American Medical Association Journal of Ethics

December 2011, Volume 13, Number 12: 847-924. The Power of Diagnosis

| What Is It? | 849 |
|--|-----|
| Shara Yurkiewicz | |
| Educating for Professionalism | |
| Clinical Cases | |
| Is Physician Self-Disclosure Ever Appropriate? Commentary by James E. Sabin | 852 |
| When Diagnosis is a Double-Edged Sword | 856 |
| Commentary by Mary Lynn Dell | 000 |
| A Virtue Ethics Approach to Framing Troublesome Diagnoses Commentary by Cynthia Geppert | 861 |
| The Code Says The AMA Code of Medical Ethics' Opinions on Disclosing Diagnoses to Patients | 866 |
| Journal Discussion Ethical Issues in the Early Diagnosis of Alzheimer Disease Matthew E. Growdon | 868 |
| State of the Art and Science | |
| Patient-Centered Revisions to the <i>DSM-5</i> | 873 |
| Emily A. Kuhl, David J. Kupfer, and Darrel A. Regier | |
| Challenging Diagnoses | 880 |
| Barry DeCoster | |
| Law, Policy, and Society | |
| Health Law | 0.0 |
| A Physician's Guide to Social Security Disability Determinations Valarie Blake | 885 |

| Policy Forum | |
|---|-----|
| Medicalizing Obesity: Individual, Economic, and | |
| Medical Consequences | 890 |
| George L. Blackburn | |
| Medicine and Society | |
| The Rise and Impending Fall of Diagnosis as a Marker | |
| of Difference | 896 |
| Matt Lamkin | |
| History, Art, and Narrative | |
| History of Medicine | |
| The Evolution of Addiction Medicine as a Medical Specialty | 900 |
| David E. Smith | |
| Op-Ed and Correspondence | |
| Op-Ed | |
| The Pharmaceutical Industry's Role in Defining Illness Elizabeth Kitsis | 906 |
| Resources | |
| Suggested Readings and Resources | 912 |
| 5 456 5 5 5 5 5 5 5 5 5 5 5 5 5 5 5 5 5 | , |
| About the Contributors | 922 |
| Uncoming Issues of Virtual Montor | |
| Upcoming Issues of Virtual Mentor January: Vaccines and Ethics | |
| February: Ethical Issues in Family Planning | |
| March: Organ Transplantation | |
| maion. Organ transplantation | |

848 *Virtual Mentor*, December 2011—Vol 13

April: Foreignness in Medicine

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 849-851.

FROM THE EDITOR What Is It?

The patient's visit to his physician feels incomplete without an answer to that question. What is the name of the ailment that is causing me to feel this way? Do my symptoms add up to something that can be recognized with a single label? Once I have a diagnosis, what comes next? This issue of Virtual Mentor looks at how the answer to "What is it?" can affect the course of someone's life.

To lead you to an overwhelming question.... Oh, do not ask, "What is it?" Let us go and make our visit [1].

The narrator of T.S. Eliot's *The Love Song of J. Alfred Prufrock* is imprisoned by others' perceptions of him to the point that they constrain his relationships and behavior. His self-image becomes a mirror of his presumed public image, and he struggles with what he dares and dares not do. Such is the power of a few choice glances or words to shape a person's interactions, self-concept, and future.

After the patient makes his "visit," the physician talks, tests, and ultimately fits the pieces into a diagnosis. This label can act as validation that a patient's condition is "real" and consistent with what other sufferers have. It can serve as a "gatekeeper," allowing patients access to particular medical treatments, programs, or financial compensation. As explained by Valarie Blake, JD, MA, in the health law section, diagnoses of cystic fibrosis or personality disorder qualify individuals for disability insurance. Similarly, a diagnosis of autism can mean that a child is able to benefit from early intervention and special resources from his or her school. In her case commentary, Mary Lynn Dell, MD, DMin, explores the pressures placed on a physician by a parent who wants her son to be able to access those early interventions. The case, borderline Asperger disorder in a child, is far from clear-cut, but only a black-and-white diagnosis will let the child reap the benefits his school would offer.

And I have known the eyes already, known them all— The eyes that fix you in a formulated phrase, And when I am formulated, sprawling on a pin, When I am pinned and wriggling on the wall, Then how should I begin To spit out all the butt-ends of my days and ways?

But labels come with downsides. A diagnosis can change how others view a patient and how the patient views himself. Diagnoses are not context-free, and a patient's individuality may be overshadowed by the medical name he or she is given. Once labeled, a person's innermost physical and mental workings become medicalized. Stigma, by self or others, is not uncommon. In her case commentary, Cynthia Geppert, MD, PhD, discusses the profound power of language, especially in diagnoses that can be harmful to the patient, and how nuances in a physician's explanation can affect a patient's psyche and self-image. How best to tailor our words, based on a holistic evaluation of a patient's needs and disposition?

Is a diagnosis of a devastating disease that has no treatment worth giving at all? We are coming closer to finding possible biomarkers to aid in early detection of Alzheimer disease. Future physicians may face the dilemma of whether the pros of providing such information outweigh the cons. Matthew E. Growdon reviews an article highlighting these challenges, which are further complicated by the fact that the disease in question eventually obliterates a person's identity.

On a grander scale, creating an entirely new set of disorders based on what used to be considered normal variation is not without consequence. Many of our authors touch upon the societal, economic, and political implications of increasing medicalization and treatment. How is the way we view disease changing, and does that change the face of particular diseases?

The result of medicalization is a double-edged sword. In the history of medicine section, David E. Smith, MD, explains how the evolution of addiction medicine as a disease specialty altered public opinion and treatment of substance abuse issues. George L. Blackburn, MD, PhD, discusses in his policy forum piece how medicalizing obesity may improve the public image of those who are obese and lead to more aggressive interventions. Elizabeth A. Kitsis, MD, MBE, explains in her oped that pharmaceutical involvement in the formation of diagnoses may increase awareness of a disease but may also mislead people into thinking that how they behave isn't "normal" and can or should be "fixed." Matt Lamkin, JD, MA, predicts in the medicine and society section that the ever-expanding number of diagnoses that portray human behavior as genetically determined will eventually cease to entitle the diagnosed to special accommodation.

In a minute there is time For decisions and revisions which a minute will reverse.

Nothing in medicine is set in stone, which may make some diagnoses arbitrary at best and misguided at worst. Diagnostic categories are not objective reflections of the world, Barry DeCoster, PhD, argues in his article. He discusses the dangers of underappreciation of how diagnoses are created and overconfidence in their certainty. And diagnostic categories are indeed shifting. Emily A. Kuhl, PhD, David J. Kupfer, MD, and Darrel A. Regier, MD, MPH, review some of the proposed

changes to the Diagnostic and Statistical Manual of Mental Disorders, as well as their rationales and possible repercussions.

And should I then presume? And how should I begin?

The narrator's fear of being misinterpreted is omnipresent in Eliot's poem. He imagines himself baring all in a hypothetical scenario, and, despite his best intentions, he sees his words taken the wrong way. Such a fear is perhaps founded: self-disclosure may forever alter the nature of a relationship. Sometimes a physician, in good faith, chooses to label herself to further establish closeness in the patientdoctor relationship. James E. Sabin, MD, discusses the appropriateness of physician self-disclosure in his clinical case. What changes once the doctor reveals a personal issue to a patient struggling with a similar problem? Perhaps counterintuitively, many patients report feeling less satisfied and less reassured when their doctor shares such information. How to toe the fine line between advising based on personal experience and oversharing?

Ultimately, Eliot's character never asks or answers his "overwhelming question." Physicians have no such luxury. An uncertain constellation of symptoms in a patient warrants an explanation if both parties are to be satisfied. From question to answer, however, is a winding path. Which questions should a physician ask to obtain a diagnosis? Which assumptions should she make when seeking one? How should she explain the diagnosis in a way that empowers the patient? How much should she share?

How should we begin?

References

1. Eliot TS. The love song of J. Alfred Prufrock. In: The Waste Land and Other Poems. Peterborough, ON: Broadview Press; 2010.

Shara Yurkiewicz MS-II Harvard Medical School Boston, Massachusetts

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 852-855.

CLINICAL CASE

Is Physician Self-Disclosure Ever Appropriate?

Commentary by James E. Sabin, MD

Dr. Goldberg is a primary care physician in a small rural town. She has been caring for Mrs. Hunter and her grown daughter, Karen, for the past decade. Mrs. Hunter has just been diagnosed with amyotrophic lateral sclerosis (ALS), and she and her daughter have been struggling to cope. Mrs. Hunter lives alone, and Karen is her only child.

Karen comes to Dr. Goldberg one day with severe anxiety and gastrointestinal symptoms. She isn't sleeping, she has no appetite, and she has been getting frequent colds. In addition to dealing with the emotional burden of her mother's diagnosis, she has financial worries. She confides in Dr. Goldberg that she is at a complete loss about how to deal with her mother's illness.

Dr. Goldberg is acutely sympathetic; her own mother passed away from ALS about 5 years prior. She remembers the intense struggle her mother had, as well as her own feelings of powerlessness as a caregiver. She isn't sure whether it would be appropriate or helpful to share this information with Karen.

Commentary

Research on the patient-physician relationship tells us that physician self-disclosure (PSD) is not rare. In one study, PSD occurred in 15 percent of primary care and surgery appointments. Most important for our advice to Dr. Goldberg, and contrary to what their physicians may have expected, patients were *less* satisfied with primary care appointments in which self-disclosure occurred and reported feeling *less* warmth, comfort, friendliness and reassurance in those appointments. By the same measures, however, surgery patients reported positive reactions to PSD [1].

In another study physician self-disclosure occurred in 34 percent of initial primary care appointments. Patients were not asked about their reactions, but a team of experts reviewing the transcripts concluded that 85 percent of the PSD was not useful to the patient [2]. In the study, PSDs were often non sequiturs, more focused on the physician's than the patient's needs. The researchers found little evidence that PSD strengthened the patient-physician relationship. And in psychiatry, review of situations in which a physician-patient sexual relationship occurred showed that seemingly harmless boundary crossings like PSD sometimes preceded and appeared to lead up to serious sexual violations [3].

Given these red flags, Dr. Goldberg's initial handling of the situation is exactly on target. She recognized the impulse to share her own experience with Karen but questioned whether or not PSD would be useful to Karen's treatment. The impulse to share *might* be good guidance, but it needs to be assessed in the most self-aware and evidence-based manner possible.

All we know at this point is that Karen has a number of symptoms that could be stress-related and that she has told Dr. Goldberg that she is at a complete loss as to how to deal with her mother's illness. But we don't yet know what Karen is at a loss about. Given the remarkable coincidence that, like Karen, Dr. Goldberg has experienced a parent's illness with ALS, it would be easy for her to project her own feelings onto Karen and conclude that she understands Karen's situation. But rather than make assumptions based on her experience with her own mother's ALS, Dr. Goldberg should delve more deeply into Karen's reactions. There are no rules that will give Dr. Goldberg the "right" answer about whether to disclose her own experience. In order to assess the potential risks and benefits she'll have to gather more "data."

It's important to ask questions in an open-ended manner and to probe for clarification. We human beings are very idiosyncratic. We react in terms of our own histories and private thoughts. Karen's term "at a complete loss" doesn't give us the precision we need to know how to be most helpful to her. We can imagine the following dialogue between them. Dr. Goldberg's thoughts are in italics:

Dr. G: (Karen is clearly distressed. But lots of different things could be causing the distress. I need to validate that it's OK to feel distressed and try to get a more precise sense of what is specifically most difficult for her.) You and your mother are dealing with a very tough situation. What aspects are most difficult for you?

KH (crying): I don't see how I'll be able to see my mother through to the end.

Dr. G: (I'm not sure how much the problem is fear of losing her mother and how much it's about how she will deal with her mother during the illness.) Can you put the tears into words?

KH: I can't stop working—my mother and I depend on my income. But how can I leave her alone?

Dr. G: (I think Karen needs practical advice, and this isn't a problem I had to deal with when my mother was ill.) Suppose I put you in touch with the visiting nurses. They're very good with this kind of practical problem.

KH: That sounds like a great idea.

Dr. G: OK. Is there more that you're having trouble dealing with?

KH (crying): It breaks my heart to see my mother so weak. I can't let myself cry in front of her. I have to be strong when we're together, but I don't know if I can do it. I hate myself for being so weak!

Dr. G: (I've known Karen for 10 years. She's a strong, independent, hard-working person, who likes to take care of others. I think she expects herself to be a Rock of Gibraltar. She may need to feel that she has "permission" to feel so distressed. Karen and I have had a good relationship. Mentioning my own experience might be useful for her, and I don't see any major risk in bringing it up.) ALS in a parent is very tough to deal with, especially since you're an only child. I know about this first hand—my mother also had ALS. I found it was helpful to me to talk with my friends and to get regular exercise. What could be most helpful to you in a really tough situation like this?

Dr. Goldberg's disclosure is brief, she focuses her comments on Karen, and she promptly comes back to Karen's needs. This is the way disclosure should be conducted. In the real office situation, her thought process would happen fast, and some of it would be implicit. It's important for Dr. Goldberg to have a sense of her "medical personality." Does she have reason to be concerned about her use of PSD, as from previous incidents where she found herself talking about her own experience in ways that didn't help her patients? Did she detect in herself any eagerness to share her experience with Karen apart from a clear sense of how disclosure would be useful for Karen? Is she at peace with the trauma of her mother's illness and death, or is it a raw wound that might make her seek solidarity with Karen to serve her own needs? And, in simplest human terms, given that she thinks sharing her experience might be helpful for Karen, is she comfortable talking about herself that way? If she is shy and private, even if sharing would be useful in principle, she might not be able to transact the exchange effectively. Instead of responding with disclosure, she might have proceeded this way:

Dr. G: (I've known Karen for 10 years. She's a strong, independent, hard-working person, who takes care of others. I think she expects herself to be a Rock of Gibraltar. She may need to feel that she has "permission" to feel so distressed. I'll try to clarify the problem for her and reframe what she's calling "weakness.") ALS in a parent is very tough to deal with, especially since you're an only child. I've known you for 10 years, so I know what a strong person you are and how much it matters to you to be able to help others. You haven't had much practice feeling needy yourself! If you were trying to help someone like yourself whose mother had ALS, how would you do it?

KH (laughing): You've got my number! I guess with someone like myself I'd just listen and let them cry on my shoulder.

Dr. G: Do you have people you can talk to that way? My guess is that doing that will help you feel better. The situation isn't going to get easier, but we can work together to take care of your mother and of you at the same time.

Self-disclosure is a common part of human relationships. When friends bring up a problem, it's natural for us to talk about a related problem we've encountered. But in medical practice we have a distinct responsibility to put our patient's needs ahead of our own. And since the time of Hippocrates we've asked ourselves to pay special attention to avoiding harm. We should be prepared to use PSD as a tool, but only after we've defined the rationale for disclosure, considered the potential risks, weighed it against other ways of addressing our patient's needs, and scrutinized our own motivation, to make sure PSD is intended to serve our patient and not ourselves.

References

- 1. Beach MC, Roter D, Rubin H, Frankel R, Levinson W, Ford DE. Is physician self-disclosure related to patient evaluation of office visits? J Gen Intern Med. 2004;19(9):905-910.
- 2. McDaniel SH, Beckman HB, Morse DS, et al. Physician self-disclosure in primary care visits: enough about you, what about me? Arch Intern Med. 2007;167(12):1321-1326.
- 3. Norris DM, Gutheil TG, Strasburger LH. This couldn't happen to me: boundary problems and sexual misconduct in the psychotherapeutic relationship. Psychiatr Serv. 2003;54(4):517-522.

James E. Sabin, MD, is a clinical professor in the Departments of Population Medicine and Psychiatry at Harvard Medical School in Cambridge, Massachusetts and the director of the ethics program at Harvard Pilgrim Health Care, a not-forprofit health plan. His research interests include the ethics of health care resource allocation. Dr. Sabin blogs at http://healthcareorganizationalethics.blogspot.com.

Related in VM

Physician Self-Disclosure and Patient Counseling, October 2008

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 856-860.

CLINICAL CASE

When Diagnosis is a Double-Edged Sword

Commentary by Mary Lynn Dell, MD, DMin

Dr. Mitchell, a psychiatrist, specializes in childhood development disorders. One day, a mother and her 5-year-old son came to Dr. Mitchell's private practice for a first visit.

"Ravi's been having problems ever since he started school," his mother explained. "He doesn't have many friends and is very shy. I've been doing research online about Asperger disorder, and I'm worried that Ravi could have it. All the articles mentioned not making eye contact, and I've noticed now that Ravi never really looks at me."

After asking Ravi some questions while she was examining him and observing him while she talked with his mother, Dr. Mitchell agreed that aspects of his behavior correlated with symptoms of Asperger disorder. She believed, in fact, that his was a borderline case. Since Ravi's problems had not been observed for long, Dr. Mitchell was reluctant to diagnose him with the condition. She worried that the diagnosis would affect how Ravi's teachers and other adults treated him and that their behavior could affect Ravi's self-perception. She was also concerned about the label's accuracy.

Ravi's mother explained that if her son were diagnosed with Asperger disorder, he would be eligible to receive special services from the school that would help him develop socially. "The sooner he receives these services, the better," she said. "He is falling farther and farther behind his classmates."

Dr. Mitchell explained her concerns about a premature diagnosis, but Ravi's mother insisted that special services would help her son enormously. Dr. Mitchell also believed that Ravi would benefit from such services.

Commentary

Asperger's disorder [1] is classified in the *Diagnostic and Statistical Manual of Mental Disorder*, *Fourth Edition (Text Revision) (DSM-IV-TR)* as one of five pervasive developmental disorders. It is characterized by impairments in social interactions and repetitive and stereotyped behaviors, activities, and interests. Difficulties in social interactions can include impaired use and interpretations of nonverbal behaviors, developmentally inappropriate peer relationships, and lack of spontaneity and social and emotional reciprocity in interpersonal interactions. These qualities and behaviors are the root of clinically significant social, interpersonal,

academic, occupational, and functional impairment. Unlike more severe forms of pervasive developmental or autism spectrum disorders, there are no significant delays in language, cognitive development, age-appropriate self-help skills, nonsocial adaptive behaviors, and general curiosity about the world [2].

Dr. Mitchell's hesitancy to diagnose Ravi with an autism spectrum disorder (ASD), in this case Asperger's disorder, highlights several important diagnostic and ethical issues that have become more relevant in the last few years as the incidence of ASDs have increased. First, while the diagnosis of Asperger's is based on patient history and may be reasonably evident at an initial appointment, it is wise to obtain collateral information from other parties with experience and knowledge of the child in multiple settings, including school personnel, primary care physicians, and other caregivers. Reports from current physical examinations, hearing screens, and, when possible, psychological testing and developmental assessments by adequately trained psychologists should be obtained. Though the diagnosis may seem readily apparent during the initial appointments with some children, premature declaration of an ASD may lead to overlooking important medical, psychiatric, family, and other information vital to treatment planning.

Secondly, debate exists in both professional and lay circles regarding the degree or extent to which Asperger's is a "disorder" rather than a way of being, perceiving the world, and interacting with others that, while particular or even peculiar to some, should not be considered pathological at all. This issue has come to the forefront recently as preparations are under way for the next Diagnostic and Statistical Manual of Mental Disorders, the DSM-5 [3]. Many experts in the field believe that Asperger's is not a unique syndrome, but a point at the high-functioning end of the more inclusive autistic disorders spectrum.

