA satisfied all three conditions. It was living in the sense that a wide range of cost-benefit results of prescribing antidepressants to pediatric patients with MDD were all plausible in light of a near-vacuum of evidence. According to James's view of pragmatic reasoning, the lack of evidential support would mean that the belief for and the belief against the use of antidepressants to safely treat pediatric MDD patients were both equally rational. To warn or not to warn constitutes a logically exhaustive dilemma. Neither could the FDA have avoided the decision. Finally, the stakes riding on the decision were obviously high.

The FDA faced a dilemma in which it was epistemically defensible to make a nonevidence-based decision. But was its decision morally defensible? By making a public recommendation, the FDA undermined the evidential-neutrality in the advisability of treating pediatric MDD with antidepressants. The warning now becomes, in itself, "evidence" even though the FDA's decision was not evidence-based.

A morally preferable route might have been to present the lack of evidence plainly and to reiterate the rationality of either choice. Allowing individuals to make their own decisions demonstrates a respect for multiple rational options in a context of evidential scarcity.

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MEDICINE AND SOCIETY

Determinism and Advances in Neuroscience

Nada Gligorov, PhD

Novel medical treatments and advancements in medical technology have given rise to numerous ethical questions including the just allocation of medical resources, endof-life dilemmas, and most recently the permissibility of human enhancement. These advances have also challenged received moral norms and, in some instances, revealed the need to revise not only those received norms but established social policies and even the primary goals of medicine. Most of those changes, however difficult, presume a human ability to adopt moral values, pursue moral goals, and take responsibility for moral choices.

In recent years, however, advancements in neuroscience, psychiatry, neurology, and related fields of inquiry have shaken the presumption that humans are capable of moral decision making by showing that many aspects of human psychology correlate with localized activity in the brain, thus raising the possibility of biologic explanations for all human behavior. This encroachment of scientific explanation into the domain of human psychology and human morality is often characterized as a serious threat to the idea that humans have free will. In this piece I argue that scientific explanation of our moral capabilities does not presently pose a threat to the idea that we possess free will, although it might change our notions of choice and responsibility.

Free Will and Responsibility

Free will is thought of as a necessary precondition for morality. In order for individuals to be held responsible for their actions, they must be free to act in more than one way and be able to choose one action over the other. We seldom, for example, blame people for their physical attributes. It would seem at best strange, and in some instances even cruel, to blame people for attributes such as short stature or eye color. It would be even more inappropriate to ascribe personal blame to an individual for becoming ill, for example developing cancer, if the illness were not in part due to lifestyle. When it comes to physical attributes individuals have little or no agency; they cannot change their physical features or prevent the onset of many diseases.

We do blame people, however, when we think they could have acted other than they did, a judgment that entails the presumption of free will. If a father spends all his money on an expensive car and as a result depletes his son's college fund, we hold the father responsible for making a choice that may disadvantage his son. If a person is convicted of murder, that person is held responsible and incarcerated. Even if an

individual can be characterized as having a personality type that makes him or her prone to act in a certain way, there is still a presumption of free will and the corollary ascription of responsibility. Indeed the belief that people can make choices and be held responsible for them plays an important role in medicine as well, evidenced by the customary respect for patient autonomy [1] or, as we often call it, patient self-determination.

We do, however, modulate our ascriptions of blame based on the known characteristics of the people performing an action. Understanding of psychiatric diseases makes us more hesitant to blame those who have psychiatric conditions. For example, people who have schizophrenia and commit violent acts are not considered responsible in the same way as people without severe psychiatric diagnoses who commit the same acts. They might be confined to a psychiatric hospital, but the cause of their violent acts is attributed to their biologically based mental illness, not to choice.

Further advancements in psychiatry, neurology, and neuroscience could explain more of human psychology in terms of its biology, specifically brain activity. If all psychological phenomena that underlie what we regard as moral reasoning and action can ultimately be explained in terms of brain processes, then those psychological capabilities required for morality could be viewed as nothing but a physical process. And, since we explain physical processes in terms of deterministic scientific laws, there would be no reason to assign praise or blame for what we currently think of as free choices. The question then is how to reconcile our increased ability to explain human behavior biologically with our social need for moral norms and moral responsibility and our personal experience of making free choices.

