

# AMA Journal of Ethics

## Formerly *Virtual Mentor*

June 2015

Volume 17, Number 6: 489-596

### From an *AMA Journal of Ethics* Special Contributor

Reuniting through the Medical Humanities: Two Educators, Two Programs 491  
Martin Kohn and Eric Kodish

## Ethics in Rehabilitation Medicine

### From the Editor

The Motor Function Specialty 496  
Gaurav Jay Dhiman

### Ethics Cases

Physician Paternalism and Severe Disability: Strengthening Autonomy  
through Therapeutic Engagement 500  
Commentary by Kristi L. Kirschner

Safety and Ethical Considerations in Discharging Patients to  
Suboptimal Living Situations 506  
Commentary by James Hill and William Filer

Athlete Return-to-Play Decisions in Sports Medicine 511  
Commentary by Adam S. Tenforde and Michael Fredericson

### Podcast

Ethics in Research with People Who Have Disabilities  
Interview with Jonathan D. Moreno

### Medical Education

Assessing Competency in Physical Medicine and Rehabilitation  
Residency: the ACGME Milestones Initiative 515  
Julian Willoughby, Vu Nguyen, and William L. Bockenek

### In the Literature

A Clinical Ethics Approach to Opioid Treatment of Chronic Noncancer Pain 521  
Mitchell J. Cohen and William C. Jangro

<p><b>Recognizing Psychological Diversity in People with End-Stage Amyotrophic Lateral Sclerosis</b> Debjani Mukherjee</p>	<p>530</p>
<p><b>State of the Art and Science</b></p>	
<p><b>Ethics in Rehabilitation: Access to Prosthetics and Quality Care Following Amputation</b> Paul F. Pasquina, Antonio J. Carvalho, and Terrance Patrick Sheehan</p>	<p>535</p>
<p><b>Health Law</b></p>	
<p><b>Service Dogs for Veterans with Posttraumatic Stress Disorder</b> Richard Weinmeyer</p>	<p>547</p>
<p><b>Policy Forum</b></p>	
<p><b>Access to Rehabilitative Care in the Affordable Care Act Era</b> Steven G. Ullmann</p>	<p>553</p>
<p><b>Veterans Health Administration Policy on Cannabis as an Adjunct to Pain Treatment with Opiates</b> Michael Krawitz</p>	<p>558</p>
<p><b>Medicine and Society</b></p>	
<p><b>The Disability Movement’s Critique of Rehabilitation’s Medical Model: a Rebuttal</b> John D. Banja</p>	<p>562</p>
<p><b>History of Medicine</b></p>	
<p><b>History of Physical Medicine and Rehabilitation and Its Ethical Dimensions</b> Levi Atanelov, Steven A. Stiens, and Mark A. Young</p>	<p>568</p>
<p><b>Images of Healing and Learning</b></p>	
<p><b><i>Multifaceted Nexus</i></b> Kyle T. Amber</p>	<p>575</p>
<p><b>Resources</b></p>	
<p><b>Suggested Readings and Resources</b></p>	<p>576</p>
<p><b>About the Contributors</b></p>	<p>593</p>

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 491-495

## FROM AN AMA JOURNAL OF ETHICS SPECIAL CONTRIBUTOR

### Reuniting Through the Medical Humanities: Two Educators, Two Programs

Martin Kohn, PhD, and Eric Kodish, MD

#### *Bashert* a Yiddish Word Meaning Preordained or Meant To Be

**MK:** My entry into the field of [medical humanities](#) at Northeast Ohio Medical University (NEOMED) in 1981 places me in the second generation of those to enter a field whose roots go back to 1960 [1]. Although not part of the initial wave of immigrants to the shores of this new multi- (or for some, trans-) disciplinary academic endeavor, the second wave was still a time when many of us from disparate fields—my training is in education—received a warm welcome. I began my work at NEOMED a few months after its inaugural class graduated. How unexpected, then—and fortunate—to find myself in exactly the same situation 28 years later (in 2009) at Cleveland Clinic Lerner College of Medicine (CCLCM) of Case Western Reserve University. Was it fate? Destiny? Or was it what we might call *bashert* that my department chair would be a former (favorite) NEOMED student—and friend—Rick Kodish.

**EK:** And if I were firmly in the medical humanities, I would be in the third wave. Starting medical school in 1982, I knew that the art of medicine interested me more than the science. Finishing my pediatrics residency and heading for a career in childhood cancer in 1989, I was told by a very prominent leader that I would never succeed unless I did hard science, that is, bench research. I responded by taking an ethics fellowship to complement my oncology training and began 20 years of research on informed consent and [pediatric research ethics](#). Is ethics a subspecialty of the medical humanities? To this day I am not sure. But I do know that hiring Marty Kohn to lead our Cleveland Clinic Program in Medical Humanities feels like it was *bashert*.

#### Curricular Challenges

**MK:** The nascent NEOMED curriculum I inherited was offered exclusively in the senior year. It was a required course that was tailored to each student through elective offerings in the humanities and the behavioral and social sciences that each student chose to engage. Our task was to move the work to the earlier years of the curriculum as well, creating full curricular integration. The task at CCLCM was different. Since its inception, the school has required medical humanities coursework throughout its five-year curriculum (including a research year). The challenge I faced was to reshape the 108 dedicated classroom hours that occurred during the first two years of the curriculum to provide a stronger foundation both for later work in the curriculum (30 hours in year 3 and approximately 10 hours each in years 4 and 5) and for our students' graduate

medical education and years of medical practice. Our team—child and adolescent psychiatrist Molly Wimbiscus, MD; performing artist and arts educator Katherine Burke, MFA; and I—has worked with a group of seasoned physician small-group discussion facilitators, thematic “block leaders,” and guest presenters to fashion a two-year foundational medical humanities program that operates out of a “big tent” curricular framework. We have coursework in both years in traditional humanities disciplines (primarily literature and history), bioethics (primarily clinical), and health care systems (from comparative, practical, policy, and justice perspectives). We’ve also developed a community-based, longitudinal arts and neighborhood health and well-being experience during the first year—Devising Healthy Communities—that includes a dollop of qualitative research fundamentals. We have [reflective writing](#) sessions throughout both years, capping each of our three first-year writing assignments with the presentation of dramatic vignettes based on a creative amalgamation of the students’ writing and performed by professional actors. This “meta-reflective” activity has been rated very highly by our students. With student assessment for all coursework at CCLCM exclusively based on electronic portfolios, we have developed over the past few years a number of opportunities for students to submit assignments in addition to their reflective writing for critical comments by faculty in a number of our teaching blocks. Most recently, we implemented a bioethics case write-up exercise that calls upon numerous bioethics staff members as well as fellows in our Cleveland Fellowship in Advanced Bioethics program to offer their critical insights to our students. Having rich resources and the willingness of so many staff members to participate in our programs makes our work significantly stronger and, according to students, increasingly valued.

**EK:** As director of our Center for Ethics, Humanities and Spiritual Care, I am responsible for setting its vision. Vision setting works best as a collaborative project, and education serves as the unifying theme. Some of our faculty are more clinically oriented, while others are primarily engaged in research. Education brings everyone together, and Marty’s leadership in *creative* approaches is universally respected. A number of other respected leaders within the clinic have come together to support the humanities vision. Most importantly, CCLCM’s executive dean, James Young, MD, has been an enthusiastic partner in our medical humanities work.

### **Collaborations**

**MK:** Perhaps because of its very nature as a consortium, NEOMED offered opportunities for collaboration. The vehicle for my initial collaborative efforts there sprang up from the William Carlos Williams poetry competition for medical students, which I established at the end of my first year [2]. The poetry competition played a central role in the building of other collaborations, including the Center for Literature and Medicine (now housed at Hiram College) and a literature and medicine book series published by Kent State University Press. My outreach efforts at CCLCM are built on my previous work at NEOMED and Hiram College—for example, co-producing with our local NPR affiliate,

WCPN-FM, a radio drama of the play *Wings*—and on new collaborations with the Cleveland Institute of Art (developing an elective, Portrait Drawing, Visual Thinking Strategies, and Increased Observational Skills), and John Carroll University (whose arts and sciences faculty members staff our medical humanities teaching blocks). Another deep collaboration among our students, four Cleveland neighborhoods, and local artists (visual, spoken word, and hip hop) is the Devising Healthy Communities project, which is entering its third year of development within the first year's Community and Calling block.

**EK:** The Devising Healthy Communities project would not be possible without the generous support of the Cleveland Foundation. Our philanthropic partners are critical to our current and future success, and I am committed to helping our Program in Medical Humanities secure the resources it needs to teach the next generation of physicians. We must ensure that the miraculous but unflagging progress on the scientific and technical sides of health care is balanced by an emphasis on professionalism, virtue, and character. This commitment was perhaps best stated by Hans Jonas [3]:

Let us not forget that progress is an optional goal, not an unconditional commitment.... Let us also remember that a slower progress in the conquest of disease would not threaten society, grievous as it is to those who have to deplore that their particular disease be not conquered, but that society would indeed be threatened by the erosion of those moral values whose loss, possibly caused by too ruthless a pursuit of scientific progress, would make its most dazzling triumphs not worth having [4].

### **A Vision for the Future**

**MK:** A spate of recently published articles theorize on the [role of medical humanities](#) in medical education [5-7]. These works add to decades of thinking about and justifying the presence of medical humanities in the curriculum. However, as Angela Woods notes, many in our field have an "indefatigable [penchant for] exploration of its identity, purpose and value" [8]. In the end, I think many of us who teach in this field simply hope to encourage (without moralizing), provoke (without propagandizing), critique (without sniping), and jest (without demeaning). Modeling and passing on these stances, however, depends greatly on a willingness to take the time to stay wide awake to others' experiences and perspectives [9], something that many of us in the field strive mightily to [imbue in our students](#) and in ourselves. With a view toward further exploration of such process-oriented goals, we are planning to convene in Cleveland, in the spring of 2016, an International Summit in Medical Humanities and the Arts. A bit further down the road, in 2019, with the opening of a new Case Western Reserve University Health Education campus at the Cleveland Clinic, we aim to have intercampus programming (with arts and sciences faculty) as well as interinstitutional programming (with, for instance, the Cleveland Museum of Art, the Cleveland Museum of Natural History, and other

University Circle educational institutions) that will be the early bloom of a regionwide health humanities, social medicine, and arts consortium flourishing in Northeast Ohio.

EK: Amen.

### References

1. Fox DM. Who we are: the political origins of the medical humanities. *Theor Med.* 1985;6(3):327-341.
2. Kohn M. A reminiscence. *J Med Humanit.* 2005;26(4):273-276.
3. Jonas H. Philosophical reflections on experimenting with human subjects. *Daedalus.* 1969;98(2):219-247.
4. Jonas, 245.
5. Kumagai AK, Wear D. "Making strange": a role for the humanities in medical education. *Acad Med.* 2014;89(7):973-977.
6. Boudreau JD, Fuks A. The humanities in medical education: ways of knowing, doing and being [published online ahead of print April 8, 2014]. *J Med Humanit.* doi:10.1007/s10912-014-9285-5.
7. Metzl JM, Hansen H. Structural competency: theorizing a new medical engagement with stigma and inequality. *Soc Sci Med.* 2014;103:126-133.
8. Woods A. Review of: Bates V, Bleakley A, Goodman S, eds. *Medicine, Health and the Arts: Approaches to the Medical Humanities.* *Med Humanit.* 2014;40(2):146-148.
9. Greene M. Towards wide-awakeness: humanities in the lives of professionals. In: Wear D, Kohn M, Stocker S, eds. *Literature and Medicine: A Claim for a Discipline: Proceedings of the Northeastern Ohio Universities College of Medicine's Literature and Medicine Conference, May 1984.* McLean, VA: Society for Health and Human Values; 1987:3-15.

**Martin Kohn, PhD**, is director of the Cleveland Clinic's Program in Medical Humanities within the Center for Ethics, Humanities and Spiritual Care and an associate professor in the Lerner College of Medicine at Case Western Reserve University in Cleveland, Ohio. His research interests are in the pedagogical aspects of the medical humanities and in developing performance pieces that engage health care professionals and the public in dialogue about the nature and future of health care.

**Eric Kodish, MD**, is the director of the Center for Ethics, Humanities and Spiritual Care at the Cleveland Clinic in Cleveland, Ohio, where he is also the F. J. O'Neill Professor and chairman of the Department of Bioethics and executive director of the Cleveland Fellowship in Advanced Bioethics. Dr. Kodish has an appointment as professor of pediatrics in the Lerner College of Medicine at Case Western Reserve University.

**Related in the *AMA Journal of Ethics***

[Multiple Exposures—Reflective Writing in the First Year of Medical School](#), July 2011

[A Complete Medical Education Includes the Arts and Humanities](#), August 2014

[Expanding Humanities Training beyond Medical School](#), August 2014

[Creating a Space for the Arts and Humanities at the University of Colorado Anschutz Medical Campus](#), August 2014

[Fostering Student Engagement in Medical Humanities Courses](#), August 2014

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 496-499

## FROM THE EDITOR

### The Motor Function Specialty

The American Academy of Physical Medicine and Rehabilitation defines the PM&R specialty as “the branch of medicine emphasizing the prevention, diagnosis, and treatment of disorders—particularly related to the nerves, muscles, bones and brain—that may produce temporary or permanent impairment” [1]. These disorders range from spina bifida and muscular dystrophy to sports injuries and musculoskeletal pain to Parkinson disease. Physiatrists—specialists in PM&R—also care for people with spinal cord injuries and fit prosthetics for those who have had limb amputations. The ultimate goal is to improve movement as much as possible and reduce the psychological, emotional, familial, and vocational stresses that come with temporary or permanent loss of motor function. The field is notable for providing long-term care and for collaborating closely with orthopedic surgeons, physical therapists, occupational therapists, and other health care professionals.

Although society was, for a long time, not particularly accommodating to people with physical impairment, and words like “cripple” or “gimp” were said aloud, great strides have been made in the last three or four decades. Arguably, individuals with disabilities like physicist Stephen Hawking (amyotrophic lateral sclerosis), actor Christopher Reeve (quadriplegia), actor Michael J. Fox (Parkinson disease), and boxer Muhammad Ali (Parkinsonism) have shown that a physical disorder or impairment is not the end to a productive and valuable life. Today, public support for research into physical disorders is more robust than ever, with disease organizations focused on physical disability—like the Michael J. Fox Foundation, Myelin Repair Foundation, Parkinson’s Disease Foundation, Muscular Dystrophy Association, ALS Association, National Multiple Sclerosis Society, American Parkinson Disease Association, National Parkinson Foundation, and Arthritis Foundation—ranking among the top 20 research grant providers in the United States [2]. More visibly, and largely subsequent to the Americans with Disabilities Act of 1990, ramps, elevators, and other assistive services are found routinely in schools, shopping centers, airports, and businesses. The Paralympic Games for athletes with disabilities are run in partnership with and in the same city and venue as their more well-known Olympic counterpart [3].

The ethics of treating patients with a variety of physical impairments and disabilities is as complex as the clinical aspects. Some physical impairments are permanent or lack “easy fixes,” so the process of rehabilitation is often a protracted and frustrating one. And because medicine does not provide a cure for many disabling conditions, patients’

expectations and hopes must be carefully informed and a fine balance of optimism and caution maintained.

The goal of this issue of the *AMA Journal of Ethics* is to identify some of the ethical concerns professional caregivers must bear in mind when helping patients recover from physical disorders and injuries while, at the same time, upholding their clinical and ethical standards. These concerns include how best to help those with impairment think realistically about the immediate and long-term future, planning safe discharge, securing equal access to rehabilitation care for all, and managing long-term pain. A secondary goal of the issue is to provide a better picture of the work that physiatrists do through a look at the history of the specialty and the education of its resident trainees.

Three articles speak to physiatrists' central task: helping patients adapt to an impaired "self." Kristi L. Kirschner, MD, a physiatrist at the Schwab Rehabilitation Hospital and faculty member at the University of Illinois in Chicago, analyzes physician paternalism in a case in which a former Navy Seal refuses recommended care. Adam S. Tenforde, MD, a PM&R fellow in sports medicine, and Michael Fredericson, MD, a professor and director of the PM&R sports medicine program at Stanford University, address the importance of managing an injured high school athlete's expectations for recovery. Debjani Mukherjee, PhD, director of the ethics program at the Rehabilitation Institute of Chicago and an associate professor of PM&R and medical humanities and bioethics at Northwestern University, discusses two articles that shed light on the relationship among amyotrophic lateral sclerosis, depression, and a wish to die.