On the other hand, many advocates, especially in lay circles, wish to retain the Asperger's concept and even the name, but redefine the category as one of a variety of "normal" human developmental patterns. This view holds that the conceptualization of Asperger's as psychopathology in need of treatment or remediation is not only inaccurate and unjust, but it may be prejudicial and minimizes the strengths and talents and limits the potential of those considered to have Asperger's. It is possible that Dr. Mitchell's sensitivity to this issue is influencing her reluctance to declare a diagnosis swiftly, especially if she cares for older adolescents and adults with Asperger's or has been in practice long enough to have followed former child patients into adulthood.

Indeed, societal stigma is a factor in coping and living with mental illness, and those with ASDs are not spared the public scrutiny and possibility of biases and misunderstandings. Historically, those with physical, intellectual, and developmental disabilities have been ignored, discriminated against, abused, and denied adequate medical care, education, vocational training, and employment opportunities. Many people without disabilities feel uncomfortable in the presence of developmentally disabled individuals. The atypical behaviors, quirks, and oddities in interpersonal

interactions of those with Asperger's syndrome and other ASDs often challenge the comfort level of people who are not well informed, have not known or spent much time with anyone with an ASD, or whose attitudes toward anyone different are rigid or who are slower to become more tolerant and accepting.

On the other hand, significant strides have been made in education of the general public about ASDs and the diagnosis, treatment, educational needs, strengths, and resiliencies of affected individuals. Recent state and federal legislation and position statements and practice parameters issued by medical specialties that work with people with ASDs have been instrumental in disseminating information to medical professionals and school officials, thereby facilitating earlier diagnosis and treatment and helping to decrease stigma. ASD research is a top priority at the National Institute of Mental Health, and organizations such as the Autism Society of America and Autism Speaks have been tireless in their efforts to support research, education, and assistance of all kinds for affected individuals and their families. Yes, stigma still exists, but noticeable progress is being made to diminish bias so that fear of discrimination does not override the benefits to be reaped with accurate diagnosis and access to services.

And so, what about Ravi, his mother, and Dr. Mitchell?

What nearly all clinicians and educators who work with individuals with Asperger's and ASDs agree upon is that early recognition of signs and symptom expressions is imperative, quickly followed by appropriate interventions tailored to a child's specific needs. Upon obtaining the initial history and examining Ravi in her office, Dr. Mitchell does note that some "aspects of his behavior correlated with symptoms of Asperger disorder." In considering what is in Ravi's best interest, clarity of diagnosis, assessment for comorbid medical and psychiatric findings, and work with the school system to achieve a daily environment that promotes optimal academic and social growth are paramount. Defining specific deficits and strategizing about how to address them (a target symptom approach) may be most helpful initially.

In most situations, the psychiatrist has the advantage of collaborating with other professionals who can formally assess and quantify hearing, speech, and language problems, accompanying medical concerns, intellectual and developmental functioning, and social development. These are all categories that merit assessment and intervention on their own, even if the target symptoms fall short of a formal Asperger's or ASD diagnosis in terms of number of symptoms or symptom severity.

If after a multidisciplinary assessment, or subsequent visits to Dr. Mitchell, the Asperger's diagnosis is indeed determined to be accurate, Ravi's mother is right that services available because of the diagnosis will be helpful. This is especially true for individuals with Asperger's, who are at greater risk than typical youth for interpersonal, academic, and occupational impairment later in adolescence and adulthood due to poor social skills.

With the increasing diagnosis of ASDs in school-age children—1 of 110 8-year-olds demonstrate a diagnosable ASD according to a 2006 study by the Autism and Developmental Disabilities Monitoring Network [4]—the educational profession offers individual education plans (IEPs) and regular monitoring of educational needs and goals for children who need evaluation and extra services. In other words, the next step for Ravi is potentially the same or similar whether or not he meets complete criteria for Asperger's—a multidisciplinary assessment, followed by an IEP or equivalent plan in the school setting, with regular reassessment of his goals and progress toward those goals. In many educational settings, services to address the concerns shared by Ravi's mother and Dr. Mitchell are available without a diagnosis of Asperger if criteria are not met. However, it behooves all clinicians to be familiar with the resources and procedures of school systems and services in the geographical area in which they practice, for access to specific services can indeed be diagnosis-driven and specific.

Finally, though it appears that Ravi's mother, teachers, and others important in his life have his best interests at heart, thorough assessment must include at least a brief consideration of other factors that could affect clinical and ethical decision making in this instance. Given Ravi's young age, his mother (or father or other guardian) is the medical decision maker. Are there concerns about her decision-making capacity, and does she have additional preferences about his care? Are there quality-of-life considerations, in addition to the social interactions she mentioned, that are relevant to diagnosis and treatment planning? Are there other family, economic, financial, religious, or cultural factors that need to be considered? How will providing optimally for Ravi's needs affect other family members? Is Dr. Mitchell aware of any issues she may have professionally or personally that will influence her medical judgment and care of Ravi? Do parents, psychiatrists, or school officials have any potential conflicts of interest that could affect Ravi's care and educational interventions [5]?

Assessing and treating patients with Asperger's syndrome and ASDs are challenging endeavors requiring up-to-date medical knowledge, compassion and respect for patients and families, and sound ethical principles and practice. Clinicians who work in this area will find collegial and collaborative partners in parents, educators, social workers, occupations, speech and language therapists, physical therapists, psychologists, and others who share common goals for the many children, adolescents, and adults whose lives are affected by autism spectrum disorders.

References

- 1. The *DSM-IV-TR* uses the term "Asperger's disorder."
- 2. American Psychiatric Association. Diagnostic and Statistical Manual, Fourth Edition (Text Revision). Washington, DC: American Psychiatric Association; 2000.
- 3. The American Psychiatric Association has changed its abbreviation system for the fifth edition of the manual.

- 4. National Institute of Mental Health. Autism. http://www.nimh.nih.gov/statistics/1AUT_CHILD.shtml. Accessed on October 9, 2011.
- 5. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. 5th ed. New York: McGraw-Hill; 2002.

Mary Lynn Dell, MD, DMin, is an associate professor of psychiatry, pediatrics, and bioethics at Case Western Reserve University School of Medicine and the director of the Child and Adolescent Psychiatry Consultation Liaison Service at Rainbow Babies and Children's Hospital in Cleveland, Ohio. Dr. Dell's clinical and academic interests are the psychiatric care of medically ill children, adolescents, and their families; bioethics; and religion and spirituality in medicine and psychiatry.

Related in VM

The Spectrum of Autism—From Neuronal Connections to Behavioral Expression, November 2010

Can Parents of a Child with Autism Refuse Treatment for Him? November 2010

Ethical Issues in the Early Diagnosis of Alzheimer Disease, December 2011

Patient-Centered Revisions to the DSM-5, December 2011

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 861-865.

CLINICAL CASE

A Virtue Ethics Approach to Framing Troublesome Diagnoses

Commentary by Cynthia Geppert, MD, MA, PhD, MPH

Dr. Chin has been treating Mr. Bryant for seizures for several years. Although he has tried several different medication regimens, his seizures have been difficult to get under control. Mr. Bryant was recently hospitalized for 3 days due to the frequency and severity of the seizures, and, over the course of the hospitalization, he had three seizures. During the last two, Dr. Chin, a neurologist, used an EEG to record his brain activity.

Reviewing the EEG results, Dr. Chin discovers something unexpected. Mr. Bryant's brain waves do not show patterns typical of epileptic seizures; they are normal, strongly implying that Mr. Bryant's seizures have no neurological cause.

Dr. Chin is concerned about the latest EEGs. Since the recent seizures do not have an organic basis, treatment may involve cognitive behavioral therapy or other psychiatric measures. In Dr. Chin's experience, many patients, upon hearing this diagnosis, deny that it can be correct and seek another physician. Other patients feel trapped and helpless, convinced that no treatment will ever works.

Dr. Chin has witnessed how strongly the seizures have disrupted his patient's emotional well-being. Mr. Bryant feels helpless, angry, mistrustful of treatments, and resigned that he will never be able to live a normal life. Knowing Mr. Bryant's personality, Dr. Chin is worried that the news about the nonneurologic nature of the seizures could cause even greater emotional pain and perhaps prompt Mr. Bryant to stop seeing a physician altogether.

Commentary

Mr. Bryant's case may seem like one of the exotic "zebras" of medicine, but from the perspective of community neurologists and consultation psychiatrists, it is actually more like a commonly encountered horse in practice. Seizures of nonneurological origin are actually more frequent than those of a neurological nature [1]. Despite the frequency of cases like that of Mr. Bryant, they tend to strike fear and trepidation into the heart of even an experienced clinician such as Dr. Chin (and me). Dr. Chin is caught in a classic clinical ethics dilemma. As a good physician, he wishes to provide an appropriate diagnosis and treatment plan for his patient, yet has a well-founded concern that this health information will not only not do good but will cause harm to Mr. Bryant.

Bioethics offers clinicians several salient theories or models that can inform and structure the analysis and resolution of such dilemmas. Jennifer Radden and John Sadler have suggested that virtue ethics is a theory especially attuned to the unique ethical challenge of psychiatry [2]. These two authors delineate the virtue ethics approach:

An aretaic or virtue-based ethics is one in which it is the self or the character of the person that is the central focus of moral assessment, rather than particular actions or their consequences. Personal qualities such as honesty, integrity, courage, fairness, and compassion are to be found in the dispositions and responses of persons possessing good characters [3].

It is these qualities of character that I think will offer Dr. Chin the most salutary means of caring for Mr. Bryant. While all of the recognized professional virtues are valuable in responding to the questions and concerns this scenario poses, the virtues of respect, humility, compassion, honesty, the practical wisdom of prudence, integrity, and, finally, courage are of especial importance in this particular scenario and in similar cases in which the organic basis of the disorder cannot be identified.

The central virtue with which Dr. Chin and all clinicians facing clinical cases fraught with uncertainty and ambiguity must be equipped is humility—knowing what we do not know as a scientific community and when, as individual practitioners, we don't know how to appropriately manage a patient. Recall that prior to the advent of neuroimaging, tumors and other neurological conditions were often misdiagnosed as "psychogenic." While such mistakes are far more rare with brain scans, "pseudo" and true epileptic seizures co-occur in 10-66 percent of patients with functional seizures, and the EEGs of 19-53 percent of such patients demonstrate an abnormality [4]. As David Kaufmann, one of the foremost experts in neurology, has written, "Applying only clinical criteria, the distinction between psychogenic and epileptic seizures in most studies is no more accurate than 80 percent to 90 percent" [5].

The awkward, albeit nonjudgmental, phrase "seizures of nonneurological origin" used to describe Mr. Bryant's spells in the scenario underscores the powerful role of diagnostic language in such cases where "names can truly hurt." Such power demands that the virtue of respect for the intrinsic dignity of Mr. Bryant as an individual and human being guide Dr. Chin's communication with his patient. What is in the name given to Mr. Bryant's problem? A great deal depends upon whatever explanatory label is chosen, as it may well determine to a great extent the trajectory of the patient's course of treatment—and even his self-image.

Research shows that physicians often fail to appreciate the insight of ancient cultures that words have power to create or alter reality, while patients are highly cognizant of the transformative force of terminology. A survey of British neurologists found that the most popular terms for seizures without a neurological origin were "functional," "psychogenic," and "hysteria" [6]. In comparison, a similar survey of

neurology patients found that "hysterical seizures" and "psychogenic seizures" were both considered offensive, while "stress-related" and "functional seizure" were felt to be less stigmatizing [7]. Jon Stone has suggested that "functional" may be the optimal term because it "has the advantage of avoiding the 'non-diagnosis' of 'medically unexplained' and side steps the unhelpful psychological versus physical dichotomy implied by many other labels" [8].

The ancients also knew that naming something gives an individual power over it and, in this situation, provides Dr. Chin an opening with Mr. Bryant. Compassion, an empathic and active response to a patient's suffering, must be the affective and volitional orientation of this interaction. Mr. Bryant may not be afflicted with the devastating disorder of epilepsy, yet we must not forget that he is still experiencing what Ron Pies calls true disease, in the sense of dis-ease with his body and being in the world [9]. Empirical evidence suggests that Mr. Bryant's functional seizures might be more debilitating in their long-term effect on his life and certainly more refractory to even expert psychiatric care than many cases of epileptic seizures [10]. A paternalistic interpretation of the meaning of compassion might lead Dr. Chin to try spare Mr. Bryant the increased emotional distress of the functional seizure diagnosis by telling him less than the entire truth; studies suggest that at least some clinicians take this route [11]. Richard Kanaan has proposed that changing the diagnosis is a key criterion for determining the ethicality of the communication [11]; if a strategy involves telling the patient a diagnosis different than what the clinician believes it actually is, that strategy likely to be ethically questionable.

The vignette shows that Dr. Chin is already keenly aware of the adverse effect of unloading information without regard for its emotional impact. The virtues of honesty and integrity here come to Dr. Chin's assistance. We have learned from the "giving bad news" literature [12] that, to be humane and heard, honesty must avoid the two poles of harsh and sugarcoated truth telling. For example Dr. Chin might say something along the lines of "Mr. Bryant, I'd like to give you some information about your condition, based on the tests that we've done. First, I'm happy to report that your condition has not worsened and that we now understand why the medications were not working."

Dr. Chin is portrayed as a physician of integrity, and he must at this juncture in the conversation trust his long-standing relationship with Mr. Bryant. Even if his best efforts at discussing the new diagnosis with Mr. Bryant fail, and the patient fires him or threatens a lawsuit, Dr. Chin must make his own faithfulness as a physician the criterion for determining the success of the encounter. Anything less will lead to various compromises of integrity such as returning the patient to his primary care physician or sending him to a psychiatrist with a report that says the patient's seizures are psychogenic, while never disclosing this diagnosis to Mr. Bryant [11].

Moral courage is a rare virtue, and its critical role in medical professionalism is underappreciated. Without courage a physician may be unable to accept the diagnosis of functional seizures and, in a dyad of denial with the patient, pursue additional invasive tests with their attendant risks—or even collude to continue antiepileptic medications despite their deleterious side effects. Courage in Aristotelian philosophy [13] is, like all the virtues, a mean between extremes. In this situation, Dr. Chin's objective is neither to spare the patient-physician relationship from conflict at the expense of the truth nor to pursue the truth singlemindedly to the detriment of the patient's feelings and the relationship.

The summative virtue of *prudence* is crucial for the resolution of the ethical dilemma represented in the clinical case scenario. Dr. Chin's knowledge of Mr. Bryant as a whole person with strengths and limitations, hopes and frustrations, as well as his previous experience informing patients that their seizures are functional in nature, must guide him. The concept of stress is well established in the mind of the public and has a neutral or even positive valence as opposed to more psychiatric designations like conversion or somatoform disorder. Most patients recognize even inchoately that events in their lives trigger responses in their bodies and that their emotions often mediate these reactions.

In my experience, most patients are far less Cartesian in their illness beliefs than are we physicians, and they are willing to entertain the possibility that the psyche and soma are not separate, but linked—that there is a mutual interaction between mind and body. Dr. Chin may then be able to build upon this understanding to construct a treatment plan that includes referral to a mental health specialist. Mr. Bryant is described as "helpless, angry, mistrustful of treatments, and resigned that he will never be able to live a normal life." A physician of altruistic character will take into account Mr. Bryant's demoralization and distrust of the past and current treatment plans and attempt to sublimate that frustration toward hope in a future course of therapy that, while difficult, at least offers some potential for achieving Mr. Bryant's goals of care.

References

- 1. Kaufman DM. *Clinical Neurology for Psychiatrists*. 5th ed. Philadelphia, PA: WB Saunders; 2001.
- 2. Radden J, Sadler JZ. *The Virtuous Psychiatrist: Character Ethics in Psychiatric Practice*. New York, NY: Oxford University Press; 2010.
- 3. Radden, Sadler, 62.
- 4. Bowman ES. Pseudoseizures. *Psychiatr Clin North Am.* 1998;21(3):649-657, vii.
- 5. Kaufman, 253.
- 6. Mace CJ, Trimble MR. 'Hysteria', 'functional' or 'psychogenic'? A survey of British neurologists' preferences. *J R Soc Med*. 1991;84(8):471-475.
- 7. Stone J, Campbell K, Sharma N, Carson A, Warlow CP, Sharpe M. What should we call pseudoseizures? The patient's perspective. *Seizure*. 2003;12(8):568-572.
- 8. Stone J, Wojcik W, Durrance D, et al. What should we say to patients with symptoms unexplained by disease? The "number needed to offend." *BMJ*. 2002;325(7378):1449-1450.

- http://www.ncbi.nlm.nih.gov/pmc/articles/PMC139034/. Accessed November 14, 2011.
- 9. Pies R. What should count as a mental disorder in DSM-V? *Psychiatric* Times. April 14, 2009.
- 10. Kroenke K. Efficacy of treatment for somatoform disorders: a review of randomized controlled trials. Psychosom Med. 2007;69(9):881-888.
- 11. Kanaan R, Armstrong D, Wessely S. Limits to truth-telling: neurologists' communication in conversion disorder. Patient Educ Couns. 2009;77(2):296-301.
- 12. Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. Lancet. 2004;363(9405):312-319.
- 13. Aristotle. The Ethics of Aristotle: The Nicomachean Ethics. Tredennick H, ed. Thomson JAK, trans. New York, NY: Penguin Books; 1976: 244.

Cynthia Geppert, MD, MA, PhD, MPH, is chief of consultation psychiatry and ethics at the New Mexico Veteran's Affairs Health Care System and associate professor of psychiatry and director of ethics education at the University of New Mexico in Albuquerque. Dr. Geppert's interests include ethics consultation, medical and ethics education, and the clinical and ethical issues involved in the practice of psychosomatic medicine, addiction and pain medicine, and hospice and palliative medicine.

Acknowledgement

The author would like to thank Ron Pies, MD, for his helpful comments on a draft of this article.

Related in VM

The American Medical Association Code of Medical Ethics' Opinions on Disclosing Diagnoses to Patients, December 2011

The Ethics of Diagnosing Nonepileptic Seizures with Placebo Infusion, November 2010

Disclaimer

The views expressed in this article are those of the author and do not necessarily reflect the position or policy of the Department of Veteran's Affairs or the University of New Mexico School of Medicine.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 866-867.

THE CODE SAYS

The American Medical Association *Code of Medical Ethics*' Opinions on Disclosing Diagnoses to Patients

Opinion 8.082 - Withholding Information from Patients

The practice of withholding pertinent medical information from patients in the belief that disclosure is medically contraindicated is known as "therapeutic privilege." It creates a conflict between the physician's obligations to promote patients' welfare and respect for their autonomy by communicating truthfully. Therapeutic privilege does not refer to withholding medical information in emergency situations, or reporting medical errors.

Withholding medical information from patients without their knowledge or consent is ethically unacceptable. Physicians should encourage patients to specify their preferences regarding communication of their medical information, preferably before the information becomes available. Moreover, physicians should honor patient requests not to be informed of certain medical information or to convey the information to a designated proxy, provided these requests appear to genuinely represent the patient's own wishes.

All information need not be communicated to the patient immediately or all at once; physicians should assess the amount of information a patient is capable of receiving at a given time, delaying the remainder to a later, more suitable time, and should tailor disclosure to meet patients' needs and expectations in light of their preferences.

Physicians may consider delaying disclosure only if early communication is clearly contraindicated. Physicians should continue to monitor the patient carefully and offer complete disclosure when the patient is able to decide whether or not to receive this information. This should be done according to a definite plan, so that disclosure is not permanently delayed. Consultation with patients' families, colleagues, or an ethics committee may help in assessing the balance of benefits and harms associated with delayed disclosure. In all circumstances, physicians should communicate with patients sensitively and respectfully.

Based on the report <u>"Withholding Information from Patients (Therapeutic Privilege),"</u> adopted June 2006.