Interpreting Reduction

Let us clarify what is meant by the claim that psychology can be reduced to physical processes. One could mean very generally that psychological states are ultimately the results of physical processes, thereby denying the existence of immaterial souls and rejecting Descartes' argument that there are two substances, the "thinking substance" and the material substance [2]. Such a claim only amounts to the endorsement of materialism or physicalism, i.e., the claim that all there is in the world is physical. This would be the least controversial way of interpreting the idea that psychology can be reduced to physical processes because it does not put forth any specific claims about *how* it is the case that human psychology is nothing other than a physical process. Such an argument would be entirely neutral on whether such reduction entails *determinism*, a term that I will explain next.

If one goes beyond the claim that human psychology results from physical processes and makes a prediction that all there is in the world will one day be explained by the laws of physics, this bolder claim involves not only the reduction of psychological states to physics but also the assumption that such a reduction entails determinism. Determinism is the claim that, given a certain set of initial conditions (for example

conditions that existed at the time of the Big Bang) and the set, unbending laws of physics, every event from the onset of the universe can be explained and predicted.

Now, if psychological processes can be, in some as yet unknown way, subsumed under the laws of physics, the laws of physics will determine human psychology. It would be false, then, to say that persons are free to make choices, in the same way it would be false to say that a ball falling from a height has the choice to follow the law of gravity. The decision one makes is caused by events preceding that decision, and those events in turn were caused by events before them, and so on, forming a long causal chain that reaches all the way back to the beginning of the universe.

The second argument above makes several unwarranted leaps. One of them is that all psychological and physiological processes can be neatly subsumed under the laws of physics. To argue that psychology is determined because the laws of physics are deterministic is to assume that all the distinct theories which aim to capture the various levels of natural organization—from those as complex as human psychology—can be explained by laws that govern lower-level organizations such as neurons, molecules, and particles [3]. This bolder reduction claim depends on the unification of all scientific theories, and it is not at all obvious that theoretical unification is achievable [4].

Finally, scientific theories, from psychology to physics, may or may not have deterministic laws independently of one another. Even if physics has deterministic laws, that fact does not entail that neuroscience have such laws. And neuroscience, thus far, has uncovered only mechanisms that are either random or probabilistic [5]. Just because psychological states occasionally correlate with brain activity does not entail that all psychological responses of the same kind are associated with the same brain activity or that the same brain activity always produces the same psychological responses. The increased ability to localize cognitive processes in the brain, and even in some cases localize individual thoughts [6], does not yet force us to relinquish the socially important notion of moral responsibility.

Determined, but Responsible

If further progress in neuroscience reveals that deterministic laws govern brain processes, which alone would not necessitate believing that moral responsibility is obsolete. Daniel Dennett argues that determinism can be compatible with free will and moral responsibility, saying that it would be wrong to think that, because determinism is true, our nature is fixed. Human nature is not fixed because it has evolved to accommodate external influences and to change in response to those influences [7]. In fact he seems to argue that the more science discovers about human nature, the more responsibility we have to do what is necessary to curb immoral or socially detrimental behaviors [8].

Presume the neurological basis of addiction is identified and some people are discovered to be prone to it while others are less susceptible. It would seem that those predisposed to addiction could be characterized as being less capable of

freedom to resist engaging in addictive behavior. But knowing that a person has this proclivity or sensitivity gives him or her the opportunity to avoid situations that exacerbate the risk of addiction. Hence, a finding that seemed at first glance to absolve people of responsibility results a new obligation: to take measures to protect themselves based on that information.

It seems, then, that in order to establish a clear conflict between determinism in science and free will one must make as yet unsupported assumptions about both. And once the assumptions are revealed it is possible to argue that determinism and moral choice are compatible. It would be an overstatement, however, to conclude that moral decision making will remain unaffected by our increased ability to explain human psychology through neuroscience and other related fields. There is no benefit to assuming the existence of human autonomy, rationality, and ability to act freely if those concepts are not supported by facts about actual human capabilities. In order to prevent our moral concepts and moral expectations from becoming outdated and inapplicable to human circumstances, we should be willing to revise them to accord with relevant scientific findings.