James Hill, MD, an assistant professor and director of the residency program at the University of North Carolina at Chapel Hill, and William Filer, MD, an assistant professor and associate director of the residency program in the Department of PM&R at the same institution, consider the topic of safe discharge through the case of a woman with a spinal cord injury who is medically ready but lacks the proper home setting for optimal discharge from an inpatient rehabilitation facility.

Equal access and equitable care for all people with all types of injuries is a PM&R goal. Paul F. Pasquina, MD, residency program director of PM&R at Walter Reed National Military Medical Center and chair of PM&R at the Uniformed Services University of the Health Sciences, Antonio J. Carvalho, researcher at Walter Reed National Military Medical Center, and Terrence Patrick Sheehan, MD, chief medical officer at Adventist Rehabilitation Hospital of Maryland, identify disparities in access to and quality of prosthetics for patients who have had limbs amputated. In the health law section, Richard Weinmeyer, JD, MA, Mphil, a senior research associate for the AMA's Council on Ethical and Judicial Affairs, explains why veterans returning with posttraumatic stress disorder are not currently entitled to service dog benefits from the Department of Veterans Affairs (VA) while those with physical disability are. And Steve Ullmann, MD,

professor and director of the Center for Health Sector Management and Policy at the University of Miami, describes how the 2010 Patient Protection and Affordable Care Act has changed delivery of rehabilitation care.

Long-term management of pain continues to challenge physicians and patients alike. Mitchell J. Cohen, MD, vice chair for education and an associate professor in the Department of Psychiatry and Human Behavior, and William C. Jangro, MD, an instructor in the Department of Psychiatry and Human Behavior, both at Thomas Jefferson University, discuss a 2010 article on the ethics of prescribing opioids for chronic noncancer pain. Michael Krawitz, a US Air Force veteran and the executive director of Veterans for Medical Cannabis Access, brings readers up to date on the VA's evolving medical marijuana policy for its patients.

The medical rehabilitation model discussed so far has come under some criticism from the disability advocacy community for its view of impairments and disabilities as "deficits." John Banja, PhD, a professor in the Department of Rehabilitation Medicine and a medical ethicist at the Center for Ethics at Emory University, offers a rebuttal to this critique.

For some background about the PM&R specialty, we enlist Levi Atanelov, MD, a resident in PM&R at Johns Hopkins University, Steven A. Stiens, MD, associate professor of rehabilitation medicine at the University of Washington, and Mark A. Young, MD, chair of PM&R at the Maryland Division of Rehabilitation Services. They recap the history of PM&R as a field and the ethical issues physiatrists commonly face. Julian Willoughby, MD, a resident in PM&R, Vu Nguyen, MD, an associate professor, the vice-chair of academics, and residency program director, and William L. Bockenek, MD, professor and chair in the Department of PM&R, all at the Carolinas Medical Center/Carolinas Rehabilitation, explain the role of competency-based milestones in assessing the training of physiatry residents.

Kyle T. Amber, a transitional year resident at MacNeal Hospital in Berwyn, Illinois, sheds some colored light on physiatry with his artistic depiction of a knee radiograph. The piece highlights the many facets that any single clinical or ethical "picture" always presents.

In this month's podcast, Jonathan D. Moreno, PhD, professor in the Department of Medical Ethics and Health Policy at the University of Pennsylvania and a senior fellow at the Center for American Progress, discusses the American military's role in developing physical enhancements for soldiers and the ethical implications of military research into physical disability.

Discussions about the ethics of many types of medical practice are commonplace, but discussions about the ethics of rehabilitation medicine are encountered less often.

Perhaps this is because most people who do not have impairments think they will never face disability. At some point, though, many will, whether it is through injury, stroke, or disease. It is therefore important that health professionals respect and understand the complexity of treating, both clinically and ethically, those with temporary or permanent impairment in motor function.

### References

1. American Academy of Physical Medicine and Rehabilitation. About physical medicine and rehabilitation (PM&R). <http://www.aapmr.org/patients/aboutpmr/Pages/default.aspx>. Accessed April 22, 2015.
2. Philippidis A. Top 20 grant-giving disease foundations. *Genetic Engineering and Biotechnology News*. May 28, 2013. <http://www.genengnews.com/insight-and-intelligence/top-20-grant-giving-disease-foundations/77899817/?page=1>. Accessed April 23, 2015.
3. Olympic Movement. Paralympic Games. <http://www.olympic.org/content/olympic-games/paralympic-games/?tab=paralympic-games>. Accessed April 24, 2015.

### Gaurav Jay Dhiman, MS-3

University of Miami/Miller School of Medicine  
Miami, Florida

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 500-505

## ETHICS CASE

### Physician Paternalism and Severe Disability: Strengthening Autonomy through Therapeutic Engagement

Commentary by Kristi L. Kirschner, MD

Dr. Gill's rehab inpatient, Joel, is a decorated former Navy Seal. By age 35, he had served around the globe for a decade. His military career ended two years later, when he suffered a spinal cord injury from two gunshot wounds to his neck. The injuries left him an incomplete quadriplegic—Joel can eat and swallow and move his arms somewhat, but he cannot use his hands; he has nerve pain and spasticity in his extremities. Three months ago, following his initial surgery and monthlong hospitalization, Joel was sent to Dr. Gill's unit.

During these months, Dr. Gill has kept a close watch on Joel's depression and adaptation to his medical condition. In general, Joel's depression is in line with what any formerly able-bodied—indeed athletic—person would experience in a like situation. Joel has rejected antidepressant medication, however, and has been determined competent to do so. He is not married and did not have a romantic relationship at the time of his injury. On the occasions when some of his friends from the Seals or from college have visited, Dr. Gill has watched Joel enjoy their company and even laugh.

Nevertheless, Joel has said and shown that he does not want to live in his current condition. Lamenting that he is unable to take his own life, he ribbed Dr. Gill, "And I'm sure you're not gonna help me, doc, are you? Even if I did keep your country safe and all that other hero stuff. Right?" Joel has had hospital staff pull up information about spinal cord injuries on the computer that he keeps in his room and has decided that his physical condition is not going to improve. Dr. Gill and the team have shown Joel an Internet support group for people with spinal cord injuries and have told him that, like many of those in the support group, Joel could be discharged from the unit to a handicap-adapted home and could live independently with round-the-clock caregivers to feed him and tend to his other activities of daily living. But Joel does not want to put any friend or family member into that role, so active discharge planning is on hold.

Now Joel has developed acute renal failure from antibiotics he was taking for infected pressure sores. Dr. Gill tells Joel that he must undergo temporary hemodialysis and that he (Dr. Gill) expects that Joel's kidney function will return to normal.

In response, Joel says, "This is the gift I've been waiting for. This kidney failure will kill me, right, doc? I'm going to refuse the hemo-whatever, so send the shrinks in to interview me again. I'm as sane as you are, and I don't want to live like this."

### **Commentary**

Joel's story sounds familiar, doesn't it?

*Physically fit, vibrant person in his prime becomes injured in an instant with [insert spinal cord injury, multiple trauma, burns]. Person survives the initial trauma but has extensive physical disability. Person questions whether life is worth living and refuses life-sustaining treatment (or requests some other form of assistance in dying).*

This narrative arc keeps us in its grip. It repeatedly scores hits at the box office: *Whose Life Is It Anyway?* (1978 stage play, 1981 movie) and *Million Dollar Baby* (the Academy Award winner in 2005). These stories raise profound questions: what gives life meaning and quality? Who decides? What role should medical professionals play? Is a request for medical assistance in dying a form of assisted suicide?

The case of [Dax Cowart](#) established this paradigm more than 40 years ago [1, 2]. Dax was a returning Vietnam fighter pilot who sustained burns over 68 percent of his body surface area in a freak gas explosion that killed his father. For decades, he waged a public battle against the medical profession for continuing to treat him for ten months following his accident despite his explicit refusal. His case settled what has become the overarching consensus: the competent patient has the right to refuse medical treatment, even life-sustaining treatment. But the devil is in the details.

Was Dax competent (or more specifically, did he have "decision-making capacity," or DMC [3]) immediately after the explosion? At that point, Dax told the farmer who came upon him to get him a gun because he was already a "dead man" [1, 2]. Did he have decision-making capacity in the ER? How about when he was in the ICU, heavily sedated, intubated, and critically ill after innumerable debridements and surgeries? Many clinicians and clinical ethicists would have serious reservations about Dax's ability to make a truly informed decision at this point in the ICU because complex medical and emotional factors (such as his severe pain, the use of narcotics, emotional shock at comprehending the extent of his injuries, and grief over the death of his father) would most likely impede his cognitive and emotional processing.

But at some point Dax did regain capacity. When? Hard to tell exactly. Reasonable people will disagree about the moment in time because there is no bright line. Decisional capacity is not an all-or-none phenomenon [4]. It's a matter of degree. It is also highly likely, indeed commonplace, that people can satisfy the criteria for decisional capacity but be unable to accurately forecast how they will adjust when faced with loss and

adversity. Psychiatrist-ethicist Jodi Halpern, MD, PhD, elegantly deconstructs errors in what is known as “affective forecasting” and why they challenge patients and clinicians who are making serious health decisions in situations such as Dax’s and Joel’s [5]. She describes three mechanisms that seem to underlie forecasting errors: (1) focalism, in which one tends to emphasize factors that will change (or have changed) over those that will remain the same; (2) immune neglect, in which the person fails to take into account that defense mechanisms (such as denial, use of humor) will aid in adapting and coping to lessen unhappiness; and (3) inability to predict genuine adaptation or to recognize that what is valued will likely shift in response to the circumstances and that lost sources of meaning will likely be replaced with new sources.

These psychological mechanisms are *why* we continue to struggle with these cases. It’s no surprise that the recent story of Tim Bowers, the 32-year-old, newly married and expectant father, re-energized and re-engaged the questions teed up by Dax’s case [6]. Tim sustained a cervical spinal cord injury ([SCI]) after falling from a tree while hunting. Within hours of admission,

his family told him they’d asked the doctors to bring him out of a drug-induced coma. They had terrible news—and a horrific question to ask. He had fallen 16 feet as he was climbing to his tree stand, and he had shattered his spine. He likely would spend the rest of his life connected to a breathing machine, unable to walk and never able to hold the baby that Abbey was carrying in her womb. Would he rather be disconnected from the respirator? Tim Bowers, just 32 years old, decided it was his time [6].

He died about 5 hours after the ventilator was withdrawn, a day after sustaining his injury. The question remains for many: was this an act of autonomy, based upon Mr. Bowers’s full informed consent? Or was it “uninformed consent to die,” as argued by Paul Tobin, president and CEO of the United Spinal Association [7]?

Halpern argues that it is extraordinarily difficult to make clear, unequivocal decisions in the face of complex unexpected tragedies [5]. One cannot simply “know” what he or she would want ahead of time and put it in writing because so much relevant information is simply not available beforehand. Indeed, studies show that many people will change their minds about what is tolerable when their conditions change, as Christopher Reeve eloquently describes in his autobiography about life after SCI, *Still Me* [8]. People like Tim Bowers—intubated, sedated, and in an ICU—simply cannot fully comprehend all the necessary relevant information at once, after a single presentation [9]. Furthermore, these decisions are also not made in a vacuum. They are highly interactional. Outcomes can be influenced by how the information is framed and by the perspectives and beliefs of others [10].

So now we are faced with Joel—a decorated Navy Seal, four months after a gunshot wound to the spine, in an inpatient rehab unit with incomplete quadriplegia. He has lived with the knowledge of his SCI for four months. He has moved from acute care to a rehabilitation unit. He can communicate freely, without the impediment of an endotracheal tube. He is also portrayed as stoic, probably depressed, but refusing antidepressant treatment. He questions whether he wants to live with SCI, but initially there is no life-sustaining treatment for him to refuse or remove. But that changes when Joel develops temporary renal failure. Now he needs short-term dialysis. Joel sees a way to facilitate his death: refuse dialysis. So here's the question Dr. Gill has to answer: does Joel have adequate decision-making capacity to refuse dialysis? And, if so, what then?

The short answer is probably *yes*. Unless his depression is severe, Joel probably meets the basic criteria for establishing DMC: he understands his condition, his choices, and the likely consequences of refusing dialysis. But that doesn't mean he is fully competent. There are [reasons](#) the conclusion he has drawn should be challenged. Does he fully appreciate what life with SCI might be like outside of a hospital? I'm not sure. We are told that "Dr. Gill and the team have shown Joel an Internet support group for people with spinal cord injuries" and told him that he "could be discharged from the unit to a handicap-adapted home and could live independently with round-the-clock caregivers to feed him and tend to his other activities of daily living." Joel, however, "does not want to put any friend or family member into that role." Let's look critically at the questions these statements raise and the physician's role.

1. Does Joel understand that a paid personal assistant (PA) is different from a family caregiver? In general, I recommend that patients hire a PA rather than rely on friends or family members when possible. The relationship between the person with the disability and the PA is then a respectful employer-employee one; the patient gets to hire and fire and direct his care. This arrangement also reduces family members' stress, resentment, and role confusion (between, e.g., marriage partner and caregiver roles).
2. Has Joel been on any outings to a restaurant, movie, or sporting event yet?
3. Has he actually met and talked to others living with SCI? Although he is four months into living with SCI, there is still much he doesn't know.

I have come to believe that my most important job as a rehab doctor is not to order consults, tests, medicines, equipment, or therapy. My most important job is to help my patients (and their families) imagine possible narratives for the next chapter of life. That requires curiosity and mental freedom. Patients who are depressed, grieving, or angry may be limited in their ability to imagine possible futures. They need our help to do so.

Thus, my primary goal with Joel would be to encourage him to give himself more time to explore what life is like for others with similar disabilities and life circumstances. He is

really just beginning to learn that he can be self-determining even if he's not physically independent. He needs to see for himself that he can go to school, a faith community, or out to a movie and dinner; re-enter the work force; play adapted sports; and participate in the arts. He needs to learn that he can still fall in love or be a parent—whether he can play ball with his future child or not. He would learn some of this from me and some of it from his nurses and therapists, but much of it he would learn from the real experts—people who live with disabilities themselves. He will need a village to help him at first. Eventually he will be part of that village helping others.

I would remind Joel that a disability such as SCI is a major disruption to one's life narrative, but so are other events such as bankruptcy, unemployment, and the death of a parent, child, or spouse. I would ask him to describe for me what feels intolerable in the here and now. What does he imagine would be intolerable when he thinks about his future? I would explain to him that many people with disabilities initially question whether life will be "worth living," but most do, with time, find that it is [11]. I would explore with him times when he has had to reinvent aspects of himself in the past. We would talk about his demonstrated ability to be resilient. I would want him to know that I believe he can have a life worth living and will be there for the duration to help him.

But, in the end, I would also tell Joel that I [respect his agency](#). I would encourage him to imagine what he thinks would happen if he refuses dialysis. What other decisions would he need to be prepared to make? Would he continue to go to therapy, eat and drink, take his medications? Will he want to go on trips outside of the hospital? See any friends or family? And what if his kidneys recover and he survives without dialysis? How would he feel? My hope would be to keep the lines of communication open, to explore any inconsistencies or feelings of ambivalence Joel may have, and to offer him opportunities to reconsider his decision. And, of course, I would offer him opportunities to talk to mental health professionals, spiritual advisers, and, most importantly, people with SCI who have been where he is now.

## References

1. White RB. *Please Let Me Die* [video]. Galveston, TX: University of Texas Medical Branch-TV; 1974.
2. Cowart D. *Dax's Case: Who Should Decide* [video]. New York, NY: Filmmakers Library; 1984.
3. Grisso T, Appelbaum PS. *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. New York, NY: Oxford University Press; 1998.
4. Etchells E, Darzins P, Silberfeld M, et al. Assessment of patient capacity to consent to treatment. *J Gen Intern Med*. 1999;14(1):27-34.
5. Halpern J, Arnold RM. Affective forecasting: an unrecognized challenge in making serious health decisions. *J Gen Intern Med*. 2008;23(10):1708-1712.