Opinion 8.12 - Patient Information

It is a fundamental ethical requirement that a physician should at all times deal honestly and openly with patients. Patients have a right to know their past and present medical status and to be free of any mistaken beliefs concerning their conditions. Situations occasionally occur in which a patient suffers significant medical complications that may have resulted from the physician's mistake or judgment. In these situations, the physician is ethically required to inform the patient of all the facts necessary to ensure understanding of what has occurred. Only through full disclosure is a patient able to make informed decisions regarding future medical care.

Ethical responsibility includes informing patients of changes in their diagnoses resulting from retrospective review of test results or any other information. This obligation holds even though the patient's medical treatment or therapeutic options may not be altered by the new information.

Concern regarding legal liability which might result following truthful disclosure should not affect the physician's honesty with a patient.

Issued March 1981; updated June 1994.

Related in VM

A Virtue Ethics Approach to Framing Troublesome Diagnoses, December 2011

Copyright 2011 American Medical Association. All rights reserved.

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 868-872.

JOURNAL DISCUSSION

Ethical Issues in the Early Diagnosis of Alzheimer DiseaseMatthew E. Growdon

Mattsson N, Brax D, Zetterberg H. To know or not to know: ethical issues related to early diagnosis of Alzheimer's disease. *Int J Alzheimers Dis.* 2010. http://www.hindawi.com/journals/ijad/2010/841941/.

While a disease-modifying treatment for Alzheimer disease (AD) remains elusive, recent advances have shed light on its pathophysiology, giving patients and researchers alike hope that a viable treatment will emerge. Research efforts have identified promising drug targets for clinical trials and uncovered cerebrospinal fluid (CSF) biomarkers and imaging studies that allow for preclinical detection of AD pathology. The recognition that the hallmark plaques and tangles of AD are detectable in the brains of individuals more then 10 years before they present with any cognitive changes underscored the need to validate biomarkers that could reliably detect AD and chart its progression.

In April 2011, the Alzheimer's Association [1] updated the criteria for the diagnosis of Alzheimer's disease dementia for the first time in 27 years. Their report emphasizes biomarker data and lays out research guidelines for the preclinical diagnosis of AD meant to facilitate ongoing clinical research and drug discovery efforts [2].

Implicit in these new guidelines is the hope that effective therapies are around the corner and the belief that interventions should be designed for individuals before their brains are irreversibly damaged. The well-placed optimism of scientific progress can obscure the humanistic dimensions of early diagnosis. In "To Know or Not to Know: Ethical Issues Related to Early Diagnosis of Alzheimer's Disease," Niklas Mattsson, David Brax, and Henrik Zetterberg examine the ethical issues surrounding the early diagnosis of AD. They emphasize the potentially harmful consequences of early diagnosis to the patient and raise important questions about personal identity and decision-making competence that are central to the diagnosis and management of AD. Their article is a timely reminder about the powerful, lifealtering effects of diagnosis and, above all, the enduring need to place the patient's desires and preferences at the center of the clinical encounter.

As a point of departure, Mattsson et al. consider the potential for misdiagnosis of AD, even in the era of sophisticated biomarker studies. Several studies underscore the high diagnostic accuracy of cerebrospinal fluid (CSF) biomarkers, with sensitivity and specificity around 85-90 percent in identifying incipient AD in

patients diagnosed with mild cognitive impairment, an intermediate stage between the expected cognitive decline of normal aging and the pronounced decline of dementia [3].

However, the authors acknowledge the enduring possibility of misdiagnosis in populations or samples in which there is a low prevalence of disease because of false positive screening results. Furthermore, while severe complications are rare, lumbar punctures to obtain CSF are associated with post-LP headaches in 2-4 percent of patients [4]. Colloquially referred to as "spinal taps," lumbar punctures are feared by many patients, to the point that there have been calls within professional circles to rename the procedure and move it into the mainstream of clinical practice in dementia care [5].

The authors offer a balanced analysis of the potential benefits and considerable drawbacks to the early diagnosis of AD. It is difficult to do justice to the intensely personal and wrenching effects for patients and families of a test result that is positive for AD. Mattsson et al. consider many of these effects: extended follow-up for the patient, feelings of hopelessness, agony, and despair, and increased risk of suicide in people with dementia (a subject about which there has been inconclusive research to date).

From a legal perspective, the diagnosis of dementia can affect rights to hold a driver's license or own a gun; a diagnosis of AD thus represents a stigmatizing label that can severely restrict the autonomy of the patient. Citing an instance in which a participant in a phase 1 clinical trial for an experimental AD preventive vaccine developed meningoencephalitis, the authors invoke the guiding principle of nonmaleficence [6]. As in other areas of medicine where disease-modifying treatments are more readily available, physicians will need to balance the positive effects of future AD treatments against the possible side effects and treatment costs for patients.

In the absence of disease-modifying therapies and in light of the devastating meaning of a diagnosis for patients and families, the benefits of early diagnosis of AD can seem paltry at best. An unambiguous and early diagnosis of dementia can be framed as an opportunity for patients and families to plan for the future in an informed manner. Following this line of reasoning, the knowledge of future cognitive decline enables individuals to set up systems and coping strategies that will support them when they have lost their ability to be competent decision makers. Patients can draw up their wills, arrange for advance directives, and make their wishes known. The authors also argue that investigations aiming at an early diagnosis may lead physicians to uncover other treatable causes of cognitive dysfunction, such as depression and hypothyroidism. Thus, the major benefits of early diagnosis generally fall under the rubric of facilitating advanced planning among patients and families.

In considering the possible benefits of early diagnosis, Mattsson et al. arrive at the most intriguing aspect of their paper: a consideration of decision-making competence and hypothetical consent in the setting of AD. Alzheimer disease strips away an individual's identity, recklessly dissolving memories and fundamentally altering emotional and behavioral traits over its long and insidious course. The ravaging, personality-altering effects of neurodegenerative disease pose a problem for individuals who have been diagnosed at a preclinical stage and who are faced with the challenge of making decisions for their future selves. Given that an accurate, preclinical diagnosis of AD spells a future loss of cognitive function, how can and should these individuals plan for their future well-being?

The authors point out that the notion of "psychological continuity" has been considered a foundational aspect of personal identity ever since the writings of John Locke. The belief that we will be fundamentally unchanged in the future—that our present self can reliably predict what will be "best" for our future self—enables us to plan for the future. An early diagnosis of AD challenges this notion by revealing that our future selves may in fact be quite different from our present selves.

The ethical challenges surrounding decision-making capacity in the context of neurodegenerative disease are far from new, but the authors rightfully argue that these issues are increasingly relevant in light of the current focus on preclinical diagnosis. Since the ability to draw up an advanced treatment directive while still cognitively intact is touted as a potential benefit of the early diagnosis of AD, it is important to examine these tools critically. Advance directives, documents in which patients spell out their future treatment preferences or designate a particular family member or trusted person to act as a future decision maker, rest on the principle of respecting individual patient autonomy (in this case, future-oriented autonomy) [7].

But it is possible to imagine a situation in which individuals specify certain treatment preferences in the present that come into conflict with their welfare in the future. This is particularly possible in the case of the early diagnosis of AD, in which there may be a period of several decades between an individual's diagnosis and the onset of clinical symptoms. How should health care professionals act when an individual's future-oriented autonomy, spelled out in a document that was drawn up at an earlier time, demands administration of a treatment that would be considered inhumane in the present moment? Scholars are split on this question, and Mattsson et al. explicitly state that they "offer no solutions to these problems" [8].

While the ethical challenges surrounding the early diagnosis of AD are daunting to patients, caregivers, and physicians, the prevailing trend towards early diagnosis suggests that this is not an issue that is likely to go away. Many studies point to the difficulty clinicians face in "breaking the news" about a diagnosis of dementia, particularly in the pressured environment of many office practices and hospitals [9]. However, as signified by the recent amendments to the Alzheimer's Association's diagnostic criteria for AD, it is clear that physicians and professional organizations must devote considerable resources and specific training to ensure that clinicians are confident and compassionate in the diagnosis and management of AD, particularly in the context of early diagnosis.

The advent of disease-modifying treatments for AD will substantially alter the meaning of a diagnosis of dementia, moving it into the domain of potentially treatable illnesses. In the meantime, clinicians will be well served by paying attention to many of the central considerations raised by Mattsson et al.: a balanced view of the potential benefits and drawbacks to an early diagnosis of AD, an awareness of the conflict between respect for future-oriented autonomy and future welfare in the context of neurodegenerative disease, and, most importantly, an abiding respect for the powerful and life-altering effects of these diagnoses.

References

- 1. Virtual Mentor, following The Chicago Manual of Style, uses the term "Alzheimer disease"; the Alzheimer's Association uses the possessive form.
- 2. McKhann GM, Knopman DS, Chertkow H, et al. The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement. 2011;7(3):263-269.
- 3. Hansson O, Zetterberg H, Buchhave P, Londos E, Blennow K, Minthon L. Association between CSF biomarkers and incipient Alzheimer's disease in patients with mild cognitive impairment: a follow-up study. Lancet Neurol. 2006;5(3):228-234.
- 4. Andreasen N, Minthon L, Davidsson P, et al. Evaluation of CSF-tau and CSF-Abeta42 as diagnostic markers for Alzheimer disease in clinical practice. Arch Neurol. 2001;58(3):373-379.
- 5. Herskovits AZ, Growdon JH. Sharpen that needle. *Arch Neurol*. 2010;67(8):918-920.
- 6. Bayer AJ, Bullock R, Jones RW, et al. Evaluation of the safety and immunogenicity of synthetic Aβ42 (AN1792) in patients with AD. Neurology. 2005;64(1):94-101.
- 7. Dresser RS. Treatment decisions for incapacitated patients. In: Ashcroft RE, Dawson A, Draper H, eds. Principles of Healthcare Ethics. 2nd ed. Chichester, England: John Wiley & Sons, Ltd; 2007: 305-310.
- 8. Mattsson N, Brax D, Zetterberg H. To know or not to know: ethical issues related to early diagnosis of Alzheimer's disease. Int J Alzheimers Dis. 2010. http://www.hindawi.com/journals/ijad/2010/841941/. Accessed November 16, 2011.
- 9. Karnieli-Miller O, Werner P, Aharon-Peretz J, Eidelman S. Dilemmas in the (un)veiling of the diagnosis of Alzheimer's disease: walking an ethical and professional tight rope. Patient Educ Couns. 2007;67(3):307-314.

Matthew E. Growdon is a second-year medical student at Harvard Medical School in Boston. Prior to medical school, he was a research coordinator for projects on Alzheimer disease and frontotemporal dementia at the UCSF Memory and Aging Center in San Francisco. His interests include behavioral neurology and the history of medicine. He received a BA in history and literature from Harvard University in 2007.

Related in VM

When Diagnosis is a Double-Edged Sword, December 2011

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 873-879.

STATE OF THE ART AND SCIENCE

Patient-Centered Revisions to the DSM-5

Emily A. Kuhl, PhD, David J. Kupfer, MD, and Darrel A. Regier, MD, MPH

The forthcoming fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5 [1]) will mark the first time in nearly 2 decades that the field has overhauled the way mental illnesses are diagnosed and classified. Anticipation of the DSM-5 has been high, and recent discussions about changes likely to be adopted have focused largely on the manual's increased integration of scientific and clinical evidence in support of proposed revisions [2, 3]. An equally important, though perhaps less frequently heard, voice in this dialogue concerns the potential ethical consequences of the DSM-5's draft revisions.

The therapeutic alliance between psychiatrist and patient is unique and requires constant vigilance on ethical matters of self-harm or harm to others, confidentiality, legal aspects of diagnosis and treatment (e.g., competency), patient autonomy, involvement of third parties, dual agency and dual relationships, and patient stigma. This last issue is of particular concern; perhaps more so than in any other area of medicine, stigma has become a routine aspect of the lived experience for many people with mental illnesses.

While the empirical basis of proposed changes to the DSM-5 have been discussed elsewhere [2-4], ethical considerations deserve increased attention. Members of the DSM-5 work groups have discussed the consequences of adopting (or not adopting) changes to the DSM concerning public perception, the likelihood of misdiagnosis, the social and cultural implications of having a mental disorder, the impact of diagnostic criteria on treatment access, and more. Hence, attention to ethical circumstances like patient stigma, the pathologizing of normal behavior, and an increased need for patient involvement in the manual's development are reflected in the proposed changes.

Reducing Patient Stigma

Compared to its understanding of general medical illnesses, the public's understanding of and attitudes about mental illnesses are relatively poor, which contributes to patients' experience of stigma. Members of the DSM-5 work groups have drafted revisions that aim to reduce stigma not only directly (e.g., revising diagnostic labels that have pejorative connotations) but also indirectly, by suggesting changes that will improve medicine's understanding of what psychiatric disorders are and how to diagnose them correctly. Such increased clarity begets the development of more effective pharmacotherapies and psychosocial interventions, as

well as a refined research base of etiological and underlying risk and prognostic factors from neuroscience, neuroimaging, and genetics.

One of the more highly praised aspects of the revisions is the extent to which the manual is grounded in the latest science. Draft diagnostic criteria were developed from extensive literature reviews and secondary data analyses to ensure that proposed changes have a clearly defined and defendable empirical basis. Consultation was also sought from experts in mental health as well as social work, neurology, pediatrics, forensics, and beyond.

By providing a compendium of criteria that universally reflect the most advanced findings from science and medicine, the *DSM-5* arms clinicians to make more accurate diagnoses. Side effects of medications may make patients with certain diagnoses more identifiable to others as having a mental illness, but the adoption of scientifically valid diagnoses may encourage the development of a new generation of psychotropic drugs with, perhaps, fewer side effects and greater efficacy in symptom reduction. Furthermore, improved diagnostic assessments are important in the development and implementation of specific psychotherapies in numerous psychiatric disorders. Finally, the stronger evidence base allows clinicians in training to be better educated about what mental disorders are, how to identify them, and how best to treat them, which also benefits research, industry, and policy.

But what does a stronger scientific foundation mean for patients? Does empirical rigor equal less stigmatization? Not entirely; stigma is a complex phenomenon with numerous sociocultural contributors. But increased awareness—among patients themselves, patients' families and support systems, the health care system, and even the general public—is perhaps our greatest weapon against stigma. Empirical research helps the field better clarify what psychiatric disorders are, how to correctly detect them, and, subsequently, how best to treat them. In this manner, science can serve to combat misperceptions that patients with mental illnesses are dangerous, "strange," incapable, or otherwise insignificant as human beings.

The *DSM-5* work groups have also put forth proposals to address patient stigma issues head-on, particularly through changes in diagnostic labels. The Neurodevelopmental Disorders Work Group has suggested renaming mental retardation "intellectual developmental disorder" partly to bring greater consistency between the *DSM* and the terminology used by the American Association for Intellectual and Developmental Disability. But the work group members were also influenced by recognition that the term "retardation" is often used disparagingly in the American lexicon.

Similarly, extensive analyses of existing literature and previously collected data led the Substance Use Disorders Work Group to propose removal of the term "dependence" from their set of disorders. Used accurately, "dependence" refers to physical dependence, including normal biological reactions of tolerance and withdrawal to, for example, opiate-based prescription medications or even certain

antidepressants. But the labels "dependence" or "drug-dependent" are often interpreted by the public and many in the medical profession as derogatory and implying substance misuse and abuse. So the work group has proposed that the diagnosis of substance dependence be combined with substance abuse to form a single diagnosis called substance use disorder. Elimination of the term "dependence" from the formal diagnosis is considered a step forward in reducing misperceptions of what substance dependence truly means.

Medicalizing Normal Variation?

Among the more prominent criticisms of the *DSM-5* is that of its potential to pathologize normal human experiences. It is understandable that critics would question the DSM's sensitivity to the medicalization of human behaviors and emotions, especially given psychiatry's somewhat checkered early history. However, members of the DSM-5 work groups have made concerted efforts to assess the possible effect of proposed changes on prevalence rates and the potential public health fallout of excluding existing diagnoses and including novel diagnoses, like Internet addiction and hypersexual disorder. For example, although its inclusion could yield greater research and treatment, some have complained that the proposal to include premenstrual dysphoric disorder as a new psychiatric diagnosis demonstrates that the field is placing a mental health label on a normal variation of biological experience. However, work group members have reiterated that diagnosis would require symptoms to be severe enough to cause distress or to disrupt functioning. Further, epidemiological and clinical data indicate that women with this condition exhibit a distinct pattern and severity of symptoms that differs from those of other mood disorders and those more commonly experienced by women before or during their menstrual cycles. Inclusion in the DSM-5 may afford women with the premenstrual dysphoric disorder diagnosis better access to treatment.

In another notable proposal, the Mood Disorders Work Group suggested that the bereavement exclusion be removed from the diagnosis of major depressive disorder. This exclusion holds that it is normal for a person in mourning to exhibit depressive symptoms and therefore such people should not be diagnosed with depression. The suggestion has drawn ire from those who claim that the experience of intense, entrenched sadness following the death of a loved one (an experience that is felt to be normal and expected in our society) should not be considered the same as clinical depression—i.e., that the exclusion should remain.

Neglected in this argument are the findings from large-scale clinical and epidemiological studies that clearly demarcate a difference between bereaved people who exhibit major depressive disorder-like symptoms and bereaved people who simply experience grief. Moreover, depression that arises in the context of bereavement appears to be nearly identical to major depressive disorder resulting from other significant psychosocial stressors, like job or relationship loss. For the bereaved person whose symptoms mirror clinical depression, diagnosis can mean access to treatment and a better, faster chance for recovery. And because the symptoms may include suicidal ideation, access to services is vital.

In a more general sense, the *DSM-5* will seek to avoid overpathologizing by more actively addressing contextual issues—such as explicating the effects of age, gender, and culture on symptomatology—that may counter, mitigate or, in some cases, confirm the diagnosis of mental disorder. For instance, the diagnostic criteria for attention deficit/hyperactivity disorder provide examples of how symptoms may manifest differentially in older adolescents and adults than in children. Where available, text within each diagnostic chapter also contains important descriptive information about gender, culture, age, functional consequences, associated features, and more. Cumulatively, these details will provide a clearer picture of psychiatric diagnoses and help clinicians better understand and interpret patients' symptoms to narrow the likelihood of improper diagnosis.

Greater Patient Involvement

Ensuring high-quality care is an ethical imperative, and one of the most innovative and anticipated proposed changes to the DSM-5—the integration of dimensional assessments and patient- and clinician-completed questionnaires on symptoms and functioning with the current categorical classification—could improve the quality of care by offering a greater opportunity for patients to actively participate in their own diagnosis and treatment planning. Psychiatric disorders frequently occur in patterns or clusters (e.g., depression with anxiety, and vice versa), and diagnoses are often unstable and change over the course of a patient's lifetime. These can make determining the thresholds that separate clinical from nonclinical conditions perplexing at best and near-impossible at worst. Patterns of excessive comorbidities also suggest the presence of a complex genetic or neurobiological underpinning to many if not most disorders, which belies the neat, clean boundaries implied by the DSM-IV's categorical system. Supplementing binary diagnostic categories (in which the diagnosis is either present or absent) with dimensional quantitative rating scales (in which symptoms are measured along a continuum) will better capture the nuances of mental illnesses, including co-occurring conditions and disease severity, and could result in earlier, more accurate identification of psychiatric illness and provision of care.

How do patients themselves fit in with this new integration? The inclusion of diagnostic dimensions across the manual would be effected through patient-reported measures, like the Nine-Item Patient Health Questionnaire for depression, which have been long supported by clinical research yet remain noticeably absent from routine clinical practice. Patient-completed measures not only contribute a quantifiable aspect to psychiatric diagnosis, tracking of illness course, and treatment planning, they encourage solicitation of patients' perceptions of symptoms, functioning, health status, and treatment that are free of interpretation (or misinterpretation) by the clinician.