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IMAGES OF HEALING AND LEARNING Mainstream Anxieties about Race in Antipsychotic Drug Ads Jonathan M. Metzl, MD, PhD

Marketing research consistently shows that pharmaceutical advertisements entice patients to ask for particular medications and physicians to prescribe them [1]. How do these advertisements work?

Supporters of pharmaceutical advertisements argue that the ads provide patients and doctors with important information about new medications in ways that help both parties make informed treatment decisions [2]. Critics meanwhile contend that pharmaceutical ads help drug companies "create new disease markets" and "expand market share" [3].

Both sides of the argument overlook an important point: in addition to creating new markets or providing new information about medications, ads also tap into existing cultural attitudes and beliefs. Pharmaceutical ads identify, reflect, and even distort prevailing popular sentiments about such matters as race, gender, politics, and class and then posit prescription medications as treatments for "social" problems as well as medical ones. Of course, many types of advertisements work by identifying social anxieties and desires. It would seem particularly important that physicians be aware of these tensions, so that they can best differentiate cultural expectations and biases from actual information about medications and diseases when they make treatment decisions. To do so, doctors need to become competent, not just in the effects and side effects of pharmaceuticals, but also in the nuances of cultural manipulation on which ads for these pharmaceuticals often depend.

The history of doctor-directed pharmaceutical advertising from American psychiatric journals presents an object lesson in the ways drug ads reflect and distort cultural stereotypes. As is well known, starting in the 1950s, advertisements played off of popular attitudes about gender, and specifically about women's roles as mothers and wives, to promote branding of antidepressants [4].

Scholars have now begun to examine the ways in which themes regarding race and racial politics inflected the marketing of antipsychotic medications in psychiatric journals over the same time period.

As a pedagogically useful example, consider a shocking advertisement for the antipsychotic medication Haldol that appeared in the May 1974 edition of *Archives of General Psychiatry*. In the ad, an angry African American man shakes his fist menacingly. The man wears the street clothes of ignominy, complete with a ruffled shirt and a wide collar, and stands in an urban scene. The man sneers, and the image

distorts his features in a manner that makes him appear particularly threatening to the psychiatrists who were the assumed audience for the ad. The text above the image then literalizes the scene. "Assaultive and belligerent?" the text asks above an angry black man constructed as exactly that. "Cooperation often begins with Haldol" [5].

One could argue ad absurdum that the ad provided psychiatrists with information about a relatively new butyrophenone-class antipsychotic medication—Haldol was released in 1967. A more likely response is to wonder how McNeil Laboratories, the makers of Haldol, could have promoted their medication through such blatantly discriminatory imagery.

"Racism" is an answer that comes to mind as we look in horror at the ad from nearly 4 decades ago. And, to be sure, racism seems an apt descriptor for an ad that sells neuroleptics by depicting a problematic stereotyped man who appears to be a cross between a pimp and the Godfather of Soul.

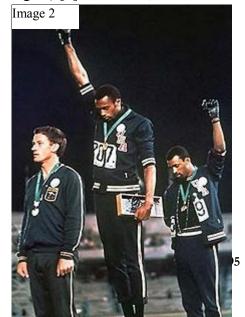
But perhaps there is more to the story. The ad appears overtly problematic from the perspective of the present day, but was it seen that way when it was produced? Moreover, were the racial assumptions in the ad volitional, and if so, on the part of whom? The advertisers? The *Archives* publishers? The journal readers? Did these actors perform acts of racism knowingly, by creating particular images, or buying particular journals? Or was it also the case, and more troublingly so, that anxieties about belligerent, psychotic black men were embedded into acceptable public discourse in ways that defied recognition at the time?

Addressing these questions requires that we critique the ad as visual historians. Doing so involves focusing less on our immediate emotional response to the image. Instead, we would attempt to place the Haldol ad in historical context by uncovering how it connects to larger 1960s- and 1970s-era mainstream American cultural assumptions about race and insanity, in order to better understand the conditions that might have allowed such an image to appear in a mainstream psychiatric journal.