6. Sabalow R, Guerra K. Injured hunter chooses death over paralysis. *USA Today*. November 6, 2013. <http://www.usatoday.com/story/news/nation/2013/11/06/injured-hunter-chooses-death-over-paralysis/3461259/>. Accessed March 5, 2015.
7. Tobin PJ. Giving my uninformed consent to die. United Spinal Association. November 8, 2013. <http://www.spinalcord.org/giving-my-uninformed-consent-to-die/>. Accessed March 5, 2015.
8. Reeve C. *Still Me*. New York, NY: Ballantine Books; 1998.
9. Volpe RL, Crites JS, Kirschner KL. Temporizing after spinal cord injury. *Hastings Cent Rep*. 2015;45(2):8-10.
10. Garcia-Retamero R, Galesic M. How to reduce the effect of framing on messages about health. *J Gen Intern Med*. 2010;25(12):1323-1329.
11. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med*. 1999;48(8):977-988.

**Kristi L. Kirschner, MD**, is on the medical staff of Schwab Rehabilitation Hospital and a faculty member in the Department of Disability and Human Development at the University of Illinois in Chicago. She specializes in neurological rehabilitation and disability ethics.

#### **Related in the AMA Journal of Ethics**

[Service Dogs for Veterans with PTSD](#), June 2015

[Through the Patient's Eyes: Conversation with a Famous Patient](#), September 2001

[On Distinguishing Justifiable from Unjustifiable Paternalism](#), February 2004

[Taking No for an Answer—Refusal of Life-Sustaining Treatment](#), June 2010

#### **Disclaimer**

The views presented are here those of Dr. Kirschner and do not represent those of the institutions with which she is affiliated.

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 in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 506-510

## ETHICS CASE

### Safety and Ethical Considerations in Discharging Patients to Suboptimal Living Situations

Commentary by James Hill, MD, MPH, and William Filer, MD

Dr. Wayne, a physiatrist, is part of an interdisciplinary team that provides comprehensive services for people with conditions that result in long-term cognitive and physical limitations, such as stroke, spinal cord injury, amputation, major trauma, and brain injury. Dr. Wayne and the rehabilitation team are meeting with Martha, a 45-year-old woman who has spent the last six weeks in an acute inpatient rehabilitation unit. Martha sustained a T12 complete spinal cord injury and a moderate traumatic brain injury as the result of a car accident.

Dr. Wayne is pleased with Martha's rehabilitation course and overall adjustment to her injuries. Martha is able to use a manual wheelchair without assistance for mobility and is independent with her bowel and bladder management. She has also made excellent progress from her [traumatic brain injury](#) and has been evaluated to make sure she is competent to make her own decisions. Based on her functional and medical status, Martha is ready for discharge, and she wants to go home with her 22-year-old son, Brett, who lived with her prior to her accident. The social work team has secured disability status for Martha, and her social security disability payments—which Martha hopes will be enough to cover her bills—will begin in a month. Dr. Wayne hopes to discuss some of the issues related to the current discharge plan with Martha and Brett.

A physical therapist has performed a home evaluation and noted that the apartment is not optimal for Martha. The bathroom is too narrow to maneuver her wheelchair, and there are no handrails near the toilet and shower to help with her transfers. Her apartment unit also lacks an appropriate ramp to allow Martha to enter and exit the apartment without assistance. While the initial discharge planning identified these concerns, Brett has refused to find more appropriate housing for his mother, stating that he prefers to stay in the same apartment. The social work team members who have interviewed Brett say that his only employment is doing odd jobs for others in the apartment building. Without Martha's income in the last four months, the electricity in the apartment had been turned off once. The nursing staff has also raised some concerns about Brett's behavior with his mother and report that he smells of alcohol when he visits her on the rehabilitation unit. Many of his visits with his mother end in his becoming angry and raising his voice at her before he stomps out of the hospital. Despite these concerns, both Martha and Brett insist that she will be safe at home.

## Commentary

Discharge planning is of paramount importance in inpatient rehabilitation care. The Centers for Medicare and Medicaid Services mandate that an anticipated discharge plan be documented *before* a patient is admitted to an inpatient rehabilitation facility [1]. However, the question of what constitutes a safe discharge plan is a subjective one. Rehabilitation physicians are familiar with the challenges a person with a new physical disability will face after discharge. This case brings up the importance of caregiver trustworthiness and a patient's autonomy to accept less-than-ideal living conditions.

Martha has had a formal assessment during her rehabilitation course that indicates that she has decisional capacity—this is an important consideration in many trauma cases, particularly after brain injury. She clearly expresses that she wants to go home, and Dr. Wayne believes it would be medically appropriate to discharge her. Often, financial and hospital administrative pressures can lead to early discharge, but, in this particular case, both Martha and the physician feel that she is ready to leave the hospital. The environmental barriers to independent living at home (lack of ramp, inaccessible bathroom) are concerning, but protections afforded by the Americans with Disabilities Act and Fair Housing Act might allow Martha to break her lease without penalty and find more accessible housing.

### Questions about Martha's Wishes

Being declared competent does not mean Martha is free from all cognitive limitations that can affect her ability to live independently. For example, mild deficits in memory or executive function can lead to difficulty keeping track of finances or paying bills. There are also concerns about her son, Brett, who will serve as her primary caregiver. A picture is painted of a young man who lacks employment and is suspected of abusing alcohol. It bears noting, however, that evidence of alcohol or drug abuse by a family member does not alone constitute a safety hazard for the patient, nor does it always indicate a physically or emotionally abusive relationship. Dr. Wayne should seek to clarify the content of the arguments with those who observed them. Furthermore, the discordance between the patient's accounts of her son's visits and those reported by staff signals the possibility of denial or "reaction formation," a psychological defense mechanism whereby the patient responds to an anxiety-producing situation by exaggerating the opposing tendency. Denial is common in victims of abuse by relatives, highlighting the need for greater watchfulness among health care professionals [2].

A physician is ethically and, in most cases, legally obligated to report suspected abuse [2]. This includes not only physical abuse, but also psychological abuse and financial exploitation. We are given little detail regarding the arguments that took place between Martha and Brett. Certainly, any observed threatening or belittling language should prompt notification of Adult Protective Services.

### **Discussing Martha's Wishes**

Exploring the patient's relationship with her son using neutral and nonjudgmental questions may offer further insight into the problem. Does Brett have a history of addiction, mental illness, or disability? Why is he refusing to move apartments? It appears he has needed to rely on his mother for housing and financial support. Caregiver financial dependency has been shown to be a risk factor for abuse [2]. Other factors that should be explored include Martha's pre-injury employment, educational background, financial resources, and social support network. Interviewing the patient and family member separately is recommended [3].

Dr. Wayne has several ways to address his concerns with the patient. Emanuel and Emanuel outline four basic models of physician-patient interaction related to medical decision making [4]. In the *paternalistic model*, the physician takes responsibility for deciding what interventions are best for the patient's health and well-being. As applied to this case, it may be that the optimal discharge plan for Martha would be to find a new, accessible apartment where she could live alone independently—without needing to rely on, and perhaps free from the destructive behaviors of, her son. This kind of paternalism is flawed, however, in that it does not take into account the patient's right to self-determine.

In the *informative model*, the physician only provides information, unbiased by his or her own values, and the patient makes an informed decision about how best to pursue his or her values given that medical information.

In the *interpretive model*, the physician elicits information about the patient's values and then helps the patient make a medical decision consistent with them. This may involve further exploring Martha's relationship with Brett. Perhaps there are cultural or other values that have played a role in Martha's cohabitation with her adult son beyond simple financial dependence.

Finally, the *deliberative model* involves the physician's helping the patient form or choose health-related values. In other words, the physician facilitates the patient's own "moral self-development," taking great care not to project his or her own moral beliefs upon the patient and refraining from taking up moral issues unrelated to health care decisions. In this case, Dr. Wayne must be careful not to inadvertently shame Martha, which would be detrimental to the patient-physician relationship. Formulating questions in a judgmental way—for example, asking Martha "Why do you choose to live with your unsupportive son?"—is unlikely to foster open communication.

Lastly, it is important to respect patient preference and autonomy. Martha has, in fact, expressed her wish to go home, which she is competent to do. A decision to return to

suboptimal living conditions is an autonomous, competent person's prerogative and may be perfectly rational, in the context of her belief and value system. However, it is important that this decision is not coerced by her son [5].

### **After Martha Returns Home**

As Martha prepares to leave the hospital, various social services may be available to her. Many newly disabled people need assistance when they first transition to home. If Martha does return to her apartment, home visits would facilitate information gathering about matters including living conditions and Martha's relationship with Brett. It is vital that Dr. Wayne follow up with the home health practitioners who are able to observe the home environment and family social dynamics. In addition, one recognized (and we believe modifiable) risk factor for abuse is social isolation [3]. Many newly disabled people find community socialization more difficult because of mobility barriers. It is important to identify support groups, transportation assistance, and other programs that can promote social reintegration.

While a physician may not be able to solve social and environmental issues such as these for every patient, it is important to assess these factors as part of comprehensive discharge planning.

### **References**

1. Centers for Medicare and Medicaid Services. Inpatient rehabilitation therapy services: complying with documentation requirements. July 2012. [http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/Inpatient\\_Rehab\\_Fact\\_Sheet\\_ICN905643.pdf](http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/Inpatient_Rehab_Fact_Sheet_ICN905643.pdf). Accessed March 3, 2015.
2. Abbey L. Elder abuse and neglect: when home is not safe. *Clin Geriatr Med*. 2009;25(1):47-60.
3. Hoover RM, Polson M. Detecting elder abuse and neglect: assessment and intervention. *Am Fam Physician*. 2014;89(6):453-460.
4. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA*. 1992;267(16):2221-2226.
5. Stiggelbout AM, Molewijk AC, Otten W, Timmermans DR, van Bockel JH, Kievit J. Ideals of patient autonomy in clinical decision making: a study on the development of a scale to assess patients' and physicians' views. *J Med Ethics*. 2004;30(3):268-274.

**James Hill, MD, MPH**, is director of the Physical Medicine and Rehabilitation Residency Program and an assistant professor at the University of North Carolina School of Medicine in Chapel Hill. Dr. Hill is a graduate of the NIH-sponsored Rehabilitation Medicine Scientist Training Program (RMSTP). His research and clinical work focus on the

intersection of work and health, including work disability, absenteeism, and return to work after injury and illness.

**William Filer, MD**, is an assistant professor at the University of North Carolina School of Medicine in Chapel Hill, where he serves as the associate director of the Physical Medicine and Rehabilitation Residency Program. His clinical interests include neuromuscular and traumatic brain injury rehabilitation, amputee care, electrodiagnosis, and performing arts medicine.

**Related in the AMA Journal of Ethics**

[Transitions of Care: Putting the Pieces Together](#), February 2013

[Physician Paternalism and Severe Acquired Disability: Strengthening Autonomy through Therapeutic Engagement](#), June 2015

[History of Physical Medicine and Rehabilitation and its Ethical Dimensions](#), June 2015

[Assessing Competency in Physical Medicine and Rehabilitation Residency: The ACGME Milestones Initiative](#), June 2015

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 in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 511-514

## ETHICS CASE

### Athlete Return-to-Play Decisions in Sports Medicine

Commentary by Adam S. Tenforde, MD, and Michael Fredericson, MD

Jordan is a 17-year-old senior in high school who has been his football team's star quarterback, led his team to two state championships, and has a real possibility of receiving a full scholarship to a top college sports program next year.

In his last session of summer training camp, Jordan took a fierce hit, a tackle that knocked him to the ground. He landed on his right arm and shoulder and instantly felt sharp pain and then lost some sensation. Jordan was taken to the hospital. An MRI was taken, which showed that Jordan had a torn labrum in his right shoulder that would require surgery and months-long recovery, meaning that he would miss the rest of his final season. A week later, Jordan underwent surgery and soon thereafter began seeing physiatrist Dr. Brown for further treatment and follow-up.

Two months after his surgery and continued treatment with Dr. Brown, Jordan felt that his recovery was lagging. He was worried that his slow recovery process coincided with the recruitment period for college programs. Top programs were increasingly inquisitive about his recovering shoulder, so he scheduled an urgent appointment with Dr. Brown.

Dr. Brown had known instances in which this particular type of injury ended a quarterback's athletic career. She had also read about a few cases in which athletes recovered fully from the injury. Since so much of recovery depends on the injured person's following the rehabilitation and physical therapy plans, Dr. Brown wanted Jordan to approach his injury with the optimism that adherence to the plan would enable him to return to athletics. At the same time, she did not want to hold out false hope that might keep Jordan focused exclusively on football when, in the long term, that might not be the best use of his senior year.

### Commentary

This scenario—frequently encountered by physiatrists who practice sports medicine—encompasses many of the common challenges in care and return-to-play decisions for high-level athletes. Physiatrists with board certification in sports medicine are physicians who complete postgraduate training in physical medicine and rehabilitation, in addition to a 12-month sports fellowship and a written examination [1]. Sports medicine physiatrists specialize in the treatment and prevention of medical and orthopedic injuries

and ailments related to sport and exercise, using a variety of diagnostic and therapeutic aids to assist athletes at all levels [1].

In the case presented, a [high school quarterback](#) has sustained an injury to the glenoid labrum, a cartilaginous structure of the shoulder that deepens the shoulder socket and provides stability. Nonoperative treatment for a labral tear traditionally includes physical therapy to restore function of the shoulder and, to reduce pain and inflammation, the use of heat/ice, ultrasound, and possibly oral analgesics, anti-inflammatory medications, and corticosteroid injections into the glenohumeral joint. Surgical management of this condition may be considered under certain circumstances, particularly if full function has not been restored after optimum nonoperative care.

Postoperative management for labral repairs by the treating physician, usually assisted by an athletic trainer, physical therapist, or both aims to improve scapular stabilization and the strength and stability of the shoulder girdle and to restore painless range of motion. Additionally, it is important to address biomechanical contributors to the injury by taking a full evaluation of the kinetic chain, including scapular strength and positioning; thoracic and lumbar spine rotation and mobility; hip strength and stability; and knee, ankle, and foot mechanics. These principles of evaluation and treatment apply to most sports injuries we treat in athletes.

Although Jordan, the athlete in the case scenario, is eager to resume playing football, the primary duty of his physiatrist, Dr. Brown, is to offer appropriate medical treatment and guidance to ensure Jordan's safe return to sports participation.

Jordan feels pressure to demonstrate that he is ready for full participation in football, possibly earlier than his recovery from surgery would allow, so the evaluation and management of his injury, like that of many sports injuries, must take into account the tension between the ethical principles of respect for autonomy and beneficence. The principle of respect for autonomy allows an athlete (or, if the athlete is a minor, his or her parents or guardian) to make a decision about whether to receive medical care and follow medical advice about when it is safe to participate in sport. However, the team physician, who is usually designated to determine medical clearance for return to play based on the rules of the institution or team, must give priority to his patient's [best orthopedic care](#). Doing so follows the principle of beneficence.

Clearly, Jordan has many personal incentives for an expedited return to play—the enjoyment of participating in sport and financial considerations such as a collegiate scholarship and the possibility of playing professionally—that place him at risk for adverse health consequences if he returns to sports participation before the injury has been properly addressed. Family members, athletic staff, and others may also have incentives to see an athlete return to sports participation. However, the long-term health

of the athlete must be the primary factor guiding medical decision making. Particularly in youth sports, the pressure to specialize and perform at a high level may increase risk for overuse injuries and burnout [2].

The scenario suggests that Jordan is not ready to return to full participation in football. A good relationship with Jordan is critical to Dr. Brown's ability to talk effectively with him about expectations for and stages of recovery to ensure Jordan's safe return to play. We find that a good patient-physician relationship can be developed by the physician's communicating commitment to the shared goals of successful return to sports, the physician's effective communication with the athlete and treatment team (including athletic trainer, physical therapists, and other staff), and regular clinical visits to evaluate treatment success and address the athlete's questions or concerns.

Dr. Brown and Jordan should discuss the goals of both safe return to sports participation and prevention of future long-term health problems by optimizing management of the current injury. A return-to-play progression plan provides goals for each stage of recovery from an injury up to full clearance for participation and can help an athlete understand when it would be appropriate to resume playing a sport without restrictions. The plan involves progression from basic isolated strengthening and stretching to advanced skill-specific tasks, noncontact practice, and participation in competition. In addition to guiding rehabilitation following an injury, the plan provides better buy-in: the athlete can focus on each goal in the progression, evaluate whether or not he or she has achieved that goal, and assess how that relates to successful participation in sport. In this way, the physician is not the "bad guy" who says that the athlete may or may not return to play. It is the athlete's meeting (or not meeting) the goals in the progression plan that determines return to play. Treatment for the athlete must address both the physical impairments and their impact on other aspects of his or her life.