The broadest dimension proposed for the *DSM-5* is cross-cutting assessments—psychiatry's version of general medicine's "review of systems"—that call attention to areas of functioning likely to "cut across" diagnostic boundaries (e.g., mood, anxiety, cognitive status, sleep, psychotic symptoms, suicidal ideation) and may be

of clinical relevance. Items endorsed on this "review of systems" would trigger more specific assessments. A patient who indicates that she has been experiencing moderately depressed mood for the past 2 weeks, for instance, would be given a corresponding assessment for depression (in the case of the DSM-5, the depression module from the National Institute of Health's Patient Reported Outcome Measurement Information System [PROMIS] initiative).

Many of the proposed dimensional assessments for the DSM-5 are drawn from existing tools (e.g., PROMIS measures) while others were generated by the DSM-5 work groups based on findings from the literature. These measures are not intended to be screens that take the place of categorical diagnoses but to be supplements that bring attention to areas of treatment need, subthreshold conditions, and co-occurring symptoms that might impact prognosis.

A second type of proposed assessment is aimed at helping clinicians document clinical change within each individual disorder. These diagnosis-specific severity measures are rated on a quantitative scale, though the scales themselves are not universal in content or format: some measures rate illness severity based on symptom count, while others use such ratings as symptom frequency, duration, or intensity. All severity measures, regardless of their quantitative approach, are designed to help clinicians track course of illness and response to treatment.

Dimensional approaches have also been embedded in the criteria themselves of select disorders, most apparent in the proposed revisions to the diagnosis and classification of personality disorders [5, 6]. The current model of personality disorders requires clinicians to fit patients into specific personality disorder types (i.e., categories) while individuals who present with personality-related dysfunction but do not meet strict criteria for an existing personality disorder are given a diagnosis of personality disorder not otherwise specified (NOS)—a vague distinction that does little to help clinicians (or patients) understand their constellation of symptoms and how best to treat them. Furthermore, personality disorders in the DSM-IV have arbitrary threshold cut points and, over long periods of time, patients may not consistently meet criteria for diagnosis.

Members of the Personality Disorders Work Group have proposed a hybrid approach that uses separate dimensional ratings of core aspects of personality functioning (of self and, interpersonally, with others) and personality traits, which map onto explicit personality types and allow clinicians to make categorical determinations of diagnosis (e.g., is a personality disorder present? yes or no?) while recognizing the continuous and heterogeneous nature of personality dysfunction.

In place of the current personality disorder NOS diagnosis, the work group has proposed a new disorder, "personality disorder trait specified," wherein clinicians can diagnose patients who meet the general criteria for a personality disorder but whose traits do not match onto any of the six defined personality disorder prototypes (e.g., borderline personality disorder, antisocial personality disorder, narcissistic

personality disorder, avoidant personality disorder, obsessive compulsive personality disorder, and schizotypal personality disorder). Theoretically, this would allow psychiatrists to document limitless variations in personality by providing dimensional ratings of personality traits, domains, and facets; this level of specificity should make a designation of personality disorder trait specified more clinically meaningful than the *DSM-IV*'s personality disorder NOS in terms of better understanding patients' symptom presentations and treatment needs.

Lastly, it is worth noting that this is the first time in the manual's history that revisions to psychiatric diagnoses and their classification are being integrated with patient and public input. Over the past 2 years, the American Psychiatric Association has twice solicited comments, questions, and concerns about proposed revisions to the *DSM-5* from patients, their loved ones, and the general public through the APA's *DSM-5* web site (www.dsm5.org). The initial commenting period (February-April 2010) garnered more than 8,000 comments and questions from Web site visitors, and a second commenting phase (May-July 2011) produced approximately 2,000 responses—all of which were systematically reviewed by the respective work groups and considered in their decision making about proposed revisions.

Feedback played a central role in subsequent revisions, such as the decision by the Child and Adolescent Disorders Work Group to revise the terminology for temper dysregulation disorder with dysphoria (currently proposed as disruptive mood dysregulation disorder), and the Sexual and Gender Identity Disorders Work Group clarifying the criteria for nearly all of the disorders in the paraphilias chapter. Given the high utility of patient and public feedback in drafting revisions thus far, a third open commenting period has been scheduled to take place in 2012, following completion of the *DSM-5* field trials.

What Lies Ahead?

The degree to which the DSM-5 will adopt proposed changes is unknown at this time. Much of the decision making will be predicated on outcomes from the DSM-5 field trials [7], which are testing draft revisions—including those to diagnostic criteria, as well as proposals for dimensional assessments and severity ratings—in large-scale medical-research settings and in smaller, routine clinical care settings. Although field trial analyses will provide some immediate answers about whether the diagnostic criteria and dimensional changes are reliable, useful, and feasible, questions about changes in prevalence, impact on clinical research (including drug development), public health implications, and patient perceptions will require greater scrutiny once the manual is released and can be studied in larger community and clinical populations. In this respect, assessment of the DSM-5's ultimate impact on patients will be an ongoing endeavor, just as the manual itself will be continuously updated in concert with advances in the mental health field and likely in more frequent iterations than before. With each revision, we expect to move closer to a diagnostic and classification system that reflects the science of psychiatry with the same authenticity with which it reflects the needs of the people it serves.

References

- 1. The American Psychiatric Association has changed its abbreviation system for the fifth edition of the manual.
- 2. Kupfer DJ, Regier DA. Neuroscience, clinical evidence, and the future of psychiatric classification in DSM-5. Am J Psychiatry. 2011;168(7):672-674.
- 3. Regier DA, Kuhl EA, Narrow WE, Kupfer DJ. Research planning for the future of psychiatric diagnosis. Eur Psychiatry. 2011 Jun 13. [Epub ahead of print]
- 4. Regier DA, Narrow WE, Kuhl EA, Kupfer DJ. The conceptual development of DSM-V. Am J Psychiatry. 2009;166(6):645-650.
- 5. Krueger RF, Eaton NR, Clark LA, et al. Deriving an empirical structure of personality pathology for DSM-5. J Pers Disord. 2011;25(2):170-191.
- 6. Skodol AE, Bender DS, Morey LC, et al. Personality disorder types proposed for DSM-5. J Pers Disord. 2011;25(2):136-169.
- 7. Kraemer HC, Kupfer DJ, Narrow WE, Clarke DE, Regier DA. Moving toward DSM-5: the field trials. Am J Psychiatry. 2010;167(10):1158-1160.

Emily A. Kuhl, PhD, is a science writer for the American Psychiatric Association's Division of Research and the American Psychiatric Institute for Research and Education in Arlington, Virginia.

David J. Kupfer, MD, is chair of the DSM-5 Task Force. He is also a professor of psychiatry and a professor of neuroscience and clinical and translational science at the University of Pittsburgh Medical Center in Pennsylvania.

Darrel A. Regier, MD, MPH, is vice chair of the DSM-5 Task Force. He is also director of the American Psychiatric Association's Division of Research and the American Psychiatric Institute for Research and Education in Arlington, Virginia.

Related in VM

Proposed DSM-5 Revisions to Sexual and Gender Identity Disorder Criteria, August 2010

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12:880-884.

STATE OF THE ART AND SCIENCE Challenging Diagnoses

Barry DeCoster, PhD

Originally, I thought about calling this article something like, "Why I No Longer Watch *House, MD*." My partner got me started on this show, convincing me that as someone with an interest in medicine and health care ethics it would be part of my homework in developing cultural references. Once I realized the show was modeled on the Sherlock Holmes-type deductive mystery—rather than, say, being an accurate portrayal of medicine, or the complicated moral dilemmas raised daily in a hospital—I could tolerate it better. Still, it's the repeated abuse of a recurring character—the diagnostic procedure—that keeps me from watching on a regular basis.

The method behind the differential diagnosis procedure (DD) is common knowledge within medical school. In *House, MD*, the DD is a prominent character, one that is created, allowed to fail repeatedly, and eventually saves the day in the last 5 minutes. (Well, at least, most of the time.) The DD begins with taking a patient's history and observing symptoms. Possible diagnoses are considered, while other possibilities are simultaneously ruled out. After compiling the list of possible causes, one can determine appropriate testing, based on urgency and likelihood. (Here enters the often repeated maxim, "When you hear hoof beats, think horses, not zebras.") One might test for competing diagnoses based on their respective likelihood or urgency, but in the end the DD is a *tool* of medicine. Its purpose is to make providing medical care easier and more consistent and to allow the patient to receive better care.

I won't extol here the virtues of developing good diagnostic skills, which is a significant portion of what is developed in medical education and enculturation. As physicians develop the skill of clinical judgment, Kathryn Montgomery writes, they must "know the rules [of medicine] and when to break them, how to use logic and when to ignore its conclusions. Putting it all together, they must decide whether to refer the patient for further tests and with what sort of expectation" [1]. The DD is not an equation into which a physician enters the proper symptomatic data; using the DD is part of a clinical judgment that needs to be crafted and refined over time and with experience.

What I want to discuss here are some of the problems that often result in using the DD without proper reflection. I take these harms to be typically unintentional and frequently underdiscussed. These harms can influence the lives of both patients and physicians. (To continue an earlier metaphor: we might examine whether and how the terrain has been disturbed after the hoof beats pass.)

Diagnosis and the Unexplained: The Harm to Patients

The decision-tree approach to differential diagnosis works rather well, allowing physicians to move from observed symptoms to limiting causal lines to the eventual diagnosis. Much of the time, this works well. But here, I'd like to complicate the process of diagnosis in a number of ways. First, it's important to consider that, despite the enormous success of the practice of medicine, significant gaps remain. For instance, by some estimates, for 20-40 percent of medical cases, no proper diagnosis or causal story is ever developed [2]. Although these cases may be untreated (or forced into one diagnostic category or another), they typically resolve. (Given Dr. House's faith in the scientific aspects of medicine, the failure to diagnose is more often treated as a failure of the physician, rather than an honest limitation to the practice of medicine.)

An important portion of these undiagnosed cases will continue as chronic illness. Kirsti Malterud describes medically unexplained disorders as "chronic and disabling conditions, presenting with extensive subjective symptoms, although objective findings or causal explanations are lacking" [3]. Common examples might be fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, or temporomandibular joint disorder (TMJ). Similarly, other physicians speak of medically unexplained symptoms [4] or somatization syndromes. Diagnosis and care remain complicated, since both physicians and patients are uncertain about the facts of the case or the best plan of treatment [5].

The problem for women [6], especially, is that the DD frequently erases their experience of suffering. Because etiology is unknown (or deeply contested), the diagnostic process often fails to categorize their suffering properly. Patients may receive multiple and conflicting diagnoses from specialists. Other patients are told the lack of clear physical causes points to a psychological origin for their suffering, that it is imagined, or that they are lying [7].

What follows when a clear cause is unknown? Here are a few suggestions of what to avoid in your thinking. First, just because a clear cause has not been identified does not mean that a cause does not exist or that it will never be discovered. Second, a lack of clear physical etiology is not, in itself, proof that the patient's suffering has psychological origins (i.e., that the source of suffering is "all in the patient's head"). Finally, many patients with chronic pain conditions report they are no longer seeking a cure. Instead, they are seeking a trusting relationship with a physician who takes their suffering seriously and is willing to continue to explore ways to lessen it. This openness to reconsidering diagnosis is more appropriate than the blind faith in the DD as a tool of certainty.

Physicians Can Be Harmed, Too

Physicians, too, may suffer a kind of moral harm from relying on an inadequate notion of the DD. In diagnosis, physicians need to adopt a certain attitude, one I've been thinking of as being "tolerantly open." So, what does this mean? It's a certain stance one can take in understanding diagnosis, in how to approach the world.

Physicians using the DD tool are often swept up into thinking that the diagnosis developed is certain and correct [8]. Realize, though, both the DD tool and categories of disease are human creations.

What does it mean to consider diseases as human constructions, rather than some purely objective discovery of the natural world? To preempt some readers' worries that this as the theory-speak of a philosopher, a few examples may help me make my point.

Consider the disease "osteopenia," or the thinning of bone that comes prior to osteoporosis. Its diagnostic criteria were largely settled in 1992 by experts on osteoporosis [9]. For many women (across a range of ages), osteopenia has caused a lingering worry that their bones are more likely to fracture [10], not to mention the specter of costly drug treatments. Here's one of the important things to keep in mind both about this disease and the process of diagnosing it: the specific boundaries between normal bone density, osteopenia, and osteoporosis were developed by committee. As Alix Spiegel reports, "So there in the hotel room someone literally stood up, drew a line through a graph depicting diminishing bone density and decreed: Every woman on one side of this line has a disease" [9]. It was not exactly a random determination, but there wasn't an objective reason why the line was drawn there (rather than a bit higher or lower). Notice, this also means thousands (and eventually, millions) of women will be diagnosed with osteopenia, while, if the criterion had been more restrictive, they would have continued to be seen as healthy and normal.

Consider another example: for much of medicine's history, homosexuality was considered to be a disease state. In 1973, the American Psychiatric Association (APA) ceased to recognize homosexuality as a disease and removed it from the Diagnostic and Statistical Manual of Mental Disorders (DSM). So, we should ask, well, what changed? Homosexuality didn't change that year, so why the removal from the manual? The story is complicated, so here are a few threads to keep in mind. The DSM has always been created by committees of experts. As we know, though, experts are slow to change. It was through the social and strategic activities of gay and lesbian psychologists and therapists who were working in complicated networks in the APA—not on better or newer scientific research—that homosexuality eventually was removed from the DSM [11]. Perhaps for some, this idea seems archaic, a throwback to a long-ago prejudice. But for many, this has changed in our lifetime. The removal was monumental in allowing gays and lesbians (therapists and lay folks) to live open lives, not to have to shoulder the unnecessary burden of a clinical diagnosis. The liberating change, though, was only possible because certain psychiatrists (conservative and liberal) remained open to reconsidering their diagnostic categories and criteria—things they once took as certain and obvious.

Again, diagnostic categories and the DD are not objective reflections of the world. They are human-created tools, and they can have unintentional consequences. While

Dr. House might see the humanity in medicine as a scientific failing, I continue to see hope. In cultivating the ability to be tolerantly open, physicians can continue to use the DD while remaining aware that they may at times need to revisit and reevaluate their diagnostic categories and procedures.

When it comes to my own TV viewing habits, though, it seems unlikely I'll reconsider allowing Dr. House back into my life. And let's face it: if he did cultivate his own tolerant openness, it would make him a better doctor...but also a less interesting medical detective.

References

- 1. Montgomery K. How Doctors Think: Clinical Judgment and the Practice of Medicine. New York: Oxford University Press; 2005: 85.
- 2. Nettleton S, Watt I, O'Malley L, Duffey P. Understanding the narratives of people who live with medically unexplained illness. Patient Educ Couns. 2005;56(2) 205-210.
- 3. Malterud K. Symptoms as a source of medical knowledge: understanding medically unexplained disorders in women. Fam Med. 2000;32(9):604.
- 4. Smith RC, Lyles JS, Gardiner JC, et al. Primary care clinicians treat patients with medically unexplained symptoms: a randomized controlled trial. J Gen Intern Med. 2006;21(7):671-677.
- 5. Barsky AJ, Borus JF. Somatization and medicalization in the era of managed care. JAMA. 1995;274(24):1931-1934.
- 6. In saying "women" here, I do not want to imply that men cannot become ill with these symptoms. Instead, it is to highlight the fact that medically unexplained disorders are importantly gendered. Women are more frequently diagnosed than are men.
- 7. DeCoster B. Lying reconsidered: a gendered history of conversion disorders and the erosion of patients' agency. AJOB Neuroscience. 2010;1(1):67-68.
- 8. For a richer and longer discussion about why the search for certainty in medicine is misguided—albeit a common goal—I would direct readers to Montgomery's How Doctors Think.
- 9. Spiegel A. How a bone disease grew to fit the prescription. National Public Radio. http://www.npr.org/templates/story/story.php?storyId=121609815&sc=emaf. Accessed November 16, 2011.
- 10. Valentine V. Gwyneth Paltrow, NPR has some news for you and your bones. Shots. National Public Radio. http://www.npr.org/blogs/health/2010/08/19/129303014/gwyneth-paltrownpr-has-some-news-for-you-and-your-bones. Accessed November 16, 2011.
- 11. 81 words. This American Life. National Public Radio. http://www.thisamericanlife.org/radio-archives/episode/204/81-words. Accessed November 16, 2011.

Barry DeCoster, PhD, is a visiting instructor of history, philosophy, and sociology of science at Lyman Briggs College of Michigan State University in East Lansing. His research in philosophy focuses on problems in health care ethics and the philosophies of science and medicine. He is working on a project analyzing what count as "good" medical explanations of disease, including looking into the complications surrounding medically unexplained disorders (e.g., fibromyalgia and chronic fatigue syndrome).

Related in VM

Why Has Evidence of Error-Filled Diagnostic Medicine Not Led Changes Within the Profession? November 2007

Medical Education and Decision-Support Systems, March 2011

Gender Stereotypes in Pain Diagnosis, July 2008

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

Virtual Mentor

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 885-889.

HEALTH LAW

A Physician's Guide to Social Security Disability Determinations Valarie Blake, JD, MA

The pen is famously mightier than the sword [1]. For physicians—especially the non-sword-wielding sort—this appears to be true. The words doctors write with their pens can have far-reaching consequences, particularly legal ones, for their patients. Matters of competency, guardianship, and disability all hinge on physicians' diagnoses. Physicians may feel intimidated by the consequences their diagnoses can have in the courtroom, particularly if they are not aware of the wider legal frameworks in which their work plays a role. This article will help physicians better understand the power of diagnosis in one area where their counsel is often sought social security disability determination. It will briefly review the history of social security benefits, explain how an individual qualifies for disability benefits, and explore the physician's role in this process.

Social Security Disability History in America

The first full-fledged attempt at providing disability benefits began during the Civil War in response to the needs of hundreds of thousands of wounded soldiers [2]. This was followed up with a disability insurance program in 1954 which, in 1960, President Eisenhower expanded to cover all Americans with disabilities and their dependents [2]. In 1960, 559,000 people were receiving these benefits, with an average benefit being worth \$80 a month [2]. By 2009, the number had risen to 9.7 million [3].

The SSA Definition of Disability

The Social Security Administration (SSA) defines disability as the "inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months" [4]. Children are disabled if they have "any medically determinable physical or mental impairment or combination of impairments that caused marked and severe functional limitations, and that can be expected to last for a continuous period of not less than 12 months" [4].

There are two types of disability benefit programs in the United States. Social Security Disability Insurance (SSDI) recipients have worked a certain length of time and within a recent duration, and they receive Medicare benefits after they have received SSDI for 24 months [4]. Social Security Income (SSI) is intended for those adults and children who have limited resources and little or no (recent) work history. These individuals generally qualify for Medicaid [4].

How is a Disability Determined?

Disability is determined by five criteria, many of which are medical.

- (1) The individual must not earn more than \$1,000 a month in wages [5].
- (2) The health condition must be "severe" and must interfere with "basic work-related activities" [5].
- (3) The individual must have either (a) a medical condition considered so severe that it is specifically listed in the Social Security Administration's disability manual or (b) of equal severity to one of those conditions [6]. Only if the individual does not meet this third requirement, then
- (4) the individual must be unable to do work he or she did previously and
- (5) must also be unable to adjust to other types of work [6].