For instance, we might contend that the ad reflects era-specific cultural anxieties about race politics and racial protest. The man in the image presents a laden political gesture from that era: a clenched black fist (see image 1) [6]. Of course, the fist



became a symbol of the Black Power
Movement. And, while that movement was often popularly misrepresented as promoting violence, the fist connoted the opposite—solidarity, resistance, and joined struggle. Olympian



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Tommie Smith [7], whose raised fist at the 1968 Mexico City Sum-mer games set off a wave of controversy, later explained the gest-ure as a "salute" to "hu-man rights" [8]. The Haldol ad appears to play with this popular misperception by invert-ing the fist in a way that suggests that the politicized figure—indeed a figure who is expressly not pictured in a treatment setting—will assault the assumed viewer of the image if not given Haldol immediately.

Similarly, the man seems to stand defiantly within an urban scene in which buildings and windows reflect an orange hue. We might contend that this color palate invokes connections to era-specific urban unrest. In the years preceding the ad, urban protests had spread across such U.S. urban centers as Detroit, Watts, and Newark. Popular representations of these revolts prominently displayed <u>burning buildings</u>. Nightly newscasts often described the scenes as "insane" while overlooking the unjust economic conditions that led to the protests in the first place. Tapping in, the ad troublingly posits Haldol as a clinical treatment for a social, political, economic, and of course highly racial "problem."

A second historical point that we might make about the Haldol ad is that its imagery is consistent with broad transformations taking place in antipsychotic advertisements—transformations that revolved expressly around race and gender in depictions of psychosis and schizophrenia. A quick flip through journals such as *Archives* and the *American Journal of Psychiatry* reveals that antipsychotic advertisements began to appear with regularity in these journals in the 1950s. At that time, images such as the one seen in the Haldol ad simply never appeared. Early antipsychotic ads [9] instead showed docile white women treated with medications such as Serpasil. Or, as in the case of 1955 Thorazine ads, depicted white-only women's wards [10].

Suddenly in the 1960s and 1970s, Africanized or African Americanized themes emerged in ways that now seem shockingly abrupt. Thorazine ads, for instance, suddenly shifted to depicting Africanized icons [11] of what it called "primitive psychiatry," while ads for Stelazine suddenly featured tribal artifacts or masks [12, 13].

One might posit many reasons for this transformation, ranging from changed marketing techniques to altered cultural aesthetics. But this transformation also provides important supporting data for our hypothesis about the racializing of antipsychotic drugs in the 1960s and 1970s and a linking of that racialization to concerns about politics as well as about mental illness.

Finally, we might note that the transformation in antipsychotic advertisements reflects larger transformations in American popular and medical representations of psychotic and schizophrenic illness [14]. Here as well, a broad transformation occurred in which understandings shifted from docility to hostility, and often from white to black. For instance, through the 1950s, psychiatric journals and textbooks often depicted schizophrenia as a condition, manifest by "emotional disharmony,"

that negatively impacted white people's abilities to "think and feel." Psychiatric authors frequently assumed that such patients were nonthreatening and were therefore to be psychotherapeutically nurtured by their doctors, as if unruly children, but not feared [15].

Meanwhile, through the 1950s, popular magazines such as Ladies' Home Journal [16] and Better Homes and Gardens [17] wrote of unhappily married, middle-class white women whose schizophrenic mood swings were suggestive of "Doctor Jekyll and Mrs. Hyde"—a theme that also appeared in Olivia de Havilland's infamous depiction of a schizophrenic housewife named Virginia Stuart Cunningham in the 1948 Anatole Litvak film, *The Snake Pit*, on which the earlier Thorazine ad appears to be based [18, 19].

American assumptions about the race, gender, and temperament of schizophrenia changed beginning in the 1960s. Many leading medical and popular sources suddenly described schizophrenia as an illness marked not by docility but by rage. Growing numbers of research articles from leading psychiatric journals asserted that schizophrenia was a condition that also afflicted "Negro men" and that black forms of the illness were more hostile and aggressive than were white ones. A 1968 article from the Archives of General Psychiatry asserted that this psychotic hostility emerged because black men listened to the words of Malcolm X, joined the Black Power Movement, or "espoused African or Islamic" ideologies—indeed, the same ideologies that seem to be referenced by the 1960s- and 1970s-era antipsychotic advertisements [20].