A multidisciplinary approach to treating sports injuries is helpful for managing the ethical issues that may arise from medical decisions and planning safe return to play. Conflicts of interest may arise in sports medicine if, as mentioned above, the goal to perform well in a sport during a specific timeline does not match the medical guidelines for successful return to play. The athlete (or guardian, for athletes younger than 18) would need to sign a waiver to disclose personal health information to others who are not directly involved in medical care—for example, the coach or athletic trainer. If athletes are younger than 18 years of age or request that family be informed of their medical status, communication of the treatment plan with the family may be helpful. By establishing effective communication among the physician, athlete, and others, ethical problems in management of sports injuries may be best addressed.

## References

1. Fredericson M. On the horizon: defining the future of sports medicine and the role of the physiatrist. *PM R*. 2012;4(10):707-710.
2. DiFiori JP, Benjamin HJ, Brenner J, et al. Overuse injuries and burnout in youth sports: a position statement from the American Medical Society for Sports Medicine. *Clin J Sport Med*. 2014;24(1):3-20.

**Adam S. Tenforde, MD**, is a physician in Redwood City, California, and a PM&R sports medicine fellow at Stanford University, where he was a former All-American long-distance runner. His clinical and research interests are in management and prevention of overuse and sports injuries in athletes.

**Michael Fredericson, MD**, is a professor and the director of physical medicine and rehabilitation sports medicine and of nonoperative sports medicine fellowships at Stanford University School of Medicine in Stanford, California. He has been a team physician with Stanford Athletics for more than 20 years and has lectured and published extensively on the treatment of sports injuries.

## Related in the *AMA Journal of Ethics*

[Nonmaleficence in Sports Medicine](#), July 2014

[Evaluating the Risks and Benefits of Participation in High-School Football](#), July 2014

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 in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 515-520

## MEDICAL EDUCATION

### Assessing Competency in Physical Medicine and Rehabilitation Residency: the ACGME Milestones Initiative

Julian Willoughby, MD, MPH, Vu Nguyen, MD, MBA, and William L. Bockenek, MD

The profession of medicine has a unique ethical obligation to ensure that it trains new practitioners to be competent and ready to serve patients who are often in a vulnerable state and unable to assess the competence of the practitioners who are treating them. For many years, the proof of a physician's competency has been relatively simple and process-oriented—if a physician passed a board exam and/or completed the residency training, then he or she was de facto deemed competent.

The traditional approach to assessment began to change in 1999, when the Accreditation Council for Graduate Medical Education (ACGME) created the six clinical competencies—patient care, medical knowledge, practice-based learning and improvement, interpersonal communication skills, professionalism, and systems-based practice [1]—that provide a framework for outcomes-focused guidelines specifying what it means to be “clinically [competent](#).” About a dozen years later, the ACGME began a second step in the process—the Next Accreditation System (NAS)—to create detailed, specialty-specific knowledge and skill milestones by which to assess a trainee's progress toward competency.

#### Why the NAS?

Historically, competency as a well-rounded physician was inferred when residency was completed. Board exams provide a more objective measure of knowledge—but to what extent can written exams evaluate what it means to be a doctor? One may argue that board tests primarily evaluate just one of the ACGME core competencies, medical knowledge. The other five competencies are much more difficult to assess with standardized testing. For these, many specialties have relied on supervising clinicians' written evaluations and Likert scales, methods that are highly subjective. Others, including [physical medicine and rehabilitation \(PM&R\)](#), have used additional standardized oral exams to bolster assessments. According to the American Board of Physical Medicine and Rehabilitation (ABMPR), “the Part II [oral] exam indeed measures something different than the Part I [written] exam...the oral examination is structured to measure the ability of the candidate to apply medical and psychiatric knowledge and skill in patient care, interpersonal and communication skills, professionalism, and systems-based practice” [2]. However, there are limitations to a one-time oral exam performed at the end of resident training.

None of these methods provides a consistent or comprehensive picture of trainee competency. While the ACGME's core competencies identify the areas in which physicians should be trained, they cannot and are not intended to identify specific activities needed for assessing competency during residency training in a specific specialty. Certain specific skills are unique to physiatrists, for example, such as understanding the complications of and how to treat patients with spinal or brain injuries, which may not be a priority of a resident training in another specialty. Thus, as part of the Next Accreditation System, residency programs were asked to create competency-based milestones that are specialty-specific and provide [standardized, objective, and reproducible data](#) on the physician-in-training's progress toward becoming an independent practitioner [3].

Milestones, as defined by the ACGME, are "competency-based developmental outcomes (e.g., knowledge, skills, attitudes, and performance) that can be demonstrated progressively by residents and fellows from the beginning of their education through graduation to the unsupervised practice of their specialties" [4]. In short, the milestones articulate, in very specific terms, the physician-in-training's demonstrable progress toward becoming an independent practitioner who is capable and, most importantly, competent in the specific tasks deemed crucial by experts in the field. The milestones for physical medicine and rehabilitation residencies were developed over two years by a working group composed of nine current or former members of the ACMGE PM&R residency review committee (RRC), including a resident representative, directors of the American Board of PM&R, and residency program directors.

How does the ACGME envision that the milestones program will improve residency training? The milestones should aid in *accreditation* by:

- allowing for continuous monitoring of programs, thus increasing time between time-consuming site visits conducted by volunteer committee members,
- providing national aggregate competency outcomes for each specialty,
- creating a community focused on evaluation and research [4].

For *education*, the milestones will:

- provide a detailed framework for evaluation of competency,
- guide curriculum development of residency programs,
- support better assessment programs,
- aid in early identification of struggling residents and fellows [4].

And for *individual trainees*, the milestones will:

- "provide more explicit and transparent expectations of performance,"
- "support better self-directed assessment and learning,"
- "facilitate better feedback for professional development" [4].

Additionally, to ensure that milestone evaluations are reported and reviewed, the NAS mandates that each residency program form a clinical competency committee (CCC) “comprising three or more members of the active teaching faculty,” which may include the program director as well as other relevant staff [5]. The ACGME has provided a comprehensive guide on how the CCC should be organized and implemented across all programs, thus ensuring some uniformity in applying the milestones in trainee evaluation. But appropriate flexibility in the constitution of the CCCs among programs and specialties is also allowed. For example, because PM&R programs emphasize teamwork with therapists and other members of the health care team, they may include some of these specialists in their CCC. In this way, residents’ progress toward the milestones is evaluated in light of both their level of training and the environment in which they are training. This system of specialty-specific milestones and program-specific CCCs provides a flexible framework within which programs can guide curriculum development and apply the milestones in the assessment of their trainees.

The milestone initiative is an ambitious undertaking that seeks to significantly improve the process of assessing medical resident and fellow competency. Applied through the CCCs, the milestones, should fill the assessment gap by providing systematic, comprehensive, and specialty-specific evaluation of ACGME competencies throughout the course of resident training.

### **Potential Pitfalls**

There is as yet little objective data on whether the milestones actually provide the intended benefits. In 2012, the members of the PM&R working group piloted the use of milestones in their own programs. Feedback regarding the clarity of the evaluated milestones was positive and constructive criticisms were offered. Respondents from larger programs were chiefly concerned that their programs would need more time to complete the evaluation process than would smaller programs, where members of the CCC were likely to be more familiar with residents’ performance. It was also noted that commonly used assessment tools such as post-rotation surveys were not adequate to fully assess the milestones and that additional [faculty development](#) would be needed to train faculty to accurately observe and rate resident behaviors [6].

The milestone system may not solve all the extant problems in resident evaluation. It does advance the process of resident evaluation beyond subjective measurement scales and brief comments by supervising physicians—it provides public accountability on a national scale, frequent feedback to guide curriculum development, and more explicit expectations for residents to use in directing their own professional development. However, a significant ethical dilemma is still inherent in both the old and new processes—that is, residency programs’ being in charge of evaluating their own residents. Because residency programs want to appear to train excellent physicians,

there may be a conflict of interest in a program's reporting the quality of the physicians it is producing. The quality of a program's graduates may affect its funding, recruitment, and stature. Furthermore, the world of residency training is unlike most other workforces because, if a resident withdraws or is dismissed from a program, the workload of other residents and faculty physicians is significantly affected, and it is usually difficult to replace the lost support until the following match cycle.

This conflict of interest can be seen as both a positive and a negative force. It may be that a program with a poorly performing resident would be motivated to remediate and improve that resident's performance, or it may be that the program would simply artificially inflate the resident's evaluations to keep from losing an important team member within the workforce until he or she left in a year or so. There is hope that, with the new milestones, a resident's failure to progress will be identified earlier in the process of training, allowing earlier remediation and a greater chance of resident success. The milestones could thus prevent programs from having to release a trainee but would still rely on them to give honest assessments.

The milestone system should also address the problem of variation in evaluations between programs by having experts in each specialty work together to create specialty-specific milestones that represent an ideal training development path for their residents. The field of PM&R did this by mobilizing voices from all corners of the field, thus taking the onus off individual programs to create shared goals and incentives to advance the specialty as a group. However, even if the milestones are shared among programs within the specialty, there can still be significant variation in how programs apply them to their cohort of residents.

For example, variation is bound to exist in the makeup and role of the CCCs. In the PM&R pilot study, it was noted that, in the larger programs, the CCC members were not completely familiar with all of the residents being evaluated. In lieu of familiarizing themselves with each resident's performance and filling gaps in their knowledge about that learner, evaluators may merely assume that a trainee's performance in one area, with which they are familiar, indicates performance in another. This could create a favorable or unfavorable disposition to the resident's evaluation. A resident's superior performance observed in one clinical area may well favorably skew the evaluation of that resident in an unobserved area—the "good guy syndrome" [1]. On the other hand, a resident's less-than-stellar performance in one observed area may be considered representative of his or her performance in all unobserved areas. A given program may not have the resources or staff to assess its resident cohort as well as another program's CCC and thus may create a situation in which the entire program's assessments are based more on assumptions than on sufficient information. Although this possibility certainly exists in current assessment methodologies, one must consider

whether the increased resources and time needed for each program to implement the milestones and CCC could further increase the variability in assessment of competency.

### **Conclusion**

Medical educators share a moral obligation to provide competent care for the public and, therefore, an obligation to train competent clinicians for the future. The milestone initiative seeks to do just that by reforming the process of assessing competence. It alters not only how we assess competence, but also how we define and achieve it. Milestones will move graduate medical education from a process of completing rotations and years of training to one of demonstrating and perfecting the skills associated with one's specialty. Making assessment more measurement based and objective will focus trainees' and curriculum designers' efforts on areas of weakness. Programs will be able to develop and reform based on objective data, and residents will have a clearer picture of the expectations they will need to meet to graduate. Pitfalls do exist but are less profound than those of prior evaluation schemes. Challenges may include the allocation of additional resources needed to implement CCCs. So far, we believe that the potential benefits far outweigh the challenges.

The milestone initiative will most certainly improve the assessment of competency in residency training in PM&R and other specialties. The full realization of milestones is still far away, but, by enhancing the evaluation of current residents and fellows, graduate medical education will continue to improve, and it will ultimately improve the lives of those we are sworn to heal.

### **References**

1. Ling L, Derstine P, Cohen N. Implementing milestones and clinical competency committees. Accreditation Council for Graduate Medical Education. April 24, 2013. <https://www.acgme.org/acgmeweb/Portals/0/PDFs/ACGMEMilestones-CCC-AssesmentWebinar.pdf>. Accessed April 15, 2015.
2. American Board of Physical Medicine and Rehabilitation. New part II examination format. *Diplomate News*. 2005;6. [http://www.abpmr.org/newsletters/documents/summer2005diplomateneews\\_002.pdf](http://www.abpmr.org/newsletters/documents/summer2005diplomateneews_002.pdf). Accessed April 15, 2015.
3. Carter WA Jr. Milestone myths and misperceptions. *J Grad Med Educ*. 2014;6(1):18-20.
4. Accreditation Council for Graduate Medical Education. Milestones. <https://www.acgme.org/acgmeweb/tabid/430/ProgramandInstitutionalAccreditation/NextAccreditationSystem/Milestones.aspx>. Accessed April 15, 2015.
5. Andolsek K, Padmore J, Hauer KE, Holmboe E. Clinical competency committees: a guidebook for programs. Accreditation Council for Graduate Medical Education; 2015:2.

<https://www.acgme.org/acgmeweb/Portals/0/ACGMEClinicalCompetencyCommitteeGuidebook.pdf>. Accessed April 15, 2015.

6. Bockenek WL, Massagli TL, Swing SR, Fischer C; the PMR Milestone Working Group. The development of the physical medicine and rehabilitation milestones. *J Grad Med Educ*. 2014;6(1)(suppl 1):204-206.

**Julian Willoughby, MD, MPH**, is a third-year resident in the Department of Physical Medicine and Rehabilitation at Carolinas Medical Center/Carolinas Rehabilitation in Charlotte, North Carolina.

**Vu Nguyen, MD, MBA**, is an associate professor and the vice chair of academics and the residency program director in the Department of Physical Medicine and Rehabilitation at Carolinas Medical Center/Carolinas Rehabilitation in Charlotte, North Carolina.

**William L. Bockenek, MD**, is a professor in and the chair of the Department of Physical Medicine and Rehabilitation at Carolinas Medical Center/Carolinas Rehabilitation in Charlotte, North Carolina.

#### **Related in the AMA Journal of Ethics**

[History of Physical Medicine and Rehabilitation and its Ethical Dimensions](#), June 2015

[Competence and Professionalism](#), February 2002

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 521-529

## IN THE LITERATURE

### A Clinical Ethics Approach to Opioid Treatment of Chronic Noncancer Pain

Mitchell J. Cohen, MD, and William C. Jangro, DO

**Ballantyne JC, Fleisher LA. Ethical issues in opioid prescribing for chronic pain. *Pain*. 2010;148(3):365-367.**

We are writing both to respond to Ballantyne and Fleisher's 2010 article on the ethics of opioid prescribing [1] and to join the authors in calling for continued progress in rational, ethical, and practical decision making surrounding the use of opioids in the treatment of patients with [noncancer chronic pain](#). Given the current state of knowledge regarding [long-term opioid treatment](#), we suggest that dilemmas associated with this treatment are best approached using patient-centered clinical ethics. We believe principle-based, deontological, and classical Hippocratic ethical approaches have less relevance in sorting out [current controversies](#) surrounding opioid treatment.

We agree with the authors' concise history of how opioid use in medicine has most often been determined by fearful attitudes and politics [1] and rarely arrived at rationally [2], let alone through application of ethical models or evidence-based practice [3]. We welcome exactly this sort of thoughtful reflection on the ethical implications of opioid prescription for chronic painful illness. Ballantyne and Fleisher accurately reflect expert consensus that the most difficult clinical dilemmas involving opioid analgesics arise in treating chronic nonmalignant pain, not acute postinjury or perioperative pain [4, 5] or even terminal painful illness [6-8]. Even though there is widespread consensus about the majority of uses for opioids for chronic malignant pain, approximately 50 percent of cancer patients still face barriers to pain care [9]. If this is the status of pain care in cancer, an area about which there is reasonable ethical consensus, it is not surprising that noncancer chronic pain is even less adequately addressed. This discrepancy highlights the need to work toward greater agreement on solutions to the ethical questions involved in delivery of care to patients with this kind of pain [10, 11].

Ballantyne and Fleisher trace the most recent wave of arbitrary limitations on opioid prescribing to the early twentieth century, when physician influence on treatments offered to patients began a steady decline. This decreasing influence has been ascribed to a combination of factors, including increased regulation of the manufacture, trade, and prescription of opioids; stigmatization of opioids through special prescribing requirements and criminalization of addiction [1]; expanded tracking and limitation of physician practice through "managed" care; attention to control of medical "utilization";

and physicians' fear of review by state licensing boards [12]. Progress in managing these potentially restrictive forces has required advocacy from patient groups, professional pain treatment organizations, and coalitions of these and other stakeholders [13]. As the twentieth and twenty-first centuries have unfolded, these limiting influences have combined with [growing concerns about prescription opioid diversion](#) and [abuse](#) [14, 15], making clear the need for a solid, ethical foundation for opioid treatment of chronic nonmalignant pain.