The SSA publishes a listing of impairments that automatically qualify as disabilities (and thus satisfy the third criterion). These may change over time, with new medical information. There are separate lists for adults (Part A) [7] and children (Part B) [8], each broken down by bodily system. Cystic fibrosis is one example. Listed under respiratory disorders in Part A, cystic fibrosis automatically qualifies an individual as disabled if he or she can prove one or more of the following, all of which deal with specific medical measures taken by a physician:

(a) a forced expiratory volume (FEV) of a specific value dependent on height without shoes (with a chart provided), or (b) episodes of bronchitis or pneumonia or hemoptysis or respiratory failure, requiring physician intervention, occurring at least once every 2 months or at least six times a year. Each inpatient hospitalization for longer than 24 hours for treatment counts as two episodes, and an evaluation period of at least 12 consecutive months must be used to determine the frequency of episodes, or (c) persistent pulmonary infection accompanied by superimposed, recurrent, symptomatic episodes of increased bacterial infection occurring at least once every 6 months and requiring intravenous or nebulization antimicrobial therapy [9].

For a personality disorder, the individual must have both of the following.

(a) Deeply ingrained, maladaptive patterns of behavior associated with one of the following: seclusiveness or autistic thinking; or pathologically inappropriate suspiciousness or hostility; or oddities of thought, perception, speech and behavior; or persistent disturbances of mood or affect; or pathological dependence, passivity, or aggressivity; or intense and unstable interpersonal relationships and impulsive and damaging behavior. (b) Resulting in at least two of the following: marked restriction of activities of daily living; or marked difficulties in maintaining social functioning; or marked difficulties in maintaining concentration, persistence, or pace; or repeated episodes of decompensation, each of extended duration [10].

Both examples show how heavily medical expertise, medical testing, and medical specialty factor into a determination of a disability.

Individuals who do not qualify because of the type or severity of their ailment might qualify if they are precluded from performing past jobs and other future jobs (the fourth and fifth criteria) [6]. The SSA looks to work the individual did in the last 15 years that involved significant for-profit mental or physical labor [11]. If the individual is deemed unable to perform past jobs, then the SSA determines whether other jobs are possible, factoring in such information as medical conditions and age, education, past work experience, and any transferable job skills [11]. The agency explores job availability through the national, rather than local, economy. For example, if an individual can no longer be a mechanic but can be a factory worker, then the individual is not disabled because the national economy has factory-worker jobs (even if the individual's local economy does not).

Certain diseases are deemed so severe that disability benefits can be expedited and the individual can bypass many of the usual steps in procuring payments. These "compassionate allowances" include most cancers, Lou Gehrig's disease, and a host of other conditions [12].

The Physician's Roles in Determining Disabilities

Physicians may be involved in determination of SSI or SSDI eligibility on a number of levels. Foremost, those making the disability determination rely heavily on the medical chart and may even request that physicians write medical reports on the patients [4]. These reports should contain as much relevant objective evidence from the chart as possible, including medical history, clinical and laboratory findings, and diagnosis, treatment, and response to treatment [4]. Physicians should tailor the letter to the question of whether the patient can work or not, based on his or her condition. (Examples of sample reports are available [13, 14].) Physicians are paid a reasonable amount for medical reports to the SSA, which can be dictated by phone for convenience.

The treating physician's input is paramount in determining whether an individual is eligible for SSI or SSDI. Although an SSA-employed physician might examine the patient's chart, the treating physician alone performs an examination of the patient. If the SSA needs data the physician does not have, the physician can choose to perform the exam for a fee paid by SSA or can decline. If the physician does not have the resources or does not wish to provide the exam, the SSA can refer the patient for a "consultative examination" by another physician [4].

The SSA gives controlling weight to the physician's opinion on what work activities the individual can or cannot do as long as that opinion is "supported by clinical and laboratory findings and...not inconsistent with any other evidence in the patient's record" [4]. However, the determination of disability under the law ultimately depends on the SSA administration, after consideration of the physician's stance [4]. Physicians play other roles in SSA determinations besides being treating physicians. They may serve as independent consultants who perform examinations for SSI/SSDI determinations and may be members of state-based teams called disability determination services that hear and analyze disability cases [4].

Many physicians will become involved in SSA determinations at some level and some point in their careers. It is important that they understand and feel comfortable with the implications of diagnoses and other professional actions that have wider repercussions, particularly legal ones, for their patients.

References

- 1. Bulwer-Lytton E. Richelieu; Or the conspiracy. Act 2, scene 2.
- 2. US Social Security Administration. Historical background and development of Social Security. http://www.ssa.gov/history/briefhistory3.html. Accessed October 20, 2011.
- 3. Congressional Budget Office. Social Security Disability Insurance: participation trends and their fiscal implications. http://www.cbo.gov/ftpdocs/116xx/doc11673/07-22-SSDisabilityIns_Brief.pdf. Published July 22, 2010. Accessed October 20, 2011.
- 4. US Social Security Administration. Disability programs: answers for doctors and other health professionals. http://www.ssa.gov/disability/professionals/answers-pub042.htm. Accessed October 20, 2011.
- 5. US Social Security Administration. Disability planner: how we decide if you are disabled. http://www.ssa.gov/dibplan/dqualify5.htm. Accessed October 20, 2011.
- 6. US Social Security Administration. Disability planner: how we decide if you are disabled, continued. http://www.ssa.gov/dibplan/dqualify6.htm. Accessed October 20, 2011.
- 7. US Social Security Administration. Disability evaluation under Social Security: listing of impairments adult listings (part A). http://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm. Accessed October 20, 2011.
- 8. US Social Security Administration. Disability evaluation under Social Security: listing of impairments childhood listings (part B). http://www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm. Updated June 7, 2011. Accessed October 20, 2011.
- 9. US Social Security Administration. Disability evaluation under Social Security: 3.04 cystic fibrosis. http://www.ssa.gov/disability/professionals/bluebook/3.00-Respiratory-Adult.htm#3 04. Accessed October 20, 2011.
- US Social Security Administration. Disability evaluation under Social Security: 12.08 personality disorders. http://www.ssa.gov/disability/professionals/bluebook/12.00-MentalDisorders-Adult.htm#12_08. Accessed October 20, 2011.

- 11. US Social Security Administration. Information we need about your work and education. http://www.ssa.gov/disability/step4and5.htm#Q4_2. Accessed October 20, 2011.
- 12. US Social Security Administration. Complete list of compassionate allowances conditions. http://www.ssa.gov/compassionateallowances/conditions.htm. Accessed October 20, 2011
- 13. Casanova KS. How to apply for social security disability benefits if you have chronic fatigue syndrome, myalgic encephalopathy, and fibromyalgia. Massachusetts CFIDS/ME & FM Association; 2009. http://www.masscfids.org/pdf/handbook/Disability%20Handbook-Appendix%20II.pdf. Accessed October 20, 2011.
- 14. Social Security Disability physician sample letter. Benign Essential Blepharospasm Research Foundation. http://www.blepharospasm.org/disability6.html. Accessed October 20, 2011.

Valarie Blake, JD, MA, is a senior research associate for the American Medical Association Council on Ethical and Judicial Affairs in Chicago. Ms. Blake completed the Cleveland Fellowship in Advanced Bioethics, received her law degree with a certificate in health law and concentrations in bioethics and global health from the University of Pittsburgh School of Law, and obtained a master's degree in bioethics from Case Western Reserve University. Her research focuses on ethical and legal issues in assisted reproductive technology and reproductive tissue transplants, as well as regulatory issues in research ethics.

Related in VM

When Disability Is in Question, April 2003

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

Virtual Mentor

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 890-895.

POLICY FORUM

Medicalizing Obesity: Individual, Economic, and Medical Consequences George L. Blackburn, MD, PhD

Defining Medicalization

As Sadler and colleagues [1] define it, "'medicalization' describes a process by which human problems become defined and treated as medical problems" [2]. According to Conrad and colleagues [3], medicalization, like globalization or secularization, is neither good nor bad; it merely notes that a condition has come under medical jurisdiction. Others suggest that the term *does* imply something suspect—that a normal variation in health or behavior has been annexed, in whole or in part, by the apparatus of medicine [3].

The Medicalization of Obesity

Research published within the past few years suggests an explosion in the treatment of conditions that previously had been subjects of "watchful waiting" or nonpharmacologic approaches [4]. Examples of medicalized disorders include menopause, alcoholism, attention deficit hyperactivity disorder (ADHD), posttraumatic stress disorder (PTSD), anorexia, infertility, sleep disorders, and erectile dysfunction (ED) [3].

For example, morbid obesity, which requires surgical treatment, is already recognized as a disease. But medicalization may lower the threshold between what is held as "common" overweight and morbid obesity, increasing the number of people who are viewed as sick. Considering obesity as a disease may therefore have consequences for the individuals affected, society, and the health care system [5].

Effects on the Individual

Individuals hold some responsibility in the development of many conditions (e.g., high cholesterol, lung cancer, sports injuries), yet routinely receive medical treatment without being questioned about their lifestyles [5]. Discrimination against those with obesity, on the other hand, has been documented in many countries and in many areas of life, for example, work [6], relationships, health care [7], education, and the media [5, 8, 9].

Medicalization may reduce social discrimination by emphasizing that some of the causes of obesity are outside individual control [8]. Inasmuch as discrimination on the basis of disease or disability is considered unacceptable, medicalization may advance the rights of the obese [5]. It may also reduce stigma among health care professionals by changing views on etiology [5]. Physicians, who often share the

negative biases of society as a whole about obese patients [7, 10-12], usually consider the treatment of the causes of illness to be standard medical practice [5, 13].

While medicalization may bring benefits to obese individuals, it will also label all of them "sick," regardless of the rest of their health status [5]. In this way, it might be harmful to those who don't see themselves as ill or who don't try (or want) to lose weight [14]. However, when considered against the effects of widespread and welldocumented prejudice, stigmatization, and discrimination [15, 16], gains from the medicalization of obesity might offset potential harms [5].

This perspective is in agreement with the findings of a panel of obesity experts [17] who "concluded that considering obesity a disease is likely to have far more positive than negative consequences and to benefit the greater good" [18].

Implications for Treatment

This same panel also concluded that categorization of obesity as a disease by the federal government and the medical establishment could lead to a fundamental change in treatment paradigms and have a profound effect on the care of obese patients [17].

If the time and effort required to engage patients in treatment protocols were reflected in remuneration for doing so, clinicians would be far more likely to do so than they currently are [17]. If physicians routinely undertook treatment for obesity, the pharmaceutical industry would be more inclined to develop new and better obesity drugs, and the FDA would come under more pressure to approve them [17].

According to the panel, FDA guidelines for approval of obesity drugs might well be altered to give less importance to metabolic biomarkers (blood pressure, triglycerides, cholesterol) and more to the loss of adipose tissue itself or particular deposits of adipose tissue that have deleterious effects on many physiological functions [17].

Effects on Medical Education

Medicalization of obesity could have an effect on the education of physicians. Currently, the subject receives little time or attention in medical schools, and the time it does receive focuses on obesity as a lifestyle issue rather than a physiological problem [17]. A greater investment in obesity education would change physicians' attitudes towards the illness and how it is treated. Obesity surgery and medical approaches, especially drug therapy, would be given more attention by physicians, health administrators, health insurance companies, and employers, resulting in more access to quality care [17].

Economic and Policy Implications

These changes, however, could trigger a backlash, particularly if they led to more aggressive drug treatment. Some observers have raised concerns that medicalization is an overexpansion of medicine's domain and a mechanism by which the

pharmaceutical industry can increase markets, thus contributing to rising health care costs [3, 19, 20]. Future development of drugs for the treatment of obesity will be dependent on whether they can survive review for safety and effectiveness. The Food and Drug Administration continues to be highly concerned that proposed obesity drugs increase cardiovascular or other risks and may require changes to clinical research protocols [21].

Recent estimates put the cost of twelve medicalized conditions, for which medicalization has been documented and cost estimated, at \$77.1 billion in annual health care spending, or close to 4 percent of national health care expenditures [3]. This figure is greater than the estimated 3 percent spent on public health in 2005 [22], raising the question of whether such spending is appropriate. The finding also focuses attention on whether policies should be put in place to curb the growth, or even decrease the amount, of spending, on medicalized conditions [3].

In addition to increased cost, medicalized obesity might also encounter the same obstacles that addiction treatment has—lack of parity in payment—i.e., insurance coverage for the treatment of obesity not on a par with that for the care of other medical illnesses [23]. With addiction, the achievement of parity required congressional legislation as well as a paradigm shift in the understanding of addiction as a biological illness. It took many developments in science and policy changes by professional organizations and governmental entities to make that shift. And the changes have yet to bring addiction medicine fully into the mainstream of the nation's health care delivery system [23].

Access to adequate medical treatment for patients must acknowledge that this biological illness is widespread, that it is important that it be treated effectively, that appropriate third-party payment for physician-provided or physician-supervised addiction treatment is critical for addiction medicine to become part of the mainstream of our nation's health care delivery system, and that medical specialty care provides the most effective benefit to patients and therefore our society.

Obesity is one of the most deadly public health crises of the 21st century. Globally, at least 2.8 million adults die each year as a result of being overweight or obese [24]. In the United States, it's the second leading cause of preventable death, with an estimated \$147 billion in associated medical costs per year [25]. Still, questions surround its status as a disease.

At the recent United Nations high-level conference on noncommunicable diseases (NCDs), delegates recognized that many chronic disease risk factors were driven by obesity [26], but they failed to number it among four groups of NCDs—cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes—designated for development of action plans to combat them by 2012 [27].

In 2004, George Bray called obesity a chronic, relapsing neurochemical disease with an etiology and a pathogenesis [27]. In doing so, he medicalized it, putting it under

the purview of doctors and other health professionals to study, diagnose, prevent, or treat. Recently, the American Association of Clinical Endocrinologists (AACE) [25] did likewise, announcing that obesity is not just a condition, but a disease state. Prior to that statement, the group viewed it as "the consequence of consistently poor lifestyle choices" [25].

The AACE found that "sufficient evidence has accumulated to implicate a number of heterogeneous hormonal and regulatory disorders in the pathogenesis and progression of the obese state—enough to justify multiple therapeutic interventions, including nutritional, pharmacological, and surgical" [25].

The AACE has recognized the need to call obesity a disease. In 1987 a coauthor and I proposed that the goal of obesity treatment should be medically significant weight loss rather than "ideal body weight," changing the criteria for the treatment and diagnosis of obesity and substantially improving evaluation programs as well as patient outcomes [28]. In 1998, the National Heart, Lung, and Blood Institute guidelines established an initial goal for weight loss (the panel recommends the loss of 10 percent of baseline weight at a rate of 1 to 2 pounds per week and the establishment of an energy deficit of 500 to 1,000 kcal per day) [29]. And in 2004 Jeffrey Flier, now dean of the Harvard Medical School, described the pathophysiology of the disease of obesity, concluding that to cease the search for safe and effective medication would be to abandon a major segment of the population to an unhealthy fate [30]. Given the ever-rising costs associated the condition and its associated comorbidities, perhaps it's time for the rest of us to recognize obesity as a medical problem as well.

References

- 1. Sadler JZ, Jotterand F, Lee SC, Inrig S. Can medicalization be good? Situating medicalization within bioethics. Theor Med Bioeth. 2009;30(6):411-425.
- 2. Sadler, Jotterand, Lee, Inrig, 412.
- 3. Conrad P, Mackie T, Mehrotra A. Estimating the costs of medicalization. Soc Sci Med. 2010;70(12):1943-1947.
- 4. Fairman KA, Curtiss FR. Does medicalization of life imperil health? Expanding indications for diagnosis and treatment of chronic "disease". J Manag Care Pharm. 2011;17(6):469-480.
- 5. Saarni SI, Anttila H, Saarni SE, et al. Ethical issues of obesity surgery--a health technology assessment. Obes Surg. 2011;21(9):1469-1476.
- 6. Giel KE, Thiel A, Teufel M, Mayer J, Zipfel S. Weight bias in work settings a qualitative review. Obes Facts. 2010;3(1):33-40.
- 7. Cheskin LJ, Kahan S, Geller G. Weight-based stigma and physician bias. Virtual Mentor. 2010;12(4):258-262.
- 8. Puhl RM, Heuer CA. The stigma of obesity: a review and update. *Obesity* (Silver Spring). 2009;17(5):941-964.
- 9. Puhl R, Brownell KD. Bias, discrimination, and obesity. Obes Res. 2001;9(12):788-805.

- 10. Schwartz MB, Chambliss HO, Brownell KD, Blair SN, Billington C. Weight bias among health professionals specializing in obesity. *Obes Res.* 2003;11(9):1033-1039.
- 11. Huizinga MM, Cooper LA, Bleich SN, Clark JM, Beach MC. Physician respect for patients with obesity. *J Gen Intern Med.* 2009;24(11):1236-1239.
- 12. Hebl MR, Xu J. Weighing the care: physicians' reactions to the size of a patient. *Int J Obes Relat Metab Disord*. 2001;25(8):1246-1252.
- 13. Ogden J, Flanagan Z. Beliefs about the causes and solutions to obesity: a comparison of GPs and lay people. *Patient Educ Couns.* 2008;71(1):72-78.
- 14. de Vries J: The obesity epidemic: medical and ethical considerations. *Sci Eng Ethics*. 2007;13(1):55-67.
- 15. Ells LJ, Lang R, Shield JP, et al. Obesity and disability a short review. *Obes Rev.* 2006;7(4):341-345.
- 16. Atlantis E, Baker M. Obesity effects on depression: systematic review of epidemiological studies. *Int J Obes (Lond)*. 2008;32(6):881-891.
- 17. Allison DB, Downey M, Atkinson RL, et al. Obesity as a disease: a white paper on evidence and arguments commissioned by the Council of the Obesity Society. *Obesity (Silver Spring)*. 2008;16(6):1161-1177.
- 18. Allison, Downey, Atkinson, 1162.
- 19. Moynihan R, Cassels A. Selling Sickness: How the World's Biggest Pharmaceutical Companies Are Turning Us All into Patients. New York: Nation Books; 2005.
- 20. Moynihan R. Medicalization. A new deal on disease definition. *BMJ*. 2011;342:d2548.
- 21. Downey M, Still C, Sharma AM. Is there a path for approval of an antiobesity drug: what did the Sibutramine Cardiovascular Outcomes Trial find? *Curr Opin Endocrinol Diabetes Obes*. 2011;18(5):321-327.
- 22. Budetti PP. Market justice and US health care. JAMA. 2008;299(1):92-94.
- 23. Roy K, Miller M. Parity and the medicalization of addiction treatment. *J Psychoactive Drugs*. 2010;42(2):115-120.
- 24. World Health Organization. Obesity and overweight: fact sheet no. 311. http://www.who.int/mediacentre/factsheets/fs311/en/. Accessed October 2, 2011.
- 25. American Association of Clinical Endocrinologists (AACE) declares obesity a disease state [news release]. Jacksonville, FL: American Association of Clinical Endocrinologists (AACE); July 29, 2011. http://media.aace.com/article_display.cfm?article_id=5075. Accessed October 2, 2011.
- 26. Non-communicable diseases deemed development challenge of "epidemic proportions" in political declaration adopted during landmark General Assembly meeting [news release]. New York: United Nations; September 19, 2011. http://www.un.org/News/Press/docs/2011/ga11138.doc.htm. Accessed October 2, 2011.
- 27. Bray GA. Obesity is a chronic, relapsing neurochemical disease. *Int J Obes Relat Metab Disord.* 2004;28(1):34-38.

- 28. Blackburn GL, Kanders BS. Medical evaluation and treatment of the obese patient with cardiovascular disease. Am J Cardiol. 1987;60(12):55G-58G.
- 29. National Heart Lung and Blood Institute, National Institute of Diabetes and Digestive and Kidney Diseases. Clinical guidelines on the Identification, Evaluation, And Treatment of Overweight and Obesity in Adults: The Evidence Report. National Institutes of Health; 1998. http://www.nhlbi.nih.gov/guidelines/obesity/ob_gdlns.pdf. Accessed November 16, 2011.
- 30. Flier JS. Obesity wars: molecular progress confronts an expanding epidemic. Cell. 2004;116(2):337-350.