Meanwhile, mainstream newspapers in the 1960s and 1970s warned of crazed, black, schizophrenic killers on the loose. "FBI Adds Negro Mental Patient To '10 Most Wanted' List" warned a Chicago Tribune headline in July 1966, above an article that advised readers to remain clear of "Leroy Ambrosia Frazier, an extremely dangerous and mentally unbalanced schizophrenic escapee from a mental institution, who has a lengthy criminal record and history of violent assaults" [21]. Hollywood films such as Samuel Fuller's 1963 B-movie classic, Shock Corridor, similarly cast the illness as arising in black men, particularly men who participated in civil-rights protests [22].

This all-too-brief history helps tell a story about the Haldol advertisement that complicates a narrative in which the inventions of a particular advertiser led to a specific doctor's prescription response. Reading historically, we begin to see that the problematic Haldol ad also emerged from a cultural moment in which concerns about race, insanity, and black political protest lodged into mainstream anxieties, social networks, and notions of common sense.

In no way is this telling meant to suggest that doctors in the 1960s and 1970s should have refrained from prescribing psychotropic medications. Indeed, many patients benefitted from Haldol in vital ways. Yet the 1974 ad also suggests that, in its worst moments, the discourse about this medication and the illness it treated reflected a larger set of cultural anxieties that doctors should have been aware of. Such

awareness might have helped psychiatrists address a much larger problem that emerged at the same time: the link between the themes of the ad and the emerging overdiagnosis of schizophrenia in African American men. Indeed, at precisely the same historical moment, a series of studies "shockingly" discovered that African American men were "significantly more likely" than other, white patients to receive schizophrenia diagnoses and were also more likely to receive higher doses of antipsychotic medications [23-27].

Ultimately, the Haldol ad presents a cautionary tale about the relationships between pharmaceuticals and society in the present day. Thankfully, we live in an era in which the racial profiling of the 1974 ad seems a relic of the past.

We also live in an era of dramatically expanded pharmaceutical advertising. Information about prescription medications permeates magazines, journals, television programs, the Internet, and seemingly everyplace else. Many times, the advertised medications help people recover from illnesses or lead more meaningful lives. But at the same time, expanded advertising presents ever-more opportunities to link expectations about these medications to cultural desires, anxieties, and stereotypes.

In other words, there has never been a greater need for physicians to become fluent in the social and cultural tensions that underlie many pharmaceutical advertisements. At the least, awareness of these tensions allows clinicians to recognize the social manipulations on which many ads depend. And, at the best, this type of cultural competency enables clinicians to get ahead of the conversation by understanding, and then talking about, the many complex gendered, racialized, and politicized meanings that Americans, patients and doctors both, ascribe invisibly to mental illnesses and prescription drugs.

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OP-ED

What Can Physicians Learn from the Neurodiversity Movement? Christina Nicolaidis, MD, MPH

When, at age 3, my son received a medical diagnosis of autism, my husband and I received a list of intensive treatments that we needed to initiate as quickly as possible and a pep talk saying that if we did these things there was a good chance we could "fix him." As a mother, I was terrified. Images of *Rain Man* filled my mind, quickly followed by painful memories of security officers trying to restrain my beloved 350pound adult autistic patient during a violent meltdown. As a physician and researcher, I did what I was best trained to do—I quickly took charge of the situation, scheduled consultations with every type of therapist in the city, and immersed myself in the autism literature. But I soon realized that expert opinions clashed greatly, there were no easy answers, and the evidence in support of the various therapies was extremely limited.

Interestingly, nowhere in my early foray as an "autism mom" (or in the years I had spent as a primary care physician) did anyone actually suggest learning from individuals on the autism spectrum. It was only by coincidence that I met a local autistic self-advocate who was active in the neurodiversity movement. Who could have guessed that she would change not only the way I looked at my autistic child, but also the way I practice medicine and focus my research? Now, the two of us codirect the Academic Autistic Spectrum Partnership in Research and Education (www.aaspire.org), a NIH-funded, community-academic partnership that uses a community-based participatory research (CBPR) approach to conduct research to improve the lives of individuals on the autism spectrum [1]. She and many other autistic self-advocates regularly challenge my thinking, teaching me important lessons about how to be a better mother, physician, and researcher.