### **Need for Pain Treatment and Status of Data on Opioid Treatment**

Our current knowledge of unaddressed pain-related suffering and the efficacy and relative safety of opioids, at least for short-term pain control, require us to address the problem of undertreatment of chronic pain. We know more about the prevalence of, cost of, and unmet needs for, treatment of chronic noncancer pain than we did in the early twentieth century.

Across the United States and Europe, up to 55 percent of patients suffer some degree of chronic pain, and up to 19 percent report [chronic pain](#) of moderate or higher intensity; an additional group, as large as 10 percent of the population, have disabling pain that undermines daily function and freedom to pursue goals and interests [4, 5]. The annual cost of chronic pain in the United States exceeds \$200 billion, with the bulk of that amount representing lost productivity, disability payments, and rising medical costs for treatments [16].

Since the early twentieth century, we have also learned a great deal more about opioids in chronic pain treatment. Opioids work on nociceptive and neuropathic pain states [17]; opioids compare favorably with gold-standard antineuralgics like tricyclics and anticonvulsants in certain disorders [18]; opioids have a reasonable safety profile and, if properly titrated and taken as prescribed, do not necessarily impair psychomotor speed or prohibit driving or working [19, 20]; and opioids can reduce pain and improve quality of life in conditions studied [21-23].

Data from animal studies raise concerns that chronic use of these drugs at high dosages may lead to hyperalgesia and opioid insensitivity, but it remains unclear whether such phenomena occur in humans [24]. Another area of uncertainty is whether opioid treatment benefits extend much beyond 16 weeks in responsive patients. We are sorely lacking in high-quality long-term outcome data for opioid treatment of chronic nonmalignant pain. During the recent quarter century of more liberal use of opioids for noncancer pain, no well-designed studies of treatment longer than 16 weeks have been published. This lack of published efficacy data for the past 25 years is a scientific stumble, if not an ethical oversight, that demands correction. Anecdotal reports, case series, and extended open treatment arms of shorter controlled trials suggest possible benefits of opioid use exceeding a year [25-27], but the best studies have involved short

treatment periods of one to three months.

### **Ethical Approaches to Opioid Treatment of Noncancer Pain**

We believe that the lack of data makes deontological and principle-based ethics difficult to apply. These are deductive forms of ethical reasoning to the extent that they rely on applying overarching concepts to data to resolve particular patient dilemmas. If we don't have long-term outcome data, deontological imperatives like "minimize suffering" and principles like "justice" become vague. Lack of data leaves us uncertain about whether painful suffering addressed in the short term might be replaced in the long term by different suffering (e.g., side effects), and it is hard to determine whether equal access is a moral fairness imperative in the case of an as-yet-unproven long-term therapy.

Certainly, foundational Hippocratic ethical values apply—for example, primacy of the patient-doctor relationship, confidentiality, and acting in patients' best interest [28]. The last Hippocratic value is relevant to opioid treatment decisions since it requires physicians to deny inappropriate treatments requested by patients, no matter how much patients or their advocates want that treatment. Opioids for pain requested by a patient who is actively abusing alcohol would therefore be prohibited. Beyond this emphasis on the clinical obligation to "say no" when opioids are not appropriate, Hippocratic values have no particular ability to clarify decisions about opioid treatment.

We argue, therefore, that, in a data-thin area of practice like chronic opioid treatment, it makes most sense to apply clinical ethics, that is, an inductive ethical reasoning process that generalizes from individual cases, because good practice will always produce rich case data. Clinical ethics is not population based; it is patient-centered, emphasizing patient autonomy, shared decision making, collaborative goal setting, attention to context and psychosocial factors, and enhancement of individual quality of life. Clinical ethics adheres to the specific realities of a particular case, such as the indications for specific treatments, education about possible adverse effects, and description of consequences of declining recommended treatments. Society-level ethical questions are not at the center of case-based ethics. For example, positing a patient right to receive pain treatment or a physician obligation to provide it doesn't revolve around individual case features and, therefore, is not best addressed with clinical ethics. Similarly, in decision making an individual patient's well-being trumps societal factors such as health care costs or equal access to care. Since we don't know the ultimate clinical value of chronic pain treatments, addressing the broader ethical and social questions like equal access and cost involve significant assumptions and speculation. In our view, therefore, clinical ethics can be most usefully applied to pain treatment at this time.

### **Six-Step Ethical Decision Making for Opioid Treatment**

We have used clinical ethics in a six-step iterative, case-based process for deciding whether opioids are appropriate for patients with chronic, nonterminal pain. Consistent

with clinical ethics and good pain care, our process requires longitudinal treatment and comprehensive assessments. Clinical data from close monitoring is at present the best data we have for making these decisions. We outline below the six steps: narrative pain history, assessment of identifiable causes of pain, collaborative goal setting, ongoing treatment plan adjustments, updating of treatment goals, and regular revisiting of pain diagnosis.

The first step is developing a patient's pain narrative, which includes noting the contextual and psychosocial [factors affecting the patient](#). "Pain" is never an adequate chief complaint. Eliciting the narrative pain history is time-consuming and extends beyond inquiring about pain quality, intensity, and location(s) to learning about the person's experience of living with chronic pain. How do particular pains limit function; how much fear and anticipation of pain are involved; to what degree are sleep and circadian rhythm disrupted; do psychiatric comorbidities like depression, anxiety, and substance use disorders (which often complicate pain-related suffering) play a role; do seasonal changes affect the pain; and what patient behaviors are relevant, helpful, or problematic? [29-33]. Examples of helpful behaviors include communicating effectively about pain, breaking tasks into subtasks, and resting by the clock when active instead of being shut down by pain. Problematic behaviors include overexertion or becoming sedentary, denying or overfocusing on pain, and seeking a cure for conditions for which pain accommodation and control are the realistic goals. Until problematic aspects of the person's pain narrative are understood and addressed, it is difficult to estimate the effectiveness an opioid trial will have in clinical practice or research.

The second step is attempting to identify pain pathophysiology and the pain generator(s) to the degree possible in the current state of our knowledge. This step addresses the ethical duty to offer only those treatments that will be appropriate and effective. Using opioids for poorly characterized or understood pain makes assessment of their efficacy difficult. Put simply, you must have reasonable clarity about what you're treating to choose rational interventions and assess benefit. While we regularly see patients with total-body pain and widespread allodynia, using an unproven treatment for these diffuse pain presentations is problematic. Which pain component or area of pain does the clinician track? How do we know if the patient is improving? Even difficult pains like brachial plexopathy, phantom-limb pain, postherpetic neuralgia, and axial low back pain, for example, are clinically clearer entities, which makes it easier to gauge opioids' effects.

If the pain is focused enough to be tracked and the physician has a reasonable sense of pain generator(s), opioid treatment may be appropriate to prevent or treat central nervous system changes—like reorganization of pain pathways, changes in dopamine levels and other neurochemicals, and lost density in cortical and precortical brain regions—that have been demonstrated in at least some patients with chronic pain [34-38]. If further clinical evidence demonstrates that such changes occur in large numbers

of patients with chronic pain, if imaging of these changes becomes practical outside of research settings, and if these changes prove to be controllable with treatment, chronic pain itself, in the absence of clear pain generator(s), may become an adequate clinical indication for ethical treatment with opioids.

The third step, goal-setting, is the most critical. True to patient-specific practice, the goal-setting process is highly individualized and collaborative. Goals must be broader than pain reduction. Assessing only pain level—a single-variable outcome—is incongruent with the quality-of-life focus so central to clinical ethics. Goals must be specific, meaningful, and personal—for example, being able to sit through a movie in a theater, cook again, drive 45 minutes to visit aging parents, or walk a child to a school bus stop. Progress toward very specific goals can be assessed in terms of steps made toward the goal, which makes the contributions of opioids and other interventions easier to collaboratively assess. A relevant assessment question might be, what did we do that made the most difference in getting you to the movies—do you think taking your pain medication or doing your home PT exercises helped more? Specific behavioral goals to be met through opioid therapy must be accompanied by a clear description of realistic expectations for pain reduction (not elimination); discussion of side effects; and disclosure of the limitations of current knowledge, especially regarding long-term benefit. Realistic expectations of opioid therapy and possible complications have been shown to correlate with improved outcomes and increased patient satisfaction [39-41].

Fourth, we periodically reassess patient progress and consider modifications to the treatment plan. Interventions that were unhelpful in this particular case (e.g., epidural injections or deep tissue massage) will be discontinued; others that helped (e.g., acupuncture, antineuralgic analgesics like gabapentin) will be continued. If opioids have been added, the same evaluation of whether to continue or discontinue treatment occurs.

The fifth and sixth steps bring us full circle in this iterative clinical ethical analysis. In step five, goals accomplished are replaced by the next goals on the list from step three, and goals not yet completed are broken into smaller subgoals. In step six, fundamental treatment decisions are revisited in light of accrued clinical data. As pain diagnoses and treatment indications become clarified over time, as the benefits and side effects of treatments become real and not theoretical for a given patient, as shaping contextual and psychosocial factors become more evident, and as the patient's own treatment preferences change with experience, these factors inform the ongoing decision making regarding continuation of opioid therapy.

### **Summary**

Untreated chronic pain, both cancer-related and not, remains unacceptably prevalent and costly, even in medically sophisticated settings across the United States and Europe.

Available treatments for chronic nonmalignant pain have not been shown efficacious by robust data, whether the treatment in question is cognitive behavioral therapy, biofeedback, interventional anesthesia, or ongoing opioid medication [16, 42, 43]. Combining these treatments in the setting of multidisciplinary treatment programs, on the other hand, has been demonstrated efficacious in more than 60 studies [44], so the negative results may be partly due to studying available treatments in isolation. Although we need better long-term data showing opioids' efficacy, the same can be said for all available treatments for chronic pain. In the meantime, data to date suggest that opioids are at least partly efficacious for reducing pain and improving quality of life, with acceptable safety, for those with various chronically painful conditions. Given the status of our current knowledge, we have suggested a six-step decision-making process for opioid treatment that is based in clinical ethics and relies on comprehensive evaluation and data accrued through longitudinal care.

## References

1. Ballantyne JC, Fleisher LA. Ethical issues in opioid prescribing for chronic pain. *Pain*. 2010;148(3):365-367.
2. Turk DC, Okifuji A. What factors affect physicians' decisions to prescribe opioids for chronic noncancer pain patients? *Clin J Pain*. 1997;13(4):330-336.
3. Cohen MJ, Jasser S, Herron PD, Margolis CG. Ethical perspectives: opioid treatment of chronic pain in the context of addiction. *Clin J Pain*. 2002;18(4)(suppl):S99-S107.
4. Noble M, Treadwell JR, Tregear SJ, et al. Long-term opioid management for chronic noncancer pain. *Cochrane Database Syst Rev*. 2010;(1):CD006605.
5. Von Korff M, Kolodny A, Deyo RA, Chou R. Long-term opioid therapy reconsidered. *Ann Intern Med*. 2011;155(5):325-328.
6. Ferrell BA, Ferrell BR. Principles of pain management in older people. *Compr Ther*. 1991;17(8):53-58.
7. Ferrell BR, Dean G. The meaning of cancer pain. *Semin Oncol Nurs*. 1995;11(1):17-22.
8. Rousseau P. The ethical validity and clinical experience of palliative sedation. *Mayo Clin Proc*. 2000;75(10):1064-1069.
9. Portenoy RK. Treatment of cancer pain. *Lancet*. 2011;377(9784):2236-2247.
10. Harden N, Cohen M. Unmet needs in the management of neuropathic pain. *J Pain Symptom Manage*. 2003;25(5)(suppl):S12-S17.
11. Goldberg DS, McGee SJ. Pain as a global public health priority. *BMC Public Health*. 2011;11:770.
12. Martino AM. In search of a new ethic for treating patients with chronic pain: what can medical boards do? *J Law Med Ethics*. 1998;26(4):332-349.
13. Sehgal N, Colson J, Smith HS. Chronic pain treatment with opioid analgesics: benefits versus harms of long-term therapy. *Expert Rev Neurother*. 2013;13(11):1201-1220.

14. Volkow ND, McLellan TA. Curtailing diversion and abuse of opioid analgesics without jeopardizing pain treatment. *JAMA*. 2011;305(13):1346-1347.
15. Webster L, St Marie B, McCarberg B, Passik SD, Panchal SJ, Voth E. Current status and evolving role of abuse-deterrent opioids in managing patients with chronic pain. *J Opioid Manag*. 2011;7(3):235-245.
16. Turk DC, Wilson HD, Cahana A. Treatment of chronic non-cancer pain. *Lancet*. 2011;377(9784):2226-2235.
17. Pappagallo M, Campbell JN. Chronic opioid therapy as alternative treatment for post-herpetic neuralgia. *Ann Neurol*. 1994;35(suppl):S54-S56.
18. Raja SN, Haythornthwaite JA, Pappagallo M, et al. Opioids versus antidepressants in postherpetic neuralgia: a randomized, placebo-controlled trial. *Neurology*. 2002;59(7):1015-1021.
19. Zacny JP. Should people taking opioids for medical reasons be allowed to work and drive? *Addiction*. 1996;91(11):1581-1584.
20. Haythornthwaite JA, Menefee LA, Quatrano-Piacentini AL, Pappagallo M. Outcome of chronic opioid therapy for non-cancer pain. *J Pain Symptom Manage*. 1998;15(3):185-194.
21. Fine PG, Mahajan G, McPherson ML. Long-acting opioids and short-acting opioids: appropriate use in chronic pain management. *Pain Med*. 2009;10(suppl 2):S79-S88.
22. Harden RN, Oaklander AL, Burton AW, et al; Reflex Sympathetic Dystrophy Syndrome Association. Complex regional pain syndrome: practical diagnostic and treatment guidelines, 4th edition. *Pain Med*. 2013;14(2):180-229.
23. Dillie KS, Fleming MF, Mundt MP, French MT. Quality of life associated with daily opioid therapy in a primary care chronic pain sample. *J Am Board Fam Med*. 2008;21(2):108-117.
24. Fishbain DA, Cole B, Lewis JE, Gao J, Rosomoff RS. Do opioids induce hyperalgesia in humans? An evidence-based structured review. *Pain Med*. 2009;10(5):829-839.
25. Franklin GM; American Academy of Neurology. Opioids for chronic noncancer pain: a position paper of the American Academy of Neurology. *Neurology*. 2014;83(14):1277-1284.
26. Manchikanti L, Ailinani H, Koyyalagunta D, et al. A systematic review of randomized trials of long-term opioid management for chronic non-cancer pain. *Pain Physician*. 2011;14(2):91-121.
27. Katz MH. Long-term opioid treatment of nonmalignant pain: a believer loses his faith. *Arch Intern Med*. 2010;170(16):1422-1424.
28. Antoniou SA, Antoniou GA, Grandrath FA, Mavroforou A, Giannoukas AD, Antoniou AI. Reflections of the Hippocratic Oath in modern medicine. *World J Surg*. 2010;34(12):3075-3079.