Further Reading

Rose N. Beyond medicalisation. *Lancet*. 2007;369(9562):700-702.

George L. Blackburn, MD, PhD, holds the S. Daniel Abraham Chair in Nutrition Medicine and is an associate professor of nutrition and associate director of nutrition in the Division of Nutrition at Harvard Medical School in Boston. He is also chief of the Nutrition/Metabolism Laboratory and director of the Center for the Study of Nutrition Medicine (CSNM) at Beth Israel Deaconess Medical Center in Boston. He graduated from the University of Kansas Medical School and earned his PhD in nutritional biochemistry from MIT. Dr. Blackburn has studied bionutrition, surgical metabolism and critical care medicine, best practice standards for weight loss surgery, and the neurobiology of food selection and dietary impulse control.

Related in VM

The Evolution of Addiction Medicine as a Medical Specialty, December 2011

A Disorder by Any Other Name: Excessive Computer Game Playing, January 2008

It Is Time for Obesity Medicine, April 2010

Applying the Principles of Professionalism to Preventing, Identifying, and Treating Obesity, April 2010

A Call for Collaborative Action against America's Greatest Health Threat, April 2010

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

Virtual Mentor

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 896-899.

MEDICINE AND SOCIETY

The Rise and Impending Fall of Diagnosis as a Marker of Difference Matt Lamkin, JD, MA

"So let's see if I have this right," one reader wrote in response to an ABC News report on selective eating disorder. "There is a genetic or neurological disorder that makes someone only eat grilled cheese sandwiches, french fries and waffles. Who knew?"

Although newly minted mental illnesses are often met with this kind of skepticism, medical diagnoses for human behaviors continue to proliferate. The criticism heaped on social anxiety disorder and ADHD diagnoses hasn't stopped doctors from writing millions of prescriptions for Paxil and Adderall or dissuaded psychiatrists from proposing new disorders—from picky eating and overuse of the Internet to hoarding and excessive shopping [1].

While critics often blame pharmaceutical companies for medicalizing disfavored features of the human condition, these companies are tilling fertile soil. As spiritual explanations for illness have given way to biological ones, there is increasing acceptance of the idea that biology determines not just the functioning of our bodies, but how we feel and behave. And since those feelings and behaviors profoundly influence (and are influenced by) our social interactions, we seem increasingly inclined to view biological differences that affect the quality of those interactions—say, short stature or frown lines—as fundamentally medical problems.

This expansion of medicine's purview has had significant social consequences. Behaviors and traits once viewed as moral failings or personality flaws, like addiction or shyness, are increasingly viewed as illnesses. Assigning conditions diagnostic labels not only makes them eligible for treatment and insurance coverage, but also entitles the afflicted to a range of important accommodations. Students diagnosed with learning disorders are entitled to supplemental tutoring, shorter tests, and extra time to complete their work. Attorneys for criminal defendants often argue, sometimes successfully [2], that their clients deserve more lenient sentences because brain disorders mitigate their responsibility for their actions.

Diagnostic labels can also confer psychological benefits that are no less important to the people who bear them. Many people seem to feel validated when the institution of medicine acknowledges their problems as "real." Online news reports on selective eating disorder are often followed by comments from picky eaters expressing some variation of "See! It's not all in my head!" While this is a perplexing reaction to having been labeled mentally ill, it illustrates how attaching a medical label to a set

of behaviors can reframe their social meaning. Instead of being childish picky eaters, selective eaters have an illness that's no fault of their own, and the people who would judge them are recast as bigots. Perhaps this reframing effect explains why the Duke Center for Eating Disorders "treats" this problem primarily by "helping picky eaters overcome their embarrassment and feel entitled to their own preferences" and "teaching friends and family members 'the person is not doing this to be willful and bratty" [3]. For disorders whose key symptom is not a health deficit but embarrassment—the disorder with a thousand faces—the diagnosis itself becomes a form of treatment, by reducing the stigma that attaches to the patient's behavior.

The fact that some people feel empowered by being labeled mentally ill is a testament to the enormous social significance of diagnosis in contemporary America. But the same forces that have expanded the scope of medicine to encompass social problems could ultimately deprive diagnosis of its importance. By becoming ubiquitous, diagnoses could become irrelevant as markers of social differences.

One reason we attach significance to mental diagnoses is that we still tend to view them as exceptions. We are still inclined to think of "normal" behaviors as expressions of our character, our values, or possibly our souls, while increasingly perceiving aberrations to be products of defective brain wiring. But if we fully accept the materialist hypothesis—that *all* behavior is the product of biology—then the fact that we have identified the biological basis of a particular behavior will increasingly be met with a shrug. A wife isn't going to care that scientists have discovered genetic causes of her husband's infidelity. Judges will tire of the claim that a criminal's brain made him do it.

Moreover, as diagnoses cover an ever-broader range of biological differences that cause social problems, and the ranks of the "diagnosed" inevitably swell [4], it becomes less feasible to offer special accommodations to people with recognized disorders. In September *The Wall Street Journal* ran a front-page story on school systems' struggles to accommodate "an expanding group of 'hidden disabilities' increasingly being diagnosed in children" [5]. It told the story of a 16-year-old boy who had been diagnosed with ADHD, anxiety, and bipolar disorder. The boy refused to go to school, preferring instead to watch TV and play basketball. His father wanted the school district to provide a private tutor to educate his son at home—a demand supported by letters from three physicians. The district refused and prevailed in the legal battle that followed.

The point is not that conditions like ADHD and anxiety aren't "real" disorders, or that they can't be debilitating. You don't have to believe this teenager was "faking" to resist the idea of providing him a full-time tutor at public expense. As we apply diagnoses to an ever-expanding share of behaviors and social difficulties—as they become the rule rather than the exceptions—accommodating every brain difference with a medical label becomes a practical impossibility.

Diagnosis will continue to be critical for purposes of obtaining access to treatment and insurance. In some cases identifying the biological bases of behaviors may also promote more compassionate responses, as in the case of addiction. But the outsized social significance of simply having a diagnosis—the signal that a problem falls within medicine's purview—is bound to decline. Many of the institutions that make special benefits available on the basis of diagnoses will have to shift their focus to the specific nature of a person's problems. If a medical intervention can reduce a criminal defendant's likelihood of recidivism, and the criminal consents to treatment, that could be a mitigating factor in sentencing. If it is feasible for a school to address a student's poor performance, it should do so regardless of whether the problem has a medical label. But the mere fact that a trait or set of behaviors fits a recognized diagnostic category may no longer be a determining factor. If the importance of diagnosis as a social category declines, medicine will have been a victim of its own success.

Reference

- 1. First MB. Research background: Obsessive Compulsive Spectrum Disorders Conference (June 20-22, 2006). American Psychiatric Association. http://www.dsm5.org/research/pages/obsessivecompulsivespectrumdisorders conference(june20-22,2006).aspx. Accessed November 11, 2011.
- 2. *Crook v State*, 908 So2d 350 (Fla 2005). The Florida Supreme Court invalidated a defendant's death sentence because the trial court had failed to consider the defendant's brain damage as a mitigating factor.
- 3. Dixon R. Adult picky eaters now recognized as having a disorder. *LiveScience*. November 28, 2010. http://www.livescience.com/10301-adult-picky-eaters-recognized-disorder.html. Accessed November 11, 2011.
- 4. A recent study estimates that nearly 40 percent of Europeans suffer from some form of mental illness. The authors refer to their methodology as "conservative," and argue that "the true size of 'disorders of the brain' in the EU is almost certainly considerably larger." Wittchen HU, Jacobi F, Rehm J, et al. The size and burden of mental disorders and other disorders of the brain in Europe 2010. *European Neuropsychopharmacol*. 2011;21(9):655-679.
- 5. Marcus AD. Wave of new disabilities swamps school budgets. *Wall Street Journal*. September 17, 2011:A1.

Matt Lamkin, JD, MA, is an attorney and a fellow at Stanford University's Center for Law and the Biosciences in Stanford, California. His research examines how our shifting health care terrain can subtly modify traditional conceptions of individual autonomy, including preconceived understandings of privacy, voluntary consent, and the rights to bodily integrity and self-determination.

Related in VM

The Pharmaceutical Industry's Role in Defining Illness, December 2011

The Evolution of Addiction Medicine as a Medical Specialty, December 2011

Medicalizing Obesity: Individual, Economic, and Medical Consequences, December 2011

A Disorder by Any Other Name: Excessive Computer Game Playing, January 2008

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

Virtual Mentor

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 900-905.

HISTORY OF MEDICINE

The Evolution of Addiction Medicine as a Medical Specialty David E. Smith, MD

Addiction medicine, the study and treatment of addictive disease, has come of age by way of a long and winding road.

Alcoholism was clearly described as a disease as long ago as the late 1700s by Dr. Benjamin Rush, a physician and signer of the Declaration of Independence. However, it wasn't until the founding of Alcoholics Anonymous in the 1930s by New Yorker Bill Wilson and Dr. Bob Smith (no relation), both of whom sought recovery from alcoholism, that the concept of alcoholism as disease spread throughout the United States and then the world. Again, it was a physician, Dr. William Duncan Silkworth, who in AA's *Alcoholics Anonymous: The Big Book* claimed the disease was caused by "an allergic reaction of the body to alcohol" and a compulsion of the mind [1].

The modern addiction medicine movement began with the formation of the New York City Medical Society on Alcoholism in 1954 and its recognition of alcoholism as a disease (Ruth Fox, one of its organizers, is considered the founder of the American Society of Addiction Medicine). This organization eventually became the American Medical Society on Alcoholism. Narcotics Anonymous (NA) began in California in the 1950s because Alcoholics Anonymous (AA) specifically excluded addiction to other drugs from its scope, describing them as outside issues [2]. NA adopted AA's Twelve Steps but included recovery from all drugs of addiction, particularly opiates such as heroin, initially using the catchphrase "clean and sober."

The drug revolution of the mid-1960s that peaked in the Haight-Ashbury district of San Francisco spurred the formation of the Haight Ashbury Free Clinics. Haight-Ashbury borders the campus of the University of California, San Francisco, where I went to medical school and graduate school in pharmacology and did postdoctoral training in clinical toxicology between 1960 and 1967. This training, my research, and my own recovery and involvement in a Twelve-Step program, coupled with living in the middle of a countercultural drug revolution, led me to view addiction as a brain disease.

In the early months of 1967, it became apparent to many health professionals in San Francisco that a potential public health nightmare was looming—the media were broadcasting a picture of an idyllic life of free love and drug use in Haight-Ashbury, while the city's Department of Public Health was pretty much ignoring all indications that the neighborhood would become a mecca for young people during

the coming summer. DPH indicated that their plan was to provide no services on the assumption that, with no services available, the newcomers would simply leave.

On June 7, 1967, using my medical license and renting a former dentist's office a block from the corner of Haight and Ashbury, we opened the Haight Ashbury Free Medical Clinic, based on the principles that health care is a right, not a privilege and that addiction is a disease and the addict has a right to treatment. These philosophies were controversial at the time but are now part of the mainstream health care and mental health parity debate [3, 4]. This represented one of the beginnings of addiction medicine, as its medicalization allowed health practitioners to view addiction as a chronic disease analogous to other chronic diseases, e.g., diabetes. As diabetes is a disease of the pancreas, addiction is a disease of the brain.

Organizing Addiction Medicine

In part because treating addicts in an outpatient medical setting was illegal at the time, the California Society for the Treatment of Alcoholism and Other Drug Dependencies, the initial state society advocating a specialty in addiction, was formed in 1972. The California Society of Addiction Medicine (CSAM) was incorporated in 1973.

Parallel to this, and in part because of the growing addiction problems among returning Vietnam veterans, the Nixon White House formed the Special Action Office of Drug Abuse Prevention (SAODAP) in 1972, followed by the National Institute of Drug Abuse (NIDA) and the National Institute of Alcoholism and Alcohol Abuse (NIAAA). These agencies made millions of dollars available for drug treatment, with lesser amounts for enforcement. (Tellingly, the proportions have been reversed today.) In 1976, Doug Talbott, a physician from Atlanta, formed the American Academy of Addictionology and moved to certify physicians specializing in alcoholism.

In 1983, a summit meeting of U.S. physicians convened at the Kroc Ranch in southern California to form a national organization to gain a seat in the American Medical Association (AMA) House of Delegates. The representatives agreed to organize under the American Medical Society on Alcoholism umbrella and soon renamed the organization the American Society on Alcoholism and Other Drug Dependencies to include all addictive drugs, eventually settling on the American Society of Addiction Medicine (ASAM). In 1986, the group adopted the CSAM certification program, which had been established in 1982. Emergency medicine had recently been approved as what was generally assumed would be the AMA's final specialty, so the ASAM delegates to the AMA decided on "addiction medicine" as a specialty name seen as more encompassing and acceptable to mainstream medicine [5]. The strategy succeeded, and, in 1988, the AMA admitted ASAM into the House of Delegates as a national medical specialty society [6].

In 1990, the AMA House of Delegates approved the "ADM" code, acknowledging addiction medicine as a practice specialty. In the years following, ASAM continued to pursue full board status within the American Board of Medical Specialties (ABMS). The first edition of *Principles of Addiction Medicine* was published in 1994, with subsequent editions in 1998, 2003, and 2009.

The Drug Abuse Treatment Act of 2000 (DATA 2000) authorizes the use of Schedule III drugs such as Subutex (buprenorphine) and Suboxone (buprenorphine and naloxone) in the treatment of narcotics addiction by qualified physicians in a medical setting [7]. With the passage of the Paul Wellstone and Pete Dominici Mental Health Parity and Addiction Equity Act in 2008, legislating parity for mental health services [3], addiction medicine has come of age. The American Board of Addiction Medicine (ABAM) awarded its first board certifications in 2009.

Addiction Medicine Today

At ASAM's 2011 annual meeting, Kevin Kunz, MD, president of ABAM, announced that 10 residency programs in addiction medicine have been accredited [6, 8]. At the same time, ASAM, in partnership with NIDA, launched a free, nationwide service to help primary care physicians identify and advise their patients who are at risk for substance abuse disorder. Led by past ASAM president Louis Baxter, MD, and David A. Fiellin, MD, as well as an advisory board drawn from family medicine, internal medicine, and emergency medicine, peer-to-peer mentorship for early intervention on substance disorders in a primary care setting will be available. In addition, NIDA developed a quick screening tool (NIDAMED) to help identify patients with unhealthy substance-related behaviors [9].

In August 2011, ASAM released a definition of addiction as its latest public policy. The short version states:

Addiction is a primary, chronic disease of brain reward, motivation, memory and related circuitry. Dysfunction in these circuits leads to characteristic biological, psychological, social and spiritual manifestations. This is reflected in an individual pathologically pursuing reward and/or relief by substance use and other behaviors.

Addiction is characterized by inability to consistently abstain, impairment in behavioral control, craving, diminished recognition of significant problems with one's behaviors and interpersonal relationships, and a dysfunctional emotional response. Like other chronic diseases, addiction involves cycles of relapse and remission. Without treatment or engagement in recovery activities, addiction is progressive and can result in disability or premature death [10].

The Importance of the Disease Model of Addiction

I have been advocating for the recognition of addiction as a brain disease for more than four decades. During those years, we have progressed from viewing addiction as strictly a criminal condition to the recognition that addiction is a disease intimately intertwined with the workings of the brain and its neurochemistry. We

have moved from illegally treating addicts in an outpatient setting to appropriately trained physicians administering pharmaceutical agonists and antagonists in their offices. We have developed increasing awareness of the importance of psychosocial therapy in addiction treatment, of the need for ongoing monitoring and follow-up, and of the greater effectiveness of treatment plans tailored to such factors as the individual's age, sex, and drug of choice. The establishment of drug courts and diversion programs acknowledges that the costs of addiction treatment are far less than those of incarceration.

Recognition of addiction as a disease has also destigmatized addicts' perception of themselves as "bad" or "weak" people and has made it more acceptable for them to seek treatment at earlier stages of their disease. Families and the medical community react less judgmentally, though the disease model does encourage addicts to take responsibility for their disease and to deal with the consequences of their addiction. Since 100 percent of addicts and alcoholics will at some time surface in the medical system, medicalization greatly improves identification, early intervention, and referral to appropriate treatment.

The peak incidence of addiction is between ages 15 and 21. The still maturing brains of adolescents are particularly susceptible to substance use disorder, because the adolescent brain is learning patterns that persist into adulthood. If the disruptive patterns laid down by substance misuse during adolescence become dominant, the adult brain becomes "wired" into them. The adult then finds it difficult, if not impossible, to respond appropriately to emotional, cognitive, and social environmental cues. Even such survival necessities as food and shelter take second place to the brain's overwhelming perceived need, or craving, for the substance to which it has become addicted. For obvious reasons, it is important that those in the "danger zone" receive treatment in a timely fashion; understanding addiction as a disease has facilitated that.

Practitioners in the field of addiction medicine have also championed support for physician health programs (PHPs) for the treatment of chemical-dependency, psychiatric, and other well-being issues. While many of these programs have been challenged or eliminated in recent years, there is growing awareness of their effectiveness and importance for practitioners who "can't keep their hands out of the cookie jar."

As ASAM past president Michael Miller, MD, puts it, "At its core, addiction isn't just a social problem or a moral problem or a criminal problem. It's a brain problem whose behaviors manifest in all these other areas"[11].

References

- 1. Alcoholics Anonymous: The Big Book Online. Alcoholics Anonymous World Services, Inc. http://www.aa.org/bigbookonline/. Accessed November 11, 2011.
- 2. Some thoughts regarding our relationship to Alcoholics Anonymous. *Narcotics Anonymous World Service Board of Trustees Bulletin*. http://www.na.org/?ID=bulletins-bull13-r. Accessed November 11, 2011.
- 3. Roy K, Miller M. Parity and the medicalization of addiction treatment. *J Psychoactive Drugs*. 2010;42(2):115-120.
- 4. Smith DE, Lee DR, Davidson LD. Health care equality and parity for treatment of addictive disease. *J Psychoactive Drugs*. 2010;42(2):121-126.
- 5. Smith DE. The evolution of addiction medicine and its San Francisco roots. *CSAM News*. 2009; Winter: 4, 6. http://www.csam-asam.org/pdf/misc/CSAM_News_Winter_2009.pdf. Accessed November 11, 2011.
- 6. American Society of Addiction Medicine. ABAM accredits 10 new ADM residencies. *ASAM News*. 2011;26(2):6. http://www.asam.org/pdf/Publica tions/2011/26-2_ASAM.News_Summer.2011.pdf. Accessed November 11, 2011
- 7. Wesson DR, Smith DE. Buprenorphine in the treatment of opiate dependence. *J Psychoactive Drugs*. 2010;42(2):161-175.
- 8. Quenqua D. Medicine adds slots for study of addictions. *New York Times*. July 11, 2011:A10, A12.
- 9. American Society of Addiction Medicine. New ASAM program mentors primary care physicians. *ASAM News*. 2011;26(2):1, 6. http://www.asam.org/pdf/Publications/2011/26-2_ASAM.News_Summer.2011.pdf. Accessed November 11, 2011.
- 10. American Society of Addiction Medicine. 2011. Public policy statement: definition of addiction. http://www.asam.org/DefinitionofAddiction-LongVersion.html. Accessed November 11, 2011.
- 11. Brauser D. Addiction a brain disease, ASAM says. *Medscape*. August 31, 2011. http://www.medscape.com/viewarticle/748867. Accessed November 11, 2011.