Most of us have been trained to think about autism using a deficit model. Such a model, which focuses almost exclusively on impairments and limitations, ultimately leads us to see autistic individuals as broken people who are ill and, as my child's first psychologist explained, need to be fixed. The neurodiversity movement challenges us to rethink autism through the lens of human diversity [2]. It asks us to value diversity in neurobiologic development as we would value diversity in gender, race, ethnicity, religion, or sexual orientation. As opposed to only focusing on impairments, the neurodiversity model sees autistic individuals as possessing a complex combination of cognitive strengths and challenges. For example, difficulties in understanding social nuances, filtering competing sensory stimuli, and planning the tasks of daily living may be coupled with strengths in detailed thinking, memory,

and complex pattern analysis [2]. Autistic self-advocates also ask us to see more than a *DSM* diagnosis. Amanda Baggs, for example, says

This is about what is, not what is missing. Forget the notion of a cosmic balancing act where a god of impartiality runs around taking things away but giving one gift for every sacrifice. It is about the fact that those of us who are viewed purely as having had things taken away—as being essentially barren wastelands—are not shut out of the richness of life by being who we are. The richness we experience is not some cheap romanticized copy of the richness others experience. The richness of life is there for everyone, and whether one experiences it or not is not dependent on whether or not one is autistic [3].

The concept of neurodiversity, and the self-advocates who promote it, are often described as highly "controversial" [4-6]. At first glance, it may seem easy to write off autism-rights advocates as radical extremists [7] or to believe, as many have claimed, that they are all "high-functioning" individuals with minimal disabilities [4]. In my experience, neither is true. I will refrain from the temptation to list my partners' limitations as some form of badge of honor. However, I can assure you that many leaders in the neurodiversity movement experience significant disabilities [8].

Members of every community and leaders in every movement disagree with each other at times, and I cannot pretend that the neurodiversity movement speaks with one voice. Yet many common themes emerge from the neurodiversity movement. Below I explore how lessons from autistic self-advocates may affect how we approach our autistic patients and their families.

First Do No Harm—the Dangers of "Autism Awareness"

Several autism awareness campaigns run by parent-led organizations or university-based psychiatry programs have incurred the wrath of the autistic self-advocacy community and its allies. In 2007, the New York University (NYU) Child Study Center ran a "public service campaign" in which autism, Asperger syndrome, and other conditions were portrayed as having kidnapped the nation's children. Billboards and newspaper advertisements were made to look like ransom notes, with text such as, "We have your son. We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the beginning. - Autism" [9].

Similarly, in 2009, Autism Speaks released a video entitled "I am Autism," in which a satanic-sounding voice declares "I am autism" and proceeds to brag about all the destruction he will cause families [8]. An earlier Autism Speaks video, "Autism Every Day," featured a woman who longed to drive off a bridge with her autistic daughter and was only kept from doing so by the thought of what that would do to her other, nonautistic child [8].

Autistic self-advocates loudly protested against these campaigns, maintaining that they "inadvertently reinforce many of the worst stereotypes that have prevented

children and adults with disabilities from gaining inclusion, equality, and full access to the services and supports they require" [10]. They objected to the campaigns "presenting Autistic people as useless burdens on society, on our families and on the world at large" [11]. They also warned that "too often, the idea that children with disabilities are less than human lies at the heart of horrific crimes committed against them" [10]—a tragic foreshadowing of several highly publicized murders of autistic individuals by their parents.

I understand firsthand the challenge of raising a child with a disability, but the last thing I want is for my child to be exposed to these campaigns. How would they affect his self-image? Do I want him to grow up in a world that sees him as a burden or some form of "changeling"? One physician/bioethicist openly challenged the NYU Ransom Notes campaign, saying it violated the American Medical Association Code of Medical Ethics [9]. But, on a smaller scale, in our daily communication with patients and families, how often do we, as physicians, inadvertently promote negative stereotypes, diminish our patients' self-worth, or portray them as broken individuals or burdens to others? Self-advocates remind us to reflect on the images and language we use. Communicating a strengths-based approach to autism may not only afford autistic patients the respect and dignity they deserve, but may also help family members better understand and support their loved ones.