29. Cohen MJ. Psychosocial aspects of evaluation and management of chronic low back pain. In: Young MA, Lavin RA, eds. *Spinal Rehabilitation*. Philadelphia, PA: Hanley and Belfus; 1995:726-746.
30. Cassell EJ. Diagnosing suffering: a perspective. *Ann Intern Med*. 1999;131(7):531-534.
31. Ashburn MA, Staats PS. Management of chronic pain. *Lancet*. 1999;353(9167):1865-1869.
32. Gureje O. Psychiatric aspects of pain. *Curr Opin Psychiatry*. 2007;20(1):42-46.
33. Loeser JD. The education of pain physicians. *Pain Med*. 2015;16(2):225-229.
34. Henry DE, Chiodo AE, Yang W. Central nervous system reorganization in a variety of chronic pain states: a review. *PM R*. 2011;3(12):1116-1125.
35. Grachev ID, Fredrickson BE, Apkarian AV. Abnormal brain chemistry in chronic back pain: an in vivo proton magnetic resonance spectroscopy study. *Pain*. 2000;89(1):7-18.
36. Apkarian AV, Sosa Y, Sonty S, et al. Chronic back pain is associated with decreased prefrontal and thalamic gray matter density. *J Neurosci*. 2004;24(46):10410-10415.
37. Hobson AR, Aziz Q. Brain imaging and functional gastrointestinal disorders: has it helped our understanding? *Gut*. 2004;53(8):1198-1206.
38. May A. Chronic pain may change the structure of the brain. *Pain*. 2008;137(1):7-15.
39. Chou R, Fanciullo GJ, Fine PG, et al; American Pain Society-American Academy of Pain Medicine Opioids Guidelines Panel. Clinical guidelines for the use of chronic opioid therapy in chronic noncancer pain. *J Pain*. 2009;10(2):113-130.
40. Wasan AD, Ross EL, Michna E, et al. Craving of prescription opioids in patients with chronic pain: a longitudinal outcomes trial. *J Pain*. 2012;13(2):146-154.
41. Bingel U, Wanigasekera V, Wiech K, et al. The effect of treatment expectation on drug efficacy: imaging the analgesic benefit of the opioid remifentanyl. *Sci Transl Med*. 2011;3(70):70ra14.
42. Malone MD, Strube MJ, Scogin FR. Meta-analysis of non-medical treatments for chronic pain. *Pain*. 1988;34(3):231-244.
43. Morley S, Eccleston C, Williams A. Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain*. 1999;80(1-2):1-13.
44. Flor H, Fydrich T, Turk DC. Efficacy of multidisciplinary pain treatment centers: a meta-analytic review. *Pain*. 1992;49(2):221-230.

**Mitchell J. Cohen, MD**, is the vice chair for education and an associate professor in the Department of Psychiatry and Human Behavior and the director of the Pain Medicine Program at Sidney Kimmel College of Medicine at Thomas Jefferson University in Philadelphia. Dr. Cohen has served on committees at national organizations, including the American Pain Society, the American Board of Pain Medicine, the Accreditation Council for Graduate Medical Education, and the National Board of Medical Examiners. His areas of expertise are medical education and pain medicine.

**William C. Jangro, DO**, is an instructor in the Department of Psychiatry and Human Behavior, the assistant director and overseer of the curriculum of the Psychiatry Residency Training Program, and an attending physician on the consultation liaison service and the pain medicine program at Sidney Kimmel College of Medicine at Thomas Jefferson University in Philadelphia. He treats patients with chronic pain and evaluates hospitalized medical and surgical patients with psychiatric and behavioral complications.

**Related in the AMA Journal of Ethics**

[Long-Term Opioid Treatment](#), May 2013

[Opioids for Nonmalignant Chronic Pain](#), March 2015

[Objectifying Chronic Pain: From the Patient to Diagnostic Metrics](#), May 2013

[Chronic Pain Patients and the Biomedical Model of Pain](#), May 2013

[Physicians' Responsibility to Understand Patients' Pain](#), May 2013

[Pain and Ethnicity](#), May 2013

[Why Must Pain Patients Be Found Deserving of Treatment?](#) January 2008

[Gender Stereotypes in Pain Diagnosis](#), July 2008

[Education to Identify and Combat Racial Bias in Pain Treatment](#), March 2015

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 530-534

## IN THE LITERATURE

### Recognizing Psychological Diversity in People with End-Stage Amyotrophic Lateral Sclerosis

Debjani Mukherjee, PhD

**Albert SM, Rabkin JG, Del Bene ML, et al. Wish to die in end-stage ALS. *Neurology*. 2005;65(1):68-74.**

**Rabkin JG, Goetz R, Factor-Litvak P, et al; The ALS Cosmos Study Group. Depression and wish to die in a multicenter cohort of ALS patients [published online ahead of print December 8, 2014]. *Amyotroph Lateral Scler Frontotemporal Degener*. doi:10.3109/21678421.2014.980428.**

A progressive incurable neurological disease is considered by some to be a “fate worse than death,” particularly at the end stage. Accordingly, the ethical debates around [amyotrophic lateral sclerosis \(ALS\)](#) frequently focus on the “right to die,” physician-assisted suicide, or withdrawal or withholding of treatment [1, 2]. Two articles, “Wish to Die in End-Stage ALS” by Albert et al. [3] and “Depression and Wish to Die in a Multicenter Cohort of ALS Patients” by Rabkin et al. [4], contribute to a more nuanced understanding of ALS patients’ experience of depression and a wish to die. Rabin et al. found in a study of 329 people with ALS that 88 percent were not depressed, and, in both their study and a prospective study of 53 people with ALS by Albert et al., 81 percent did not express the wish to die. By focusing the conversation about ALS on depression and ethical issues at the end of life, we risk minimizing the psychological diversity and multiplicity of ways that people live and die with ALS.

### Psychological Diversity

People who acquire ALS are as psychologically diverse as people who acquire any other disease. By “psychologically diverse,” I mean that characteristics such as openness to experience, conscientiousness, extraversion, agreeableness, neuroticism—the “big 5” personality factors—and beliefs, attitudes, motivations, social connectedness, perceived locus of control, and other aspects vary widely. Each one of these characteristics, some more enduring and fixed, some more fluid, can impact the way people react to a progressive neurological disease and cope with uncertainty, fear, and their last days. It is also difficult to rate someone else’s quality of life and to predict who will become clinically depressed. In fact, caregivers and partners rate the quality of life of people with ALS lower than the individuals themselves [5].

In a prospective study of patients with end-stage ALS by Albert and colleagues, “patients who expressed a wish to die reported less optimism, less comfort in religion, and greater hopelessness” [6]—these factors are also aspects of psychological diversity. Most notably, optimism and hopelessness have been linked to disease outcomes because they impact [coping strategies](#). Of course, situational factors matter, too, and the physical impairments that come with ALS contribute to emotional functioning. However, to frame discussions around the characteristics of a disease rather than a psychologically complex individual living with the disease focuses our attention on symptoms and imagined fates rather than the individual patients’ disease courses and quality of life.

### **Depression and Fear**

Most ALS patients in Rabkin and colleagues’ multicenter cohort study were not clinically depressed, even when they were in the end stage. These authors found that 12 percent of the ALS patients they studied met criteria for a depressive disorder, including the 5 percent who had major depression. Although this incidence is higher than in the general population, “the observed rate of 12 percent is, however, lower than reported for patients with a variety of other medical and neurological conditions such as multiple sclerosis, coronary artery disease and diabetes” [7]. These findings seem counterintuitive but the intuitions of ethicists, clinicians, and others without ALS are based on their own cognitive framing and their perceptions, beliefs, and experiences, and, perhaps most notably, their fears.

Fears are based on imagining the progression of the disease. For example, the “Facts You Should Know” section of the ALS Association website (the organization that raised more than \$115 million through the “Ice Bucket Challenge” in the summer of 2014) states:

The onset of ALS is insidious with muscle weakness or stiffness as early symptoms. Progression of weakness, wasting and paralysis of the muscles of the limbs and trunk as well as those that control vital functions such as speech, swallowing and later breathing generally follows [8].

It is true that ALS is progressive and incurable and fear-instilling. Yet we err when we leap from hearing about the symptoms of the disease to speculating about reactions to living with the disease. A former colleague of mine, who was an occupational therapist living with ALS, wrote eloquently about her journey [9, 10]. It is of note that she was trained to think about function and adaptation in her profession; she knew how to advocate for services and technological supports; her father, aunt, and cousin had died from the disease; and she was surrounded by loving family, friends, and coworkers.

It is also interesting to note that, according to the ALS Association, “although the life expectancy of an ALS patient averages about two to five years from the time of diagnosis, this disease is variable and many people live with quality for five years and more. More than half of all patients live more than three years after diagnosis” [8]. In fact, about 20 percent live 5 years or more and 5 percent will live 20 years [8]. That gives us years to work with people with ALS before they are in the [end stage](#) of the disease.

### **Implications for Treating People with ALS**

What are the implications of these statistics for health care professionals and clinical ethicists treating people with ALS? It is important to clarify what is going on with the individual person with ALS at a given moment in time. Patients with ALS who are depressed need effective treatment as do patients with treatable anxiety. Clinical depression often responds to treatment; psychotherapy and psychotropic medication, often in combination, can ameliorate the symptoms.

When people are near the end of life or at the point at which they believe their quality of life has become unbearable, they may request to hasten death. The line at which life becomes unbearable is often shifting and is defined by the patient. These wishes or desires should be addressed, discussed, and *accompanied*. Critically, accompanying is not actively treating or trying to fix altered patterns of thinking or feeling. It involves presence, engagement, and a focus on being with the person in the present moment. This open exchange is different from avoidance and from trying to change ALS patients’ cognitions, reframe their situations, or optimize their functioning by providing medications that affect neurotransmitters.

The accompaniment may change the wish, or it may not. We all have wishes that others can try to dissuade us from, but the decision about what we believe and feel is largely up to us as individuals. And in a situation in which one is progressively losing functions, the ability to self-determine, communicate, and be heard is even more critical.

A key aspect is to determine what is a treatable depression and what is an (also perhaps treatable) existential wish to die and then to find the right clinician to work with this particular person at this point in time. The right clinician could be from neurology, rehabilitation, palliative care, or hospice. When people with ALS are nearing the end of life, rehabilitation clinicians can partner with palliative care and hospice clinicians or hand off the case to experts in another aspect of the disease process who can support the patient. There is no definitive point at which this hand-off or referral to hospice comes; it is a fuzzy line. Knowing that we are out of our comfort zone and practical expertise and that it is time to hand off is part of sound clinical practice in general.

## Conclusion

Finally, it is important to acknowledge and address other common ethical issues in working with people living with ALS. Some of these include fostering self-determination in the context of progressive neurological compromise; allocation of resources, financial and emotional; access to services, both high-tech and low-tech; humility when dealing with a condition that we have not lived through; and showing solidarity or cultivating connectedness to decrease isolation. In summary, for clinicians, including ethics consultants, working with patients with ALS, the facts of the particular situation—patients' perceived locus of control, their social support, their spiritual beliefs, and their ways of coping with uncertainty and progressive decline—are as important as the diagnosis of ALS itself, even at the end stage.

## References

1. Ganzini L, Johnston WS, McFarland BH, Tolle SW, Lee MA. Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med*. 1998;339(14):967-973.
2. McCluskey L. Amyotrophic lateral sclerosis: ethical issues from diagnosis to end of life. *NeuroRehabilitation*. 2007;22(6):463-472.
3. Albert SM, Rabkin JG, Del Bene ML, et al. Wish to die in end-stage ALS. *Neurology*. 2005;65(1):68-74.
4. Rabkin JG, Goetz R, Factor-Litvak P, et al; The ALS Cosmos Study Group. Depression and wish to die in a multicenter cohort of ALS patients [published online ahead of print December 8, 2014]. *Amyotroph Lateral Scler Frontotemporal Degener*. doi: 10.3109/21678421.2014.980428.
5. Kübler A, Winter S, Ludolph AC, Hautzinger M, Birbaumer N. Severity of depressive symptoms and quality of life in patients with amyotrophic lateral sclerosis. *Neurorehabil Neural Repair*. 2005;19(3):182-193.
6. Albert et al., 72.
7. Rabkin et al., 6.
8. ALS Association. Facts you should know. <http://www.alsa.org/about-als/facts-you-should-know.html>. Accessed February 27, 2015.
9. Jasch C. My journey with ALS: an occupational therapist's story. Rehabilitation Institute of Chicago. <https://lifecenter.ric.org/index.php?tray=content&tid=top441&cid=6830>. Accessed April 20, 2015.
10. Reis JP, Ballerini K, O'Farrell S, et al. Is an appropriate wheelchair becoming out of reach? – Part 2. *PM R*. 2014;6(10):934-944.

**Debjani Mukherjee, PhD**, is director of the Donnelley Ethics Program at the Rehabilitation Institute of Chicago and an associate professor of physical medicine and rehabilitation and of medical humanities and bioethics at Northwestern University Feinberg School of Medicine. Her interests include ethical dilemmas posed by

neurological impairments, cultural contexts of medical decisions, and the impact of emotionally demanding cases on clinical staff.

**Related in the *AMA Journal of Ethics***

[Whole-Person, Whole-Community Care at the End of Life](#), December 2013

[Coping Mechanisms and Quality of Life](#), May 2006

[Presymptomatic Genetic Testing for ALS](#), January 2006

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 535-546

## STATE OF THE ART AND SCIENCE

### Ethics in Rehabilitation: Access to Prosthetics and Quality Care Following Amputation

Colonel Paul F. Pasquina, USA (Ret), MD, Antonio J. Carvalho, and Terrence Patrick Sheehan, MD

#### A Profile of Amputation

The most recent large-scale study of amputation in the United States found that 1.6 million people were living with limb loss in the country in 2005 [1]. With 185,000 amputations occurring annually [2], the total number of people with amputation in the US (accounting for mortality) is projected to double by the year 2050. The most common causes of amputation are vascular disease, trauma, cancer, and congenital malformation. Vascular disease and trauma account for 54 percent and 44 percent of the current prevalence, respectively, while less than 2.5 percent of people who have had amputations cite cancer or congenital deformity as the cause [3]. The rising incidence of amputations observed in the United States thus can largely be attributed to vascular disease and comorbid diabetes, the latter accounting for more than 60 percent of nontraumatic amputations in the United States today [4]. Furthermore, the number of people living with diabetes in the US in 2011—25.8 million—is predicted to double by 2030 [1, 5]. As a result, amputation presents an ever-increasing challenge to our health care system.

Those who sustain an amputation encounter multiple challenges during their recovery, rehabilitation, and reintegration into their homes and communities. Learning and adopting new strategies for basic mobility, personal hygiene, and activities of daily living with or without prosthesis is difficult. In prosthetic fitting, multiple attempts at socket fabrication are often needed to improve tolerance and comfort. Phantom limb and residual limb pain are extremely common and frequently require a multidisciplinary approach for optimal management [6-8].

Major limb amputation is associated with a higher incidence of secondary health complications, such as obesity, cardiovascular disease (CVD), peripheral vascular disease (PVD), renal disease, and diabetes [9, 10]. More than half of those who have a leg or arm amputated secondary to vascular disease and diabetes will require an amputation of the contralateral limb within two to three years [11]. And the five-year mortality rate for those who have lost limbs because of vascular disease is over 50 percent—the same or higher as that for prostate, breast, and colorectal cancer [10, 12, 13]. Despite advances in prosthetic technology, evidence still indicates that people who have had an

amputation (even those who use a prosthetic device) are at a biomechanical disadvantage that makes them more likely to develop musculoskeletal complications such as osteoarthritis, back pain, joint pain, and osteoporosis/osteopenia [14]. In addition, because of the challenges with socket interfaces, people with prosthetic limbs are likely to develop frequent skin complications, including irritation, breakdown, ulceration, cysts, and necrosis [15].

The psychological impact of amputation can be just as significant as the physical challenges. The perceived loss of ability to engage in previous vocational, avocational, social, sexual, and leisure activities can play a greater role in postamputation quality of life than the absence of the limb itself [16]. Body image, self-esteem, and quality of life can be significantly negatively influenced by amputation [17], and health survey scores are often far lower for patients who have had lower limb amputations than for control subjects. Ide et al. also found that nearly 50 percent of those who have had amputations are dissatisfied with their sexual life following limb loss [18]. Many of those surveyed reported that their interest in sexual issues deteriorated following amputation. Return to work following amputation can also be difficult and has been found to be dependent on a wide variety of factors such as amputation level, age, gender, level of education, and employer support [19]. Although reports vary, a large number of people do not return to work following amputation(s) and a significant percentage of those who do return to work change occupations [19]. As a result of these and other factors, depression and anxiety are significant concerns in the amputee population, with reports of as many as 20-30 percent of all amputees being diagnosed with major depressive disorder [20, 21].

The key to improving outcomes for those who have lost limbs is to ensure that they receive appropriate and comprehensive interdisciplinary care to address [both their physical and psychosocial needs](#). Fundamental to the rehabilitative care and recovery of many people who have lost limbs is their fitting for and training on the use of prostheses. Increased prosthetic usage is associated with higher levels of employment [22], increased quality of life [23], decreased phantom limb pain [22], and lower levels of general psychiatric symptoms [24]. Additionally, prosthetic use has been shown to facilitate a reduction in secondary health issues [25] and therefore a larger degree of mobility and functional independence for those with amputation.