Further Readings

American Society of Addiction Medicine. ASAM historical timeline. http://www.asam.org/Timelines.html. Accessed November 11, 2011.

Dobrin CV, Roberts DCS. The anatomy of addiction. In: Ries RK, Fiellin DA, Miller SC, Saitz R, eds. *Principles of Addiction Medicine*. 4th ed. Philadelphia: Lippincott Williams & Wilkins; 2009: 27-38.

Katcher BS. Benjamin Rush's educational campaign against hard drinking. *Am J Public Health*. 1993;83(2):273-281. www.ncbi.nlm.nih.gov/pmc/articles/pmc 1694575/pdf/amjph00526-0115.pdf. Accessed November 11, 2011.

Nestler EJ. From neurobiology to treatment: progress against addiction. In: Ries RK, Fiellin DA, Miller SC, Saitz R, eds. Principles of Addiction Medicine. 4th ed. Philadelphia: Lippincott Williams & Wilkins; 2009: 39-44.

David E. Smith, MD, is the founder of the Haight Ashbury Free Medical Clinic and a pioneering advocate of the disease model of addiction. He is a past president of the American Society of Addiction Medicine and the California Society of Addiction Medicine.

Related in VM

Medicalizing Obesity: Individual, Economic, and Medical Consequences, December 2011

The Rise and Impending Fall of Diagnosis as a Marker of Difference, December 2011

The Pharmaceutical Industry's Role in Defining Illness, December 2011

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

Virtual Mentor

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 906-911.

OP-ED

The Pharmaceutical Industry's Role in Defining Illness

Elizabeth A. Kitsis, MD, MBE

The pharmaceutical industry develops, manufactures, and sells drugs. Defining illness is not its mission. Generally, the medications produced by drug companies target diseases that have been defined previously by the medical profession. However, there are several indirect ways in which the industry contributes to the definition of illness. Are these contributions beneficial to society and ethically sound, or are they solely aimed at maximizing corporate profit? To address these questions, I analyze some examples of how the pharmaceutical industry has played a role in defining illness.

No sharp line divides health from disease. Defining an illness is a complex process, and definitions typically evolve over time, facilitated by advances in science and validated by societal recognition. Thus, it is expected that the definition of what constitutes disease will change with time, with additions (e.g., Lyme disease), subtractions (e.g., homosexuality), and modifications (e.g., autoimmune disorders). While some of these modifications are universally accepted, others—particularly those regarding conditions that lack objective signs or laboratory abnormalities—are controversial. The term "medicalization" was introduced in the 1970s by Illich and others [1] to challenge the characterization of normal variation among humans as disease. However, defining illness can be the first step toward reducing human suffering. Thus, medicalization can alternatively be defined as "a process by which human problems come to be defined and treated as medical problems" [2].

A case in point is fibromyalgia, a chronic pain condition associated with tender points on certain parts of the body. Physicians began to see patients with this constellation of symptoms in the 1980s and cautiously and provisionally defined a new syndrome. As with many syndromes, elucidating its pathogenesis was not so easy and has lagged behind the description of the disorder. It is not uncommon, however, for clinicians and drug companies to search empirically for new treatments even without a precise understanding of pathogenesis. Several medications—including pregabalin (approved in 2007), duloxetine (approved in 2008), and milnacipran (approved in 2009)—were found to alleviate the symptoms of fibromyalgia and were the first medications to be approved by the Food and Drug Administration (FDA) for treating it.

What are the implications of these new drugs for fibromyalgia? Most importantly, they may provide relief to patients with a potentially debilitating condition. However, there may also be other, important downstream effects. First, the very fact

that drugs have been approved provides some validation that fibromyalgia is, in fact, an illness. Receiving treatment for fibromyalgia may legitimize a patient's chronic pain symptoms that might otherwise be dismissed by family, friends, or employers as hypochondriasis. Indeed, some fibromyalgia patients report improved health after diagnosis [3]. Second, if the treatment is truly effective, one would anticipate that it would reduce the use and cost of health care for sufferers, perhaps benefiting patients as well as society. Some investigators have reported these outcomes [4, 5]. Third, in a reversal of the usual direction of translational medicine, knowing the mechanisms by which effective drugs act may provide important insights into pathogenesis.

On the other hand, are there potential risks to medicalizing the symptoms of fibromyalgia? Some rheumatologists still dispute the existence of this condition. If they are correct, its medicalization could encourage inappropriate sick-role behavior. It could also expose otherwise healthy patients to medications with potential side effects and unnecessarily increase the costs of medical care. Some data indicate that pharmacy and health care costs go up among patients who have been treated with pregabalin and duloxetine [6].

In either case, it is clear that the pharmaceutical industry has played a role in the medicalization of fibromyalgia. While this process is usually driven by physician experts, the decision to develop and seek approval for new drugs can strongly influence the medicalization process—especially when those drugs are efficacious. One might question the motivations of drug companies—are they after profit, patient welfare, or both? Regardless, in the case of fibromyalgia, several new medications have been added to the treatment armamentarium.

In contrast to fibromyalgia, there are other examples in which pharmaceutical companies have played a less positive role in the definition of disease. For example, some allege that GlaxoSmithKline developed a business plan to promote paroxetine as a treatment for social phobia by depicting the disease as a severe medical problem [7]. Although the prevalence of social phobia was noted as "rare" in the 1980 DSM-III, it was noted to be "extremely common" by 1994. GlaxoSmithKline's extensive media campaign included posters displayed prominently across the country that showed a dejected man playing with a teacup and proclaimed "Imagine being allergic to people." Labeling people who may simply be shy as severely ill may be stigmatizing. Encouraging them to take a medication with potential side effects raises a concern about whether patient welfare is the key objective. Expanding the boundaries of a treatable illness simply to enlarge the market for a drug has been termed "disease mongering" [8].

Occasionally, a pharmaceutical company develops a medication for a specific purpose, but later discovers that a "side effect" has the potential to solve a completely different medical problem. The well-known example is minoxidil, initially developed and effective for hypertension. Upon realizing that excessive hair growth was also observed in a significant percentage of patients [9], Upjohn developed the drug for baldness. This could be considered a form of medicalization

initiated by a drug company. Is baldness a bona fide medical disease, worthy of drug treatments and all the positive and negative consequences that entails? Or is it simply part of the normal aging process, similar to the development of facial wrinkles? Or is "medicalized" being extended here to connote any condition that is treated with a drug?

Considering whether aspects of normal aging should be treated with medical interventions raises many ethical questions. For example, respect for autonomy, a strongly held principle in Western societies, may justify allowing individuals to opt for such treatments as long as they are aware of potential risks. On the other hand, critics might argue that such "nonessential" therapies waste resources that could be better used for more serious medical conditions. Concerns about justice come into play here, since only those with adequate resources can afford elective or cosmetic treatments not routinely covered by health insurance.

Sildenafil is a somewhat different case. Initially developed for a cardiovascular indication, the efficacy of the drug proved insufficient, leading to discontinuation of the clinical development program. However, a product safety specialist at Pfizer observed that a substantial number of male patients enrolled in clinical trials of the drug reported erections as a side effect [10]. Erectile dysfunction was already recognized as a medical condition, often caused by diabetes or subsequent to prostate surgery. Previously available treatments were not well-tolerated by patients. This led Pfizer to develop sildenafil for erectile dysfunction. In this case, the company did not medicalize the condition. Rather, using Bob Dole as its spokesperson, it raised awareness of a little-discussed medical problem and lent credibility to its diagnosis and treatment. Thus, the drug appeared to address an unmet medical need.

But Pfizer did not stop there. Realizing the potential for further profits, it began advertising sildenafil to a broader audience [11]. Other companies developed similar drugs. Marketing strategies leveraged the fact that many men experience occasional erectile dysfunction unrelated to organic causes. Eventually, these drugs were perceived by the public as "lifestyle modifiers" that could enhance sexual function rather than solely treat disease. This broadening of the use of sildenafil raises questions similar to those involved with treating the normal aging process.

Some of the drive for public demand for medications comes from direct-to-consumer (DTC) advertising. Corporate expenditures on DTC advertising were \$4.2 billion in 2005 [12]. While this approach does not necessarily result in the definition of new disease, it can facilitate the expansion of a market, as in the cases of social phobia and erectile dysfunction.

Critics of the pharmaceutical industry rail that the main motive for industry involvement in DTC advertising is to increase market size and profitability [12]. DTC advertising, they say, is a ploy to make people think that normal variations in their level of social comfort, satisfaction with life, sleep habits, or numerous other complaints are medical disorders, and to request, by name, the specific drugs being

promoted. The FDA Revitalization Act of 2007 reauthorized the Prescription Drug User Fee Act, which—among other things—allowed the FDA to levy fines of \$250,000-\$500,000 for false and misleading advertisements. This act could have helped to keep DTC advertising in check. However, in 2008, the part of the act that created a user fee program to review television commercials was terminated due to insufficient funding by Congress [13].

Not all DTC advertisements should be vilified. Some, in fact, can empower patients. DTC advertisements provide information, possibly enabling people to make more informed, individualized decisions about their health care. That said, it is in the public's best interest that all DTC advertisements be reviewed stringently by independent referees—FDA or otherwise—to insure that pharmaceutical companies do not equate symptoms with diseases and suggest that diseases are more common or serious than they really are.

As we complete the first decade of the twenty-first century, some would argue that the pendulum has swung too far toward medicalization, and that the pharmaceutical industry has contributed significantly to this situation. Aspects of normal human life, including childbirth, weight control, and menopause, that used to be managed without medical intervention have been placed into the medical care paradigm. Behaviors deemed unacceptable by society, such as alcoholism, drug addiction, and attention deficit hyperactivity disorder, have also been medicalized. They are now ascribed in large part to chemical imbalances or genetic predispositions, potentially absolving affected individuals of personal responsibility for their behavior [14].

However, defining a problem in medical terms is not necessarily bad [14]. For example, data about maternal and fetal death in groups with poor access to health care suggest that considering pregnancy within a medical framework may lead to positive outcomes. Recognizing the severe medical consequences of obesity and providing treatment options can reduce comorbidities associated with this condition. Helping people overcome problems that cause them distress—whether through changes in behavior or pharmacologic intervention—can help physicians fulfill their obligation to optimize patient welfare.

As the major developer of new drugs, the pharmaceutical industry unquestionably influences the process of defining illness. This influence can be positive, as when drug companies increase public awareness of disease and develop effective therapies for distressing conditions. On the other hand, the influence of the industry becomes harmful if it pushes the boundaries of illness too far in pursuit of profit. The pharmaceutical industry could augment its positive contributions by consistently providing the public with unbiased information and by supporting biological and population research that would more precisely define specific diseases. This information could help to identify those individuals who would most likely be helped by specific drugs. Discoveries such as these would benefit both the industry and society.

References

- 1. Metzl JM, Herzig RM. Medicalisation in the 21st century: introduction. *Lancet*. 2007;369(9562):697-698.
- 2. Sadler JZ, Jotterand F, Lee SC, Inrig S. Can medicalization be good? Situating medicalization within bioethics. *Theor Med Bioeth*. 2009;30(6):411-425.
- 3. White KP, Nielson WR, Harth M, Ostbye T, Speechley M. Does the label "fibromyalgia" alter health status, function, and health service utilization? A prospective, within-group comparison in a community cohort of adults with chronic widespread pain. *Arthritis Rheum*. 2002;47(3):260-265.
- 4. Annemans L, Wesslely S, Spaepen E, et al. Health economic consequences related to the diagnosis of fibromyalgia syndrome. *Arthritis Rheum*. 2008;58(3):895-902.
- 5. Hughes G, Martinez C, Myon E, Taieb C, Wessely S. The impact of a diagnosis of fibromyalgia on health care resource use by primary care patients in the UK: an observational study based on clinical practice. *Arthritis Rheum.* 2006;54(1):177-183.
- 6. Gore M, Tai KS, Chandran A, Zlateva G, Leslie D. Clinical comorbidities, treatment patterns, and healthcare costs among patients with fibromyalgia newly prescribed pregabalin or duloxetine in usual care. *J Med Econ*. October 20, 2011. [Epub ahead of print]
- 7. Angell M. Drug companies and doctors: a story of corruption. *New York Review of Books*. January 15, 2009. http://www.nybooks.com/articles/archives/2009/jan/15/drug-companies-doctorsa-story-of-corruption/?pagination = false. Accessed October 17, 2011.
- 8. Moynihan R, Heath I, Henry D. Selling sickness: the pharmaceutical industry and disease mongering. *BMJ*. 2002;324(7342):886-891.
- 9. Fenton DA, Wilkinson JD. Topical minoxidil in the treatment of alopecia areata. *BMJ*. 1983;287(6398):1015-1017.
- 10. Boolell M, Allen MJ, Ballard SA, et al. Sildenafil: an orally active type 5 cyclic GMP-specific phosphodiesterase inhibitor for the treatment of penile erectile dysfunction. *Int J Impot Res.* 1996;8(2):47-52.
- 11. Lexchin J. Bigger and better: how Pfizer redefined erectile dysfunction. *PLoS Med.* 2006;3(4):e132.
- 12. Shah AA, Finucane TE. Yes, industry influence is excessive. *Int Psychogeriatr.* 2007;19(6):1004-1010.
- 13. Shaw A. Direct-to-consumer advertising of pharmaceuticals. http://www.csa.com/discoveryguides/direct/review3.php. Accessed October 13, 2011.
- 14. President's Commission on Bioethics. Medicalization: its nature, causes, and consequences (2003) [transcript]. http://bioethics.georgetown.edu/pcbe/transcripts/jun03/session2.html. Accessed August 3, 2011.

Elizabeth A. Kitsis, MD, MBE, is director of bioethics education at the Albert Einstein College of Medicine in the Bronx, New York, and a practicing rheumatologist. She was previously vice president of a global pharmaceutical company.

Related in VM

The Rise and Impending Fall of Diagnosis as a Marker of Difference, December 2011

Medicalizing Obesity: Individual, Economic, and Medical Consequences, December 2011

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2011 American Medical Association. All rights reserved.

Virtual Mentor

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 912-921.

Suggested Readings and Resources

81 words. *This American Life*. National Public Radio. http://www.thisamericanlife.org/radio-archives/episode/204/81-words. Accessed November 16, 2011.

Alcoholics Anonymous: The Big Book Online. Alcoholics Anonymous World Services, Inc. http://www.aa.org/bigbookonline/. Accessed November 11, 2011.

Allison DB, Downey M, Atkinson RL, et al. Obesity as a disease: a white paper on evidence and arguments commissioned by the Council of the Obesity Society. *Obesity (Silver Spring)*. 2008;16(6):1161-1177.

American Association of Clinical Endocrinologists (AACE) declares obesity a disease state [news release]. Jacksonville, FL: American Association of Clinical Endocrinologists (AACE); July 29, 2011.

http://media.aace.com/article_display.cfm?article_id=5075. Accessed October 2, 2011.

American Psychiatric Association. *Diagnostic and Statistical Manual, Fourth Edition (Text Revision)*. Washington, DC: American Psychiatric Association; 2000.

American Society of Addiction Medicine. 2011. Public policy statement: definition of addiction. http://www.asam.org/DefinitionofAddiction-LongVersion.html. Accessed November 11, 2011.

American Society of Addiction Medicine. ABAM accredits 10 new ADM residencies. *ASAM News*. 2011;26(2):6.

http://www.asam.org/pdf/Publications/2011/26-2_ASAM.News_Summer.2011.pdf. Accessed November 11, 2011.

American Society of Addiction Medicine. New ASAM program mentors primary care physicians. *ASAM News*. 2011;26(2):1, 6.

http://www.asam.org/pdf/Publications/2011/26-2_ASAM.News_Summer.2011.pdf. Accessed November 11, 2011.

Andreasen N, Minthon L, Davidsson P, et al. Evaluation of CSF-tau and CSF-Abeta42 as diagnostic markers for Alzheimer disease in clinical practice. *Arch Neurol*. 2001;58(3):373-379.

Angell M. Drug companies and doctors: a story of corruption. *New York Review of Books*. January 15, 2009.

http://www.nybooks.com/articles/archives/2009/jan/15/drug-companies-doctorsastory-of-corruption/?pagination=false. Accessed October 17, 2011.

Annemans L, Wesslely S, Spaepen E, et al. Health economic consequences related to the diagnosis of fibromyalgia syndrome. Arthritis Rheum. 2008;58(3):895-902.

Aristotle. The Ethics of Aristotle: The Nicomachean Ethics. Tredennick H, ed. Thomson JAK, trans. New York, NY: Penguin Books; 1976: 244.

Atlantis E, Baker M. Obesity effects on depression: systematic review of epidemiological studies. Int J Obes (Lond). 2008;32(6):881-891.

Barsky AJ, Borus JF. Somatization and medicalization in the era of managed care. JAMA. 1995;274(24):1931-1934.

Bayer AJ, Bullock R, Jones RW, et al. Evaluation of the safety and immunogenicity of synthetic AB42 (AN1792) in patients with AD. Neurology. 2005;64(1):94-101.

Beach MC, Roter D, Rubin H, Frankel R, Levinson W, Ford DE. Is physician selfdisclosure related to patient evaluation of office visits? J Gen Intern Med. 2004;19(9):905-910.

Blackburn GL, Kanders BS. Medical evaluation and treatment of the obese patient with cardiovascular disease. Am J Cardiol. 1987;60(12):55G-58G.

Boolell M, Allen MJ, Ballard SA, et al. Sildenafil: an orally active type 5 cyclic GMP-specific phosphodiesterase inhibitor for the treatment of penile erectile dysfunction. Int J Impot Res. 1996;8(2):47-52.

Bowman ES. Pseudoseizures. Psychiatr Clin North Am. 1998;21(3):649-657, vii.

Brauser D. Addiction a brain disease, ASAM says. *Medscape*. August 31, 2011. http://www.medscape.com/viewarticle/748867. Accessed November 11, 2011.

Bray GA. Obesity is a chronic, relapsing neurochemical disease. Int J Obes Relat Metab Disord. 2004;28(1):34-38.

Budetti PP. Market justice and US health care. JAMA. 2008;299(1):92-94.

Bulwer-Lytton E. *Richelieu*; *Or the conspiracy*. Act 2, scene 2.

Casanova KS. How to apply for social security disability benefits if you have chronic fatigue syndrome, myalgic encephalopathy, and fibromyalgia. Massachusetts CFIDS/ME & FM Association: 2009.

http://www.masscfids.org/pdf/handbook/Disability%20Handbook-Appendix%20II.pdf. Accessed October 20, 2011.

Cheskin LJ, Kahan S, Geller G. Weight-based stigma and physician bias. *Virtual Mentor*. 2010;12(4):258-262.

Congressional Budget Office. Social Security Disability Insurance: participation trends and their fiscal implications. http://www.cbo.gov/ftpdocs/116xx/doc11673/07-22-SSDisabilityIns_Brief.pdf. Published July 22, 2010. Accessed October 20, 2011.

Conrad P, Mackie T, Mehrotra A. Estimating the costs of medicalization. *Soc Sci Med.* 2010;70(12):1943-1947.

Crook v State, 908 So2d 350 (Fla 2005). The Florida Supreme Court invalidated a defendant's death sentence because the trial court had failed to consider the defendant's brain damage as a mitigating factor.

de Vries J: The obesity epidemic: medical and ethical considerations. *Sci Eng Ethics*. 2007;13(1):55-67.

DeCoster B. Lying reconsidered: a gendered history of conversion disorders and the erosion of patients' agency. *AJOB Neuroscience*. 2010;1(1):67-68.