Do Not Separate "the Person" from "the Autism"

Many autistic self-advocates maintain that being autistic cannot be separated from who they are [12]. This issue often comes up in debates about the use or rejection of person-first language, e.g., "a person with autism" rather than "an autistic person," (and hence my choice not to use person-first language when referring to autistic individuals), but it also affects how we think of our patients. Like gender, race, or sexual orientation, one's neurobiology is only one part of a person's identity and certainly not the sole defining factor of who he or she is. But by separating the autism from the person, are we encouraging our patients' family members to love an imagined nonautistic child that was never born, forgetting about the real person who exists in front of us? What would I be like if my parents had spent my childhood mourning the son they never had and trying to cure me of my femaleness? Before discussing an autism diagnosis with a parent, it is worthwhile for any physician to read Jim Sinclair's seminal 1993 essay to parents called "Don't Mourn for Us" [13].

Recognizing the Social Context of Disability

Despite claims to the contrary, leaders in the neurodiversity movement clearly recognize autism as a disability [8, 14]. Autistic self-advocates often vividly describe the disabilities they experience [3, 15]. They also maintain, however, that difficulties experienced by people with disabilities are contextual and that living in a society designed for nonautistic people exacerbates the challenges experienced by autistic individuals [2]. This concept may not be intuitive to many of us trained in a medical model. But imagine a world where 99 percent of people were deaf. That society would likely not have developed spoken language. With no reason for society to curtail loud sounds, a hearing person may be disabled by the constant barrage of

loud, distracting, painful noises that become commonplace in that world. The deaf majority might not even notice that the ability to hear could be a "strength" or might just view it as a cool party trick or savant skill.

We don't have to resort to imagination to find other cases in which medical disorders have been socially construed. Homosexuality was listed a psychiatric condition in the American Psychiatric Association's *Diagnostic and Statistical Manual* until 1973, and egodystonic homosexuality was listed in the *DSM* until 1986 [16]. (And I vividly recall my psychiatry professor still teaching about the utility of treating homosexuality when I was in medical school in 1990.) I am not advocating for removal of autism spectrum disorders from the *DSM*, but for a thought-provoking, comical challenge to our medical model of autism, see the satirical website of the Institute for the Study of the Neurologically Typical, which defines neurotypic syndrome (666.00) as "a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity" [17].

Neurodiversity, Support, Services, and Therapies Are Not Mutually Exclusive.

Much of the controversy in the media about neurodiversity centers on the debate over whether or not autism can or should be "cured." The neurodiversity movement maintains that autism is a natural variation and should not be cured, an idea which greatly angers many parent advocates and scientists [6]. At some levels, the two sides of the debate may be irreconcilable. However, I believe that a great deal of the neurodiversity argument has been misunderstood. Neurodiversity advocates are arguing against the goal of "a world without autistic people" but they are not saying they don't want to "be engaged in trying to ameliorate the many challenges associated with being autistic" [14]. They advocate for increased acceptance, accommodations, and supports [14] and are very welcoming of research, therapies, and services that help them improve their quality of life [2].

As a parent, I have chosen to try a variety of accommodations, services, medications, technologies, and therapies to help my child communicate better, improve his ability to function in society, regulate his emotions, lessen his anxiety and sensory discomfort, allow him to obtain a good education, and foster positive interactions with autistic and non-autistic peers. None of these things will "cure" him of autism or make him "indistinguishable from his peers." But I am not trying to change who my son is—I just want to give him every possible opportunity to enjoy the same quality of life as my typically developing daughters. As health care professionals, it is our responsibility to advocate for access to services, therapies, and accommodations that may help improve quality of life. But it is also our responsibility to fully inform patients and families about potential treatments and interventions, many of which have relatively little documented benefit and significant risks [18, 19].

The Fallacy of the Linear Autism Spectrum

Some have argued that the concept of neurodiversity may make sense for the "high-functioning" end of the autism spectrum, but not the "low-functioning" end [4].