Even in the United States, patient access to appropriate rehabilitation and prosthetic care is still [significantly limited](#). Geographical barriers, gender, age, socioeconomic position, race, education, and cost all contribute to health care disparities. These disparities may not only obstruct access to the most appropriate prosthetic and rehabilitative care but may contribute to prosthetic abandonment, psychological problems, reduced quality of life, and unsuccessful return to meaningful community participation.

## Health Disparities

*Race, socioeconomics, and gender.* In the 2005 study mentioned earlier [1], 42 percent of those who had lost limbs belonged to a racial or ethnic minority group. Poverty, too, is a noted risk factor for amputation [26]. African Americans are four times more likely to undergo an amputation and 2.5 times as likely to have a second lower limb amputation than non-Hispanic white Americans, even controlling for age, sex, and diabetes severity [27, 28]. Similarly, Hispanic Americans are 1.5 times as likely to suffer an amputation as white Americans [29]. Non-whites, those with low income, and those without commercial insurance are more likely than members of other groups to undergo a lower limb amputation for PVD rather than revascularization (a limb-saving procedure associated with better outcomes), even controlling for the severity of disease [30]. In the rehabilitation period, those with an income at or near the poverty line are 2.5 to 3 times as likely as their peers who are not in poverty to perceive barriers in their access to work or community life, and some studies have found that a smaller percentage of women with limb loss remained employed following their amputation(s) than their male counterparts [31, 32].

*Facility type.* The type of rehabilitation facility a patient is sent to can have a tremendous effect on the eventual outcome for that patient. Following discharge from a hospital, rehabilitation typically occurs in one of three places—at home, at a skilled nursing facility (SNF), or at an inpatient rehabilitation facility (IRF). Per Medicare guidelines, IRFs provide, at minimum, physician services, onsite physical therapy, and social or psychological services [33]. They usually also provide access to prosthetic services or expertise. Rehabilitation physicians typically oversee day-to-day operations and medical procedures and create rehabilitation plans for each patient.

By contrast, SNFs are staffed by licensed nurses (RNs, LPNs, and LVNs) and nurse aides, with contracted physicians visiting the facility periodically. Rehabilitation often must begin or occur entirely without the input of a rehabilitation physician or physical therapist because regulations require that each patient see a doctor only once every 30 days for the first 90 days and once every 60 days after that [33]. DaVanzo et al. conducted a review of Medicare patient outcomes at these two types of facilities over a two-year period [33]. They found that people rehabilitating from amputations who were treated at an IRF returned home from their stays 16 days earlier, were able to live at home nearly 3 months longer, stayed alive more than 2.5 months longer, and experienced a 12 percent lower mortality rate. Hospital emergency room visits were reduced from 1,016.7 per 1,000 patients per year at SNFs to 861.3 per 1,000 patients per year at IRFs, while the number of hospital readmissions saw an even greater difference, with 1,966.6 per 1,000 patients per year at SNFs and 1,538.3 per 1,000 patients per year at IRFs. This is despite the fact that IRFs typically treat more severely affected patients who require more intensive rehabilitation efforts.

Prior to rehabilitation, the hospital where the patient undergoes initial treatment and receives acute care can impact recovery. Those patients who undergo amputations at a trauma center are 1.5 times more likely to be sent to an IRF for rehabilitation than those treated at hospitals without trauma centers [34]. Teaching hospitals are more likely than nonteaching institutions to attempt revascularization rather than amputation for patients with PVD [30]. Such limb-saving procedures also incur only one-third of the projected lifetime costs of amputation [35]. Less than one-fifth of all US hospitals are teaching hospitals, however, and less than 15 percent of hospitals qualify as level I, II, or III trauma centers [36, 37]. As recently as 10 years ago, more than 33 million people did not live within an hour of a level I, II, or III facility, and more than 45 million people did not have any access to a level I or II facility [38]. Those who do have access may simply be unaware of the differences between treatment at and referrals from teaching hospitals or trauma centers and hospitals that are neither. In either case, it is often the location and the physician at the bedside that determine the type of treatment (amputation or revascularization) and the success or failure of rehabilitation for many who have had an amputation.

*Costs.* Perhaps the greatest cause of prosthesis- and rehabilitation-related disparities in outcomes for those who have had amputations is cost, and there are also, in some cases, drastic limitations on insurance coverage of the necessary prosthetic devices and services. As many as 20 percent of nonmilitary amputees report an unmet need for rehabilitation services, largely because of inability to pay [39].

The costs related to amputation, prosthesis, and rehabilitation can be roughly divided into two categories: (1) those directly associated with the amputation event or surgery (including rehabilitation care, prosthetic fitting, and adjustment of devices) and (2) indirectly associated costs (including those for secondary health complications and their treatment). Costs in even one of these categories can be significant:

- On average, the two-year total cost of amputation exceeds \$90,000 [35]. Rehabilitation care, fitting of prostheses, and adjustment of devices alone were the fifteenth most expensive condition treated in US hospitals in 2011, with a total cost of more than \$5.4 billion for these services [40, 41]. Hospital charges for amputation procedures amounted to more than \$8.3 billion in 2009, not including prosthetic or rehabilitation costs [13].
- Common secondary health conditions following amputation, including diabetes, are also among the top twenty most expensive conditions billed by hospitals in 2011. Osteoarthritis and back problems, also common, fall within the top six [40].
- Lifetime estimates for directly associated costs range from \$345,000 to nearly \$600,000, depending on how often the prosthesis is replaced and the age at time of amputation [10, 13, 35, 40].

- Based on the statistics available, direct and indirect health costs as a result of amputation could easily exceed \$1 million for an individual *before* accounting for any loss of wages or salary due to an inability to work.

These costs are far outside the financial capabilities of most people. As a result, insurance providers (including Medicare, Medicaid, and private insurance) typically cover the majority of costs [42]. Insurance type also determines the patient's access to prosthetic components and services [42]. For those with Medicare, the prosthesis provided is based on the patient's rehabilitation potential as determined by a prosthetist and the ordering physician [43]. While a number of states have enacted laws to create parity and equal access to prosthetic devices for those who have had an amputation, many policies and laws still do not facilitate financial access to the most advanced prosthetic systems, despite the fact that such systems have become the clinical standard of care and have been shown to provide improved outcomes by reducing secondary health problems [44-46] and to decrease costs by improving quality adjusted life years (QALYs) [43].

Prosthesis funding alone can independently influence both the selection and use of a prosthetic device [47]. Obtaining a second device for specific activities, such as work or avocational activities, can be difficult, requiring extended processes of verification and justification. Many private insurance providers have also added yearly and lifetime spending and visit caps in their policies, limiting the number of outpatient visits allowed as well as the covered costs of those visits. Yearly caps for prosthetic services ranged from \$500 to \$3,000 in 2012; lifetime maximums can be as little as \$10,000 or only cover a single prosthetic device for a person's entire lifetime [39]. Given that, even without fitting and training services, a single prosthesis can range in cost from \$3,000 to \$100,000 for lower limbs and \$4,000 to \$75,000 for upper limbs and that even the most advanced and sturdy of these systems typically require replacement every two to five years [39], some patients face extreme costs not covered by insurance. That patients who undergo amputation are already likely to have financial disadvantages compounds the issue of ability to pay.

## **Discussion**

Rehabilitation after amputation is a complex physical and psychological challenge. Obtaining access to appropriate prosthetic services is an important part of this process. Yet the disparities that exist in the current health care system pose substantial barriers for people who have lost limbs. For the reasons we have discussed, those with the least resources and education are disproportionately represented in the amputee population. Not only are they at higher risk for sustaining an amputation, but they often have less access to appropriate comprehensive care. Furthermore, there are no specific guidelines for standards of care or prosthetic management and there are great discrepancies in the competence and capacity of health care facilities across the nation, many of which lack

substantial experience and expertise in caring for people who have lost limbs. Finally, the costs of advanced prosthetic devices, training, and services continue to act as a significant barrier that a large majority of patients cannot overcome.

Over the past several decades, the US government has funded the development of model systems of care for complex debilitating disorders that are intended to stimulate research and improve quality of care [13]. Such models have been created for spinal cord injury, traumatic brain injury, and burn injury, and they have demonstrated encouraging results in their ability to influence and improve care [13]. It is apparent that such a model could have substantial benefits for postamputation rehabilitation.

The United States military's Military Amputee Treatment Centers (MATCs) are an example of such a model. These centers facilitate the coordination of the various services involved in rehabilitation for servicemembers injured in combat operations, including education, prosthetic services, surgery, physical therapy, occupational therapy, pain medicine, and psychosocial services. Studies show that Iraq and Afghanistan veterans treated at these centers have higher self-reported quality of life and health status, higher rates of prosthetic usage, and higher rates of satisfaction with the care received than Vietnam veterans [48, 49].

In 1984 Ham et al. reported on an overhaul at two hospitals performing amputations that did not have in-house prosthetic care [50]. This overhaul included standardizing physiotherapy for those who had had amputation(s), increasing patient education, enlisting the services of a surgeon trained in amputation techniques, encouraging vascular surgeons to use a standard protocol, using prosthetists and senior coordinating physiotherapists, and mandating prosthetic fitting before discharge. Four years of progressively increasing efforts resulted in a decrease of inpatient stays by 20 days, a 94 percent reduction in postdischarge physiotherapy, a fivefold increase in prosthetic fitting prior to discharge (17 percent to 100 percent), and a 150 percent increase in long-term prosthetic use (36 percent to 94 percent) from baseline. The majority of these gains were achieved in the first year of the system's implementation. Such success demonstrates the benefit that proper training, prosthetic devices, and coordination can provide for those who have had an amputation.

Pitfalls in education, treatment, costs, and care engender prosthetic abandonment, rehabilitation failure, and lower quality of life for those who have lost limbs, often without decrease in medical costs. The Davanzo et al. survey of Medicare patient outcomes at IRFs versus SNFs also tracked the cost incurred, per day and in total, for those who had had amputations at each facility type [33]. While the price for initial rehabilitation services was substantially higher per person at IRFs, the overall rehabilitation cost for an individual person at an IRF was not statistically different from rehabilitating him or her at an SNF, yet the outcomes were far superior.

It is worth asking if, in the current system of payment and insurance coverage, an initial prescription and training with advanced prosthetic devices would in fact result in overall cost savings for private insurance companies as it does for the military and Veterans Administration, by reducing the likelihood of secondary health issues. For example, those treated by the United States military or Veterans Health Administration are typically allowed to test multiple sockets and prosthetic devices to maximize their comfort and function [39]. Although comfort and fit remain two of the most significant prosthetic issues reported by those who have had an amputation, civilian insurance often only covers two test sockets and a single prosthesis [14, 39], despite the fact that no single prosthesis can achieve all the functions necessary for everyday life. A comprehensive cost analysis of Medicare patients who had had lower limb amputations within the previous year and had utilized orthotic and prosthetic services found that those who received physical therapy had fewer acute care hospitalizations and emergency room admissions and less facility-based health care than patients who had not [51]. Within a year, the prosthetic device cost was almost amortized by the other cost savings, and patients had higher quality of life and increased independence than the matched controls who did not receive a prosthesis.

The current access to prosthetic devices, prosthetic services, and rehabilitation services for the majority of those who have lost limbs leaves much to be desired. Model systems of amputation care and education would provide dedicated locations for assessing different treatment regimens, training protocols, and technology for caring for those who have had an amputation. A comprehensive investigation of cutting-edge prosthetic systems is necessary to establish not only their definitive clinical benefits, but also their impact on the overall cost incurred by a patient following amputation. These measures might make it possible to alleviate some of the health care disparities associated with geography, gender, socioeconomic status, and minority group membership that grip the prosthetic and amputation fields today.

## References

1. Ziegler-Graham K, MacKenzie EJ, Ephraim PL, Travison TG, Brookmeyer R. Estimating the prevalence of limb loss in the United States: 2005 to 2050. *Arch Phys Med Rehabil*. 2008;89(3):422-429.
2. Owings MF, Kozak LJ, National Center for Health. *Ambulatory and Inpatient Procedures in the United States, 1996*. Hyattsville, MD: National Center for Health Statistics; 1998. Vital and Health Statistics 139. [http://www.cdc.gov/nchs/data/series/sr\\_13/sr13\\_139.pdf](http://www.cdc.gov/nchs/data/series/sr_13/sr13_139.pdf). Accessed April 30, 2015.
3. Varma P, Stineman MG, Dillingham TR. Epidemiology of limb loss. *Phys Med Rehabil Clin N Am*. 2014;25(1):1-8.

4. American Diabetes Association. Fast facts: data and statistics about diabetes. March 2015.  
<http://professional.diabetes.org/ResourcesForProfessionals.aspx?cid=91777&loc=dorg-statistics>. Accessed March 10, 2015.
5. Centers for Disease Control and Prevention. National diabetes fact sheet, 2011. [http://www.cdc.gov/diabetes/pubs/pdf/ndfs\\_2011.pdf](http://www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf). Accessed March 8, 2015.
6. Le Feuvre P, Aldington D. Know pain know gain: proposing a treatment approach for phantom limb pain. *J R Army Med Corps*. 2014;160(1):16-21.
7. Ehde DM, Czerniecki JM, Smith DG, et al. Chronic phantom sensations, phantom pain, residual limb pain, and other regional pain after lower limb amputation. *Arch Phys Med Rehabil*. 2000;81(8):1039-1044.
8. Pasquina PF, Miller M, Carvalho AJ, et al. Special considerations for multiple limb amputation. *Curr Phys Med Rehabil Rep*. 2014;2(4):273-289.
9. Pasquina PF, Hendershot BD, Isaacson BM. Secondary health effects of amputation. In: *Atlas of Amputations and Limb Deficiencies*. 4th ed. Rosemont, IL: American Academy of Orthopedic Surgeons. In press.
10. Sheehan TP, Gondo GC. Impact of limb loss in the United States. *Phys Med Rehabil Clin N Am*. 2014;25(1):9-28.
11. Pandian G, Hamid F, Hammond M. Rehabilitation of the patient with peripheral vascular disease and diabetic foot problems. In: DeLisa JA, Gans BM, eds. *Rehabilitation Medicine: Principles and Practice*. Philadelphia, PA: Lippincott-Raven; 1998: 1544-1571.
12. Brem H, Tomic-Canic M. Cellular and molecular basis of wound healing in diabetes. *J Clin Invest*. 2007;117(5):1219-1222.
13. Limb Loss Task Force/Amputee Coalition. *Roadmap for Preventing Limb Loss in America: Recommendations from the 2012 Limb Loss Task Force*. Knoxville, TN: Amputee Coalition; 2012. [http://www.amputee-coalition.org/wp-content/uploads/2014/09/lsp\\_Roadmap-for-Limb-Loss-Prevention-and-Amputee-Care-Improvement\\_241014-092312.pdf](http://www.amputee-coalition.org/wp-content/uploads/2014/09/lsp_Roadmap-for-Limb-Loss-Prevention-and-Amputee-Care-Improvement_241014-092312.pdf). Accessed April 29, 2015.
14. Gailey R, Allen K, Castles J, Kucharik J, Roeder M. Review of secondary physical conditions associated with lower-limb amputation and long-term prosthesis use. *J Rehabil Res Dev*. 2008;45(1):15-29.
15. Bui KM, Raugi GJ, Nguyen VQ, Reiber GE. Skin problems in individuals with lower-limb loss: literature review and proposed classification system. *J Rehabil Res Dev*. 2009;46(9):1085-1090.
16. Roberts TL, Pasquina PF, Nelson VS, Flood KM, Bryant PR, Huang ME. Limb deficiency and prosthetic management. 4. Comorbidities associated with limb loss. *Arch Phys Med Rehabil*. 2006;87(3)(suppl 1):S21-S27.
17. Holzer LA, Sevelde F, Fraberger G, Bluder O, Kicking W, Holzer G. Body image and self-esteem in lower-limb amputees. *PLoS One*. 2014;9(3):e92943.