Dixon R. Adult picky eaters now recognized as having a disorder. *LiveScience*. November 28, 2010. http://www.livescience.com/10301-adult-picky-eaters-recognized-disorder.html. Accessed November 11, 2011.

Downey M, Still C, Sharma AM. Is there a path for approval of an antiobesity drug: what did the Sibutramine Cardiovascular Outcomes Trial find? *Curr Opin Endocrinol Diabetes Obes.* 2011;18(5):321-327.

Dresser RS. Treatment decisions for incapacitated patients. In: Ashcroft RE, Dawson A, Draper H, eds. *Principles of Healthcare Ethics*. 2nd ed. Chichester, England: John Wiley & Sons, Ltd; 2007: 305-310.

Eliot TS. The love song of J. Alfred Prufrock. In: *The Waste Land and Other Poems*. Peterborough, ON: Broadview Press; 2010.

Ells LJ, Lang R, Shield JP, et al. Obesity and disability - a short review. *Obes Rev.* 2006;7(4):341-345.

Fairman KA, Curtiss FR. Does medicalization of life imperil health? Expanding indications for diagnosis and treatment of chronic "disease". *J Manag Care Pharm.* 2011;17(6):469-480.

Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet*. 2004;363(9405):312-319.

Fenton DA, Wilkinson JD. Topical minoxidil in the treatment of alopecia areata. BMJ. 1983;287(6398):1015-1017.

First MB. Research background: Obsessive Compulsive Spectrum Disorders Conference (June 20-22, 2006). American Psychiatric Association. http://www.dsm5.org/research/pages/obsessivecompulsivespectrumdisordersconfere nce(june20-22,2006).aspx. Accessed November 11, 2011.

Flier JS. Obesity wars: molecular progress confronts an expanding epidemic. Cell. 2004;116(2):337-350.

For a richer and longer discussion about why the search for certainty in medicine is misguided—albeit a common goal—I would direct readers to Montgomery's How Doctors Think.

Giel KE, Thiel A, Teufel M, Mayer J, Zipfel S. Weight bias in work settings - a qualitative review. Obes Facts. 2010;3(1):33-40.

Gore M, Tai KS, Chandran A, Zlateva G, Leslie D. Clinical comorbidities, treatment patterns, and healthcare costs among patients with fibromyalgia newly prescribed pregabalin or duloxetine in usual care. J Med Econ. October 20, 2011. [Epub ahead of print]

Hansson O, Zetterberg H, Buchhave P, Londos E, Blennow K, Minthon L. Association between CSF biomarkers and incipient Alzheimer's disease in patients with mild cognitive impairment: a follow-up study. Lancet Neurol. 2006;5(3):228-234.

Hebl MR, Xu J. Weighing the care: physicians' reactions to the size of a patient. *Int* J Obes Relat Metab Disord. 2001;25(8):1246-1252.

Herskovits AZ, Growdon JH. Sharpen that needle. Arch Neurol. 2010;67(8):918-920.

Hughes G, Martinez C, Myon E, Taieb C, Wessely S. The impact of a diagnosis of fibromyalgia on health care resource use by primary care patients in the UK: an observational study based on clinical practice. Arthritis Rheum. 2006;54(1):177-183.

Huizinga MM, Cooper LA, Bleich SN, Clark JM, Beach MC. Physician respect for patients with obesity. *J Gen Intern Med.* 2009;24(11):1236-1239.

Jonsen AR, Siegler M, Winslade WJ. Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine. 5th ed. New York: McGraw-Hill; 2002.

Kanaan R, Armstrong D, Wessely S. Limits to truth-telling: neurologists' communication in conversion disorder. Patient Educ Couns. 2009;77(2):296-301. Karnieli-Miller O, Werner P, Aharon-Peretz J, Eidelman S. Dilemmas in the (un)veiling of the diagnosis of Alzheimer's disease: walking an ethical and professional tight rope. *Patient Educ Couns*. 2007;67(3):307-314.

Kaufman DM. *Clinical Neurology for Psychiatrists*. 5th ed. Philadelphia, PA: WB Saunders; 2001.

Kraemer HC, Kupfer DJ, Narrow WE, Clarke DE, Regier DA. Moving toward DSM-5: the field trials. *Am J Psychiatry*. 2010;167(10):1158-1160.

Kroenke K. Efficacy of treatment for somatoform disorders: a review of randomized controlled trials. *Psychosom Med.* 2007;69(9):881-888.

Krueger RF, Eaton NR, Clark LA, et al. Deriving an empirical structure of personality pathology for DSM-5. *J Pers Disord*. 2011;25(2):170-191.

Kupfer DJ, Regier DA. Neuroscience, clinical evidence, and the future of psychiatric classification in DSM-5. *Am J Psychiatry*. 2011;168(7):672-674.

Lexchin J. Bigger and better: how Pfizer redefined erectile dysfunction. *PLoS Med*. 2006;3(4):e132.

Mace CJ, Trimble MR. 'Hysteria', 'functional' or 'psychogenic'? A survey of British neurologists' preferences. *J R Soc Med.* 1991;84(8):471-475.

Malterud K. Symptoms as a source of medical knowledge: understanding medically unexplained disorders in women. *Fam Med.* 2000;32(9):604.

Marcus AD. Wave of new disabilities swamps school budgets. *Wall Street Journal*. September 17, 2011:A1.

Mattsson N, Brax D, Zetterberg H. To know or not to know: ethical issues related to early diagnosis of Alzheimer's disease. *Int J Alzheimers Dis.* 2010. http://www.hindawi.com/journals/ijad/2010/841941/. Accessed November 16, 2011.

McDaniel SH, Beckman HB, Morse DS, et al. Physician self-disclosure in primary care visits: enough about you, what about me? *Arch Intern Med*. 2007;167(12):1321-1326.

McKhann GM, Knopman DS, Chertkow H, et al. The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement*. 2011;7(3):263-269.

Metzl JM, Herzig RM. Medicalisation in the 21st century: introduction. *Lancet*. 2007;369(9562):697-698.

Montgomery K. How Doctors Think: Clinical Judgment and the Practice of Medicine. New York: Oxford University Press; 2005: 85.

Moynihan R, Cassels A. Selling Sickness: How the World's Biggest Pharmaceutical Companies Are Turning Us All into Patients. New York: Nation Books; 2005.

Moynihan R, Heath I, Henry D. Selling sickness: the pharmaceutical industry and disease mongering. BMJ. 2002;324(7342):886-891.

Moynihan R. Medicalization. A new deal on disease definition. BMJ. 2011;342:d2548.

National Heart Lung and Blood Institute, National Institute of Diabetes and Digestive and Kidney Diseases. Clinical guidelines on the Identification, Evaluation, And Treatment of Overweight and Obesity in Adults: The Evidence Report. National Institutes of Health; 1998. http://www.nhlbi.nih.gov/guidelines/obesity/ob_gdlns.pdf. Accessed November 16, 2011.

National Institute of Mental Health. Autism. http://www.nimh.nih.gov/statistics/1AUT_CHILD.shtml. Accessed on October 9, 2011.

Nettleton S, Watt I, O'Malley L, Duffey P. Understanding the narratives of people who live with medically unexplained illness. Patient Educ Couns. 2005;56(2) 205-210.

Non-communicable diseases deemed development challenge of "epidemic proportions" in political declaration adopted during landmark General Assembly meeting [news release]. New York: United Nations; September 19, 2011. http://www.un.org/News/Press/docs/2011/ga11138.doc.htm. Accessed October 2, 2011.

Norris DM, Gutheil TG, Strasburger LH. This couldn't happen to me: boundary problems and sexual misconduct in the psychotherapeutic relationship. Psychiatr Serv. 2003;54(4):517-522.

Ogden J, Flanagan Z. Beliefs about the causes and solutions to obesity: a comparison of GPs and lay people. *Patient Educ Couns.* 2008;71(1):72-78.

Pies R. What should count as a mental disorder in DSM-V? *Psychiatric Times*. April 14, 2009.

President's Commission on Bioethics. Medicalization: its nature, causes, and consequences (2003) [transcript].

http://bioethics.georgetown.edu/pcbe/transcripts/jun03/session2.html. Accessed August 3, 2011.

Puhl R, Brownell KD. Bias, discrimination, and obesity. *Obes Res.* 2001;9(12):788-805.

Puhl RM, Heuer CA. The stigma of obesity: a review and update. *Obesity (Silver Spring)*. 2009;17(5):941-964.

Quenqua D. Medicine adds slots for study of addictions. *New York Times*. July 11, 2011:A10, A12.

Radden J, Sadler JZ. *The Virtuous Psychiatrist: Character Ethics in Psychiatric Practice*. New York, NY: Oxford University Press; 2010.

Radden, Sadler, 62.

Regier DA, Kuhl EA, Narrow WE, Kupfer DJ. Research planning for the future of psychiatric diagnosis. *Eur Psychiatry*. 2011 Jun 13. [Epub ahead of print]

Regier DA, Narrow WE, Kuhl EA, Kupfer DJ. The conceptual development of DSM-V. *Am J Psychiatry*. 2009;166(6):645-650.

Roy K, Miller M. Parity and the medicalization of addiction treatment. *J Psychoactive Drugs*. 2010;42(2):115-120.

Roy K, Miller M. Parity and the medicalization of addiction treatment. *J Psychoactive Drugs*. 2010;42(2):115-120.

Saarni SI, Anttila H, Saarni SE, et al. Ethical issues of obesity surgery--a health technology assessment. *Obes Surg.* 2011;21(9):1469-1476.

Sadler JZ, Jotterand F, Lee SC, Inrig S. Can medicalization be good? Situating medicalization within bioethics. *Theor Med Bioeth.* 2009;30(6):411-425.

Sadler JZ, Jotterand F, Lee SC, Inrig S. Can medicalization be good? Situating medicalization within bioethics. *Theor Med Bioeth*. 2009;30(6):411-425.

Sadler, Jotterand, Lee, Inrig, 412.

Schwartz MB, Chambliss HO, Brownell KD, Blair SN, Billington C. Weight bias among health professionals specializing in obesity. *Obes Res.* 2003;11(9):1033-1039.

Shah AA, Finucane TE. Yes, industry influence is excessive. *Int Psychogeriatr*. 2007;19(6):1004-1010.

Shaw A. Direct-to-consumer advertising of pharmaceuticals. http://www.csa.com/discoveryguides/direct/review3.php. Accessed October 13, 2011.

Skodol AE, Bender DS, Morey LC, et al. Personality disorder types proposed for DSM-5. J Pers Disord. 2011;25(2):136-169.

Smith DE, Lee DR, Davidson LD. Health care equality and parity for treatment of addictive disease. J Psychoactive Drugs. 2010;42(2):121-126.

Smith DE. The evolution of addiction medicine and its San Francisco roots. CSAM News. 2009; Winter: 4, 6. http://www.csamasam.org/pdf/misc/CSAM_News_Winter_2009.pdf. Accessed November 11, 2011.

Smith RC, Lyles JS, Gardiner JC, et al. Primary care clinicians treat patients with medically unexplained symptoms: a randomized controlled trial. J Gen Intern Med. 2006;21(7):671-677.

Social Security Disability physician sample letter. Benign Essential Blepharospasm Research Foundation. http://www.blepharospasm.org/disability6.html. Accessed October 20, 2011.

Some thoughts regarding our relationship to Alcoholics Anonymous. Narcotics Anonymous World Service Board of Trustees Bulletin. http://www.na.org/?ID=bulletins-bull13-r. Accessed November 11, 2011.

Spiegel A. How a bone disease grew to fit the prescription. National Public Radio. http://www.npr.org/templates/story/story.php?storyId=121609815&sc=emaf. Accessed November 16, 2011.

Stone J, Campbell K, Sharma N, Carson A, Warlow CP, Sharpe M. What should we call pseudoseizures? The patient's perspective. Seizure. 2003;12(8):568-572.

Stone J, Wojcik W, Durrance D, et al. What should we say to patients with symptoms unexplained by disease? The "number needed to offend." BMJ. 2002;325(7378):1449-1450.

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC139034/. Accessed November 14, 2011.

US Social Security Administration. Complete list of compassionate allowances conditions. http://www.ssa.gov/compassionateallowances/conditions.htm. Accessed October 20, 2011

US Social Security Administration. Disability evaluation under Social Security: listing of impairments - adult listings (part A).

http://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm. Accessed October 20, 2011.

US Social Security Administration. Disability evaluation under Social Security: listing of impairments - childhood listings (part B).

http://www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm. Updated June 7, 2011. Accessed October 20, 2011.

US Social Security Administration. Disability evaluation under Social Security: 3.04 cystic fibrosis. http://www.ssa.gov/disability/professionals/bluebook/3.00-Respiratory-Adult.htm#3_04. Accessed October 20, 2011.

US Social Security Administration. Disability evaluation under Social Security: 12.08 personality disorders.

http://www.ssa.gov/disability/professionals/bluebook/12.00-MentalDisorders-Adult.htm#12_08. Accessed October 20, 2011.

US Social Security Administration. Disability planner: how we decide if you are disabled. http://www.ssa.gov/dibplan/dqualify5.htm. Accessed October 20, 2011.

US Social Security Administration. Disability planner: how we decide if you are disabled, continued. http://www.ssa.gov/dibplan/dqualify6.htm. Accessed October 20, 2011.

US Social Security Administration. Disability programs: answers for doctors and other health professionals. http://www.ssa.gov/disability/professionals/answers-pub042.htm. Accessed October 20, 2011.

US Social Security Administration. Historical background and development of Social Security. http://www.ssa.gov/history/briefhistory3.html. Accessed October 20, 2011.

US Social Security Administration. Information we need about your work and education. http://www.ssa.gov/disability/step4and5.htm#Q4_2. Accessed October 20, 2011.

Valentine V. Gwyneth Paltrow, NPR has some news for you and your bones. *Shots*. National Public Radio.

http://www.npr.org/blogs/health/2010/08/19/129303014/gwyneth-paltrow-npr-hassome-news-for-you-and-your-bones. Accessed November 16, 2011.

Wesson DR, Smith DE. Buprenorphine in the treatment of opiate dependence. *J Psychoactive Drugs*. 2010;42(2):161-175.

White KP, Nielson WR, Harth M, Ostbye T, Speechley M. Does the label "fibromyalgia" alter health status, function, and health service utilization? A prospective, within-group comparison in a community cohort of adults with chronic widespread pain. Arthritis Rheum. 2002;47(3):260-265.

Wittchen HU, Jacobi F, Rehm J, et al. The size and burden of mental disorders and other disorders of the brain in Europe 2010. European Neuropsychopharmacol. 2011;21(9):655-679.

World Health Organization. Obesity and overweight: fact sheet no. 311. http://www.who.int/mediacentre/factsheets/fs311/en/. Accessed October 2, 2011.

Copyright 2011 American Medical Association. All rights reserved.

Virtual Mentor

American Medical Association Journal of Ethics December 2011, Volume 13, Number 12: 922-924.

About the Contributors

Theme Issue Editor

Shara Yurkiewicz is a second-year student at Harvard Medical School in Boston. She graduated cum laude from Yale University with an intensive BS in biology. Shara has conducted ethics research on personalized medicine at the Hastings Center and on palliative care at Harvard. Her other academic interests include medical education and medical journalism, and she has written for a variety of publications, including the *Los Angeles Times* and *Discover*. Shara's blog can be found at http://blogs.plos.org/thismayhurtabit/.

Contributors

George L. Blackburn, MD, PhD, holds the S. Daniel Abraham Chair in Nutrition Medicine and is an associate professor of nutrition and associate director of nutrition in the Division of Nutrition at Harvard Medical School in Boston. He is also chief of the Nutrition/Metabolism Laboratory and director of the Center for the Study of Nutrition Medicine (CSNM) at Beth Israel Deaconess Medical Center in Boston. He graduated from the University of Kansas Medical School and earned his PhD in nutritional biochemistry from MIT. Dr. Blackburn has studied bionutrition, surgical metabolism and critical care medicine, best practice standards for weight loss surgery, and the neurobiology of food selection and dietary impulse control.

Valarie Blake, JD, MA, is a senior research associate for the American Medical Association Council on Ethical and Judicial Affairs in Chicago. Ms. Blake completed the Cleveland Fellowship in Advanced Bioethics, received her law degree with a certificate in health law and concentrations in bioethics and global health from the University of Pittsburgh School of Law, and obtained a master's degree in bioethics from Case Western Reserve University. Her research focuses on ethical and legal issues in assisted reproductive technology and reproductive tissue transplants, as well as regulatory issues in research ethics.

Barry DeCoster, PhD, is a visiting instructor of history, philosophy, and sociology of science at Lyman Briggs College of Michigan State University in East Lansing. His research in philosophy focuses on problems in health care ethics and the philosophies of science and medicine. He is working on a project analyzing what count as "good" medical explanations of disease, including looking into the complications surrounding medically unexplained disorders (e.g., fibromyalgia and chronic fatigue syndrome).

Mary Lynn Dell, MD, DMin, is an associate professor of psychiatry, pediatrics, and bioethics at Case Western Reserve University School of Medicine and the director of

the Child and Adolescent Psychiatry Consultation Liaison Service at Rainbow Babies and Children's Hospital in Cleveland, Ohio. Dr. Dell's clinical and academic interests are the psychiatric care of medically ill children, adolescents, and their families; bioethics; and religion and spirituality in medicine and psychiatry.

Cynthia Geppert, MD, MA, PhD, MPH, is chief of consultation psychiatry and ethics at the New Mexico Veteran's Affairs Health Care System and associate professor of psychiatry and director of ethics education at the University of New Mexico in Albuquerque. Dr. Geppert's interests include ethics consultation, medical and ethics education, and the clinical and ethical issues involved in the practice of psychosomatic medicine, addiction and pain medicine, and hospice and palliative medicine.

Matthew E. Growdon is a second-year medical student at Harvard Medical School in Boston. Prior to medical school, he was a research coordinator for projects on Alzheimer disease and frontotemporal dementia at the UCSF Memory and Aging Center in San Francisco. His interests include behavioral neurology and the history of medicine. He received a BA in history and literature from Harvard University in 2007.

Matt Lamkin, JD, MA, is an attorney and a fellow at Stanford University's Center for Law and the Biosciences in Stanford, California. His research examines how our shifting health care terrain can subtly modify traditional conceptions of individual autonomy, including preconceived understandings of privacy, voluntary consent, and the rights to bodily integrity and self-determination.

Elizabeth Kitsis, MD, MBE, is director of bioethics education at the Albert Einstein College of Medicine in the Bronx, New York, and a practicing rheumatologist. She was previously vice president of a global pharmaceutical company.

Emily A. Kuhl, PhD, is a science writer for the American Psychiatric Association's Division of Research and the American Psychiatric Institute for Research and Education in Arlington, Virginia.

David J. Kupfer, MD, is chair of the DSM-5 Task Force. He is also a professor of psychiatry and a professor of neuroscience and clinical and translational science at the University of Pittsburgh Medical Center in Pennsylvania.

Darrel A. Regier, MD, MPH, is vice chair of the DSM-5 Task Force. He is also director of the American Psychiatric Association's Division of Research and the American Psychiatric Institute for Research and Education in Arlington, Virginia.

James E. Sabin, MD, is a clinical professor in the Departments of Population Medicine and Psychiatry at Harvard Medical School in Boston and the director of the ethics program at Harvard Pilgrim Health Care, a not-for-profit health plan. His

research interests include the ethics of health care resource allocation. Dr. Sabin blogs at http://healthcareorganizationalethics.blogspot.com.

David E. Smith, MD, is the founder of the Haight Ashbury Free Medical Clinic and a pioneering advocate of the disease model of addiction. He is a past president of the American Society of Addiction Medicine and the California Society of Addiction Medicine.

Copyright 2011 American Medical Association. All rights reserved.