Many autistic self-advocates and researchers, however, maintain that the use of concepts such as "high- and low-functioning" are inaccurate, demeaning, and potentially harmful [8, 20]. There is just no such thing as a linear autism spectrum on which we can place individuals based on their functioning. How do you categorize an individual with minimal spoken language and very little ability to perform activities of daily living but excellent written communication skills and the ability to analyze complex patterns? How about an individual whose functioning varies tremendously from day to day or in different environments?

Many of my autistic colleagues have been categorized as both high- and lowfunctioning, with both categorizations working to take away their power or voice. If anything, there are many separate spectra related to, for example, spoken language, written communication, adaptive skills, different types of intelligence, need for consistency, sensory processing, and so on, with individuals moving to different parts of each spectrum at different points in time.

As health care professionals, we must resist the temptation to categorize people as high- or low-functioning, inasmuch as such categorizations only serve to inadvertently harm our patients. We risk unnecessarily depriving patients categorized as "low-functioning" of their self-determination and opportunities to reach their potential. Similarly, we often deprive our patients categorized as "high-functioning" of necessary supports and services, or we make dangerously false assumptions about their ability to understand what we say or carry out our recommendations. Instead, we must try to understand an individual's complex combinations of strengths and challenges, as well as the potential for wide variations in functioning. Doing so is necessary to promote self-determination and increase the effectiveness of our care.

Including Autistic Individuals in Research about Autism

Prior to becoming involved with the autistic self-advocacy community, I predominantly conducted research to improve the health care of other marginalized communities, including African Americans, Latinos, and domestic violence survivors. When I first started listening to autistic self-advocates, I was struck by the strong parallels between their frustrations with research and the well-recognized criticism of traditional research from members of ethnic and racial minority groups. They pointed to a misalignment between academic and community research priorities, lack of inclusion in the research process, inadequate informed consent, threats to study validity due to poor understanding of participants' experiences, dehumanizing and stigmatizing language, and use of findings to advance agendas that oppose community values.

My community partners and I thus founded the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE, www.aaspire.org) to promote the inclusion of autistic individuals in the research process. Using a community-based participatory research approach, community members influence each stage of the research process from choosing the research questions to ensuring that our consent materials, protocols, and data collection instruments are accessible to autistic

participants to interpreting data and disseminating findings. Including autistic individuals and family members as equal partners in the research process is not always easy, but together we have developed many structures and processes to ensure effective collaboration [1]. I believe the community members' involvement on the team has greatly enhanced the quality of our research and the validity of our findings. I strongly encourage others to find ways to effectively partner with autistic self-advocates when conducting research about autism.

Providing Optimal Health Care to Individuals on the Spectrum

Our AASPIRE research has largely aimed at improving the health care experiences of adults on the autism spectrum. Our initial study showed significant disparities in health care outcomes between autistic and nonautistic adults [21]. We are now developing an interactive health care toolkit for autistic adults, supporters, and primary care clinicians. While our work is still in progress, preliminary findings point to many potential strategies and accommodations that health care professionals can use to improve communication, help minimize sensory challenges, reduce anxiety, foster shared decision-making, and improve patient self-management. In the meantime, probably the best thing a clinician can do is explore what accommodations each patient needs and what strategies the patient and his or her supporters feel may best facilitate quality health care.

Conclusions

Who knows what the future will bring? Maybe research will discover a "cure" for autism. Maybe scientists will identify an autism gene and parents will choose to abort all autistic fetuses before they are born. Maybe we will find ways to better accommodate and support autistic individuals so that they are afforded the same opportunities as typical peers, while maintaining their autistic strengths and differences. Maybe we will look back at our current understanding of autism and shudder at our many misconceptions. Which future do you hope for? Regardless of how each of us answers that question, I believe it is our responsibility to try to understand our patients as well as possible, to value them as human beings deserving of our full respect, to recognize their strengths and the richness of their existence, to minimize the harm caused by negative, dehumanizing images and concepts, and to accommodate their needs as well as possible. I cannot possibly do justice to the many voices of autistic individuals, but I hope my random musings entice you to further explore their world. Let them challenge your thinking—who knows what you may learn?

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