18. Ide M, Watanabe T, Toyonaga T. Sexuality in persons with limb amputation. *Prosthet Orthot Int*. 2002;26(3):189-194.
19. Burger H, Marincek C. Return to work after lower limb amputation. *Disabil Rehabil*. 2007;29(17):1323-1329.
20. Horgan O, MacLachlan M. Psychosocial adjustment to lower-limb amputation: a review. *Disabil Rehabil*. 2004;26(14-15):837-850.
21. Meyer TM. Psychological aspects of mutilating hand injuries. *Hand Clin*. 2003;19(1):41-49.
22. Raichle KA, Hanley MA, Molton I, et al. Prosthesis use in persons with lower- and upper-limb amputation. *J Rehabil Res Dev*. 2008;45(7):961-972.
23. Akarsu S, Tekin L, Safaz I, Göktepe AS, Yazicioğlu K. Quality of life and functionality after lower limb amputations: comparison between uni- vs. bilateral amputee patients. *Prosthet Orthot Int*. 2013;37(1):9-13.
24. Durmus D, Safaz I, Adigüzel E, et al. The relationship between prosthesis use, phantom pain and psychiatric symptoms in male traumatic limb amputees. *Compr Psychiatry*. 2015;59:45-53.
25. Reiber GE, McFarland LV, Hubbard S, et al. Servicemembers and veterans with major traumatic limb loss from Vietnam war and OIF/OEF conflicts: survey methods, participants, and summary findings. *J Rehabil Res Dev*. 2010;47(4):275-297.
26. Fisher ES, Goodman DC, Chandra A. *Geography Is Destiny: Differences in Health Care among Medicare Beneficiaries in the United States and California*. Oakland, CA: California HealthCare Foundation; 2008.  
<http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/G/PDF%20GeographyIsDestiny08.pdf>. Accessed April 28, 2015.
27. Fisher ES, Goodman DC, Chandra A. Disparities in health and health care among Medicare beneficiaries: a brief report of the Dartmouth Atlas Project. Robert Wood Johnson Foundation; 2008.  
[http://www.dartmouthatlas.org/downloads/reports/AF4Q\\_Disparities\\_Report.pdf](http://www.dartmouthatlas.org/downloads/reports/AF4Q_Disparities_Report.pdf). Accessed April 29, 2015.
28. Rucker-Whitaker C, Feinglass J, Pearce WH. Explaining racial variation in lower extremity amputation: a 5-year retrospective claims data and medical record review at an urban teaching hospital. *Arch Surg*. 2003;138(12):1347-1351.
29. Lavery LA, van Houtum WH, Ashry HR, Armstrong DG, Pugh JA. Diabetes-related lower-extremity amputations disproportionately affect blacks and Mexican Americans. *South Med J*. 1999;92(6):593-599.
30. Eslami MH, Zayaruzny M, Fitzgerald GA. The adverse effects of race, insurance status, and low income on the rate of amputation in patients presenting with lower extremity ischemia. *J Vasc Surg*. 2007;45(1):55-59.
31. Whyte AS, Carroll LJ. A preliminary examination of the relationship between employment, pain and disability in an amputee population. *Disabil Rehabil*. 2002;24(9):462-470.

32. Ephraim PL, MacKenzie EJ, Wegener ST, Dillingham TR, Pezzin LE. Environmental barriers experienced by amputees: the Craig Hospital Inventory of Environmental Factors-Short Form. *Arch Phys Med Rehabil.* 2006;87(3):328-333.
33. DaVanzo JE, El-Gamil A, Li JW, Shimer M, Manolov N, Dobson A. Assessment of patient outcomes of rehabilitative care provided in inpatient rehabilitation facilities (IRFs) and after discharge. Vienna, VA: Dobson DaVanzo; 2014. <https://www.amrpa.org/newsroom/Dobson%20DaVanzo%20Final%20Report%20-%20Patient%20Outcomes%20of%20IRF%20v%20%20SNF%20-%207%2010%2014%20redated.pdf>. Accessed April 9, 2015.
34. Dillingham TR, Pezzin LE, MacKenzie EJ. Incidence, acute care length of stay, and discharge to rehabilitation of traumatic amputee patients: an epidemiologic study. *Arch Phys Med Rehabil.* 1998;79(3):279-287.
35. Mackenzie EJ, Jones AS, Bosse MJ, et al. Health-care costs associated with amputation or reconstruction of a limb-threatening injury. *J Bone Joint Surg Am.* 2007;89(8):1685-1692.
36. American Hospital Association. Trendwatch: teaching hospitals: their impact on patients and the future health care workforce. September 2009. <http://www.aha.org/research/reports/tw/twsept2009teaching.pdf>. Accessed April 29, 2015.
37. American Hospital Association. Fast facts on US Hospitals. January 2015. <http://www.aha.org/research/rc/stat-studies/fast-facts.shtml>. Accessed April 29, 2015.
38. Branas CC, MacKenzie EJ, Williams JC, et al. Access to trauma centers in the United States. *JAMA.* 2005;293(21):2626-2633.
39. Resnik L, Meucci MR, Lieberman-Klinger S, et al. Advanced upper limb prosthetic devices: implications for upper limb prosthetic rehabilitation. *Arch Phys Med Rehabil.* 2012;93(4):710-717.
40. Torio CM, Andrews RM. Statistical brief #160: national inpatient hospital costs: the most expensive conditions by payer, 2011. Healthcare Cost and Utilization Project. <http://www.hcup-us.ahrq.gov/reports/statbriefs/sb160.pdf>. Accessed April 29, 2015.
41. Ma VY, Chan L, Carruthers KJ. Incidence, prevalence, costs, and impact on disability of common conditions requiring rehabilitation in the United States: stroke, spinal cord injury, traumatic brain injury, multiple sclerosis, osteoarthritis, rheumatoid arthritis, limb loss, and back pain. *Arch Phys Med Rehabil.* 2014;95(5):986-995.
42. In 2011, Medicare was billed for more than three-fifths of the total "direct costs" incurred at hospitals, representing nearly 68 percent of all patient discharges (see reference 39, Resnik et al.). The rest was billed to Medicaid, private insurance, or the (uninsured) patient directly. Patients are themselves expected to make some contribution to their care, typically in the form of a copayment for products or services. Medicare and Medicaid both require a 20 percent patient

- copy for prosthetic devices. Private insurers have widely varying rates. National Limb Loss Information Center. Fact sheet: financial assistance for prosthetic services, durable medical equipment, and other assistive devices. Amputee Coalition of America; 2008. [http://www.amputee-coalition.org/fact\\_sheets/assist\\_orgs.html](http://www.amputee-coalition.org/fact_sheets/assist_orgs.html). Accessed April 29, 2015.
43. Highsmith MJ, Kahle JT, Bongiorno DR, Sutton BS, Groer S, Kaufman KR. Safety, energy efficiency, and cost efficacy of the C-Leg for transfemoral amputees: a review of the literature. *Prosthet Orthot Int*. 2010;34(4):362-377.
  44. Fish D. The development of coverage policy for lower extremity prosthetics: the influence of the payer on prosthetic prescription. *J Prosthet Orthot*. 2006;18(6):125-129.
  45. Cigna. Cigna medical coverage policy: lower limb prosthetic devices (including vacuum-assisted socket system and microprocessor/computer-controlled lower limb prostheses). September 15, 2013. [http://www.spsco.com/media/wysiwyg/download/mm\\_0194\\_coveragepositioncriteria\\_lower\\_limb\\_prosthet\\_vass\\_computer\\_control%20copy.pdf](http://www.spsco.com/media/wysiwyg/download/mm_0194_coveragepositioncriteria_lower_limb_prosthet_vass_computer_control%20copy.pdf). Accessed March 11, 2015.
  46. Otto Bock. International C-leg studies. 3rd ed. [http://www.ottobock.com/cps/rde/xbcr/ob\\_com\\_en/646B33-GB-01-1003w.pdf](http://www.ottobock.com/cps/rde/xbcr/ob_com_en/646B33-GB-01-1003w.pdf). Accessed March 11, 2015.
  47. Biddiss E, McKeever P, Lindsay S, Chau T. Implications of prosthesis funding structures on the use of prostheses: experiences of individuals with upper limb absence. *Prosthet Orthot Int*. 2011;35(2):215-224.
  48. Dougherty PJ, McFarland LV, Smith DG, Reiber GE. Bilateral transfemoral/transtibial amputations due to battle injuries: a comparison of Vietnam veterans with Iraq and Afghanistan servicemembers. *Clin Orthop Relat Res*. 2014;472(10):3010-3016.
  49. McFarland LV, Hubbard Winkler SL, Heinemann AW, Jones M, Esquenazi A. Unilateral upper-limb loss: satisfaction and prosthetic-device use in veterans and servicemembers from Vietnam and OIF/OEF conflicts. *J Rehabil Res Dev*. 2010;47(4):299-316.
  50. Ham R, Regan JM, Roberts VC. Evaluation of introducing the team approach to the care of the amputee: the Dulwich study. *Prosthet Orthot Int*. 1987;11(1):25-30.
  51. Dobson A, El-Gamil A, Shimer M, DaVanzo JE. Retrospective cohort study of the economic value of orthotic and prosthetic services among Medicare beneficiaries. Vienna, VA: Dobson DaVanzo; 2013. [http://mobilitysaves.org/docs/Dobson\\_Davanzo\\_Study\\_on\\_Cost\\_Effectiveness.pdf](http://mobilitysaves.org/docs/Dobson_Davanzo_Study_on_Cost_Effectiveness.pdf). Accessed April 14, 2015.

**Colonel Paul F. Pasquina, USA (Ret), MD**, is the inaugural chair of the Department of Physical Medicine and Rehabilitation and director of the Center for Rehabilitation Sciences Research at the Uniformed Services University of the Health Sciences and director of the Physical Medicine and Rehabilitation Residency Training Program at Walter Reed National Military Medical Center in Bethesda, Maryland. His research efforts explore new technologies to enhance the recovery, rehabilitation, and reintegration of those with combat casualties, particularly traumatic brain injury and extremity trauma.

**Antonio J. Carvalho** is a researcher for the Henry M. Jackson Foundation for the Advancement of Military Medicine and its programs at the Walter Reed National Military Medical Center and the Uniformed Services University of the Health Sciences in Bethesda, Maryland. He is involved in research that investigates treatments and therapies to advance the care, recovery, and rehabilitation of those with extremity trauma and traumatic brain injury, and he is interested in the impact of scientific advancements on law and regulation.

**Terrence Patrick Sheehan, MD**, is the chief medical officer of Adventist Rehabilitation Hospital in Rockville, Maryland. He is also the division director for rehabilitation medicine at The George Washington University Hospital and an associate professor of rehabilitation medicine in the Department of Neurology at The George Washington School of Medicine in Washington, DC. He has served as the national medical director for of the Amputee Coalition since 2006.

#### **Related in the AMA Journal of Ethics**

Physician Paternalism and Severe Acquired Disability: Strengthening Autonomy through Therapeutic Engagement, June 2015 /2015/06/ecas1-1506.html  
Service Dogs for Veterans with PTSD, June 2015 /2015/06/hlaw1-1506.html  
Veterans Health Administration Policy on Cannabis as an Adjunct to Pain Treatment with Opiates, June 2015 /2015/06/pfor2-1506.html

#### **Disclaimer**

The opinions expressed herein are those of the authors, and are not necessarily representative of those of the Uniformed Services University of the Health (USUHS), Walter Reed National Military Medical Center (WRNMMC), the Department of Defense (DOD), or the United States Army, Navy, or Air Force.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 547-552

## HEALTH LAW

### Service Dogs for Veterans with Posttraumatic Stress Disorder

Richard Weinmeyer, JD, MA, MPhil

#### Introduction

Tori Stitt has dedicated most of her adult life to the armed services. After attending college on a Reserve Officers' Training Corps scholarship, she was commissioned as a naval officer and accepted a position working on a guided-missile destroyer [1]. Due to the familiarity she developed in working with the sophisticated electronic equipment, she was recruited to join an army battalion in Iraq, where her technical skills would be used to remotely detect or jam roadside bombs. Although Tori was excited about the opportunity to be so close to combat, her experiences left her traumatized. Amidst the chaotic episodes of exploding bombs, enemy fire, and tense bomb-search patrols, Lieutenant Stitt found herself frozen with terror and confusion, and, within a few months, toughened and exhausted. While in Iraq, Tori began having nightmares and problems sleeping, withdrawing from others socially, and, soon, drinking to cope with her psychological issues. Upon returning to the United States when her tour of duty was over, her drinking intensified and her mental anguish grew so great that she began contemplating suicide.

Treatment for her substance abuse and for her posttraumatic stress disorder (PTSD) helped Lieutenant Stitt to regain some semblance of control over her life, but she continued to struggle with nightmares, flashbacks, and social isolation. In search of another outlet to help her cope with her ongoing problems, she sought relief through a tried-and-true resource: a dog. This was not simply any dog, however; this was a trained service dog, a golden retriever named Devon that Tori procured from a local service dog organization for \$3,000. Devon has been immensely beneficial for Tori, who notes, "It doesn't matter what bad things are going on, I can pet Devon, give him a hug, and they turn around 180 degrees." When Tori is nervous or anxious, Devon stands close to her or places his paw in her lap. Should she thrash about in her sleep because of a nightmare, Devon wakes her up by licking her face. And because he is a dog, Tori has to take Devon for walks, which forces her to leave her home and, on occasion, interact with people.

Hundreds of thousands of veterans who have served in the most recent wars in Iraq and Afghanistan are returning from their tours of duty with [myriad physical and mental injuries](#) that have reawakened the public's consciousness of the long-term consequences that combat can have [2]. Whether the injury sustained is from shrapnel, a roadside bomb, or witnessing carnage, the pain and suffering of servicewomen and men

is real and, for many, chronic. But the relief available is not necessarily the same for all veterans, particularly when it comes to the rehabilitative care offered by service dogs. Veterans who return home with physical impairments that hamper their mobility have the opportunity to obtain service dog benefits (which include financial assistance with veterinary expenses, the costs for obtaining and training a dog, and the costs of equipment required for the dog to perform its tasks) covered by the United States Department of Veterans Affairs (VA). Yet for those veterans whose injuries are psychological in nature, no service canine benefits are bestowed by the VA. I will discuss just how and why this inequality exists in federal law and the actions being taken both within the federal government and outside of the political arena to address it.

### **Service Dogs and the VA**

[PTSD](#) is a psychological response to extreme trauma that involves long-term, persistent changes in mood (generally depressive), behavior (often aggressive), and experience (flashbacks, nightmares, and intrusive thoughts) [3-5]. The VA uses a variety of [treatment methods](#) to help veterans deal with PTSD, much of it focused on forms of cognitive behavioral therapy (CBT), in conjunction with antidepressants, group therapy, psychodynamic therapy, and family therapy [6]. In recent years, however, veteran advocacy organizations, service dog organizations, and mental health advocates have come out strongly in favor of using service dogs not only to provide veterans with companionship in facing the daily challenges of their postmilitary lives, but also to aid in their ongoing recovery from the traumatizing consequences of battle [1, 7, 8]. The VA itself alludes to the benefits for veterans dealing with PTSD of having a (nontherapeutic) pet dog, noting that dogs may help a cautious veteran to interact better with strangers or deal with crowded public spaces while providing him or her an opportunity to experience and express love and to oversee an animal's training [9]. But when it comes to service dogs, the VA does not necessarily endorse their use, and the reasoning for this lies within the legal framework guiding veteran rehabilitation via service animals.

*Restrictions on conditions for use of service dogs.* The VA has been providing service dogs for veterans since 1958, beginning with the need of blind veterans for guide dogs to assist their mobility [10]. In 2002, access to service dogs was granted for veterans who were hearing impaired or who had "spinal cord injury or dysfunction or other chronic impairment that substantially limits mobility" [11]. And in 2009, Congress gave further power to the VA to provide "service dogs trained for the aid of persons with mental illnesses, including post-traumatic stress disorder" [12]. In 2012, however, the VA, using the rule-making authority granted it by Congress, ultimately promulgated a final rule that restricted service dog provision to "veterans with visual, hearing, or substantial mobility impairments" [13].

*Discrimination?* During the rule-making process, which was open to public comment, the VA received considerable feedback from those concerned about the exclusion of service

dog benefits for mental illness. Commentators characterized the denial as unlawfully discriminatory because it treated veterans with mental health impairments differently than those with physical impairments [13]. They argued that this differential treatment violated section 504 of the Rehabilitation Act of 1973, which states: “No otherwise qualified individual with a disability in the United States...shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance” [14].

The VA disagreed with this argument. In countering the claim of discrimination, the VA argued that not providing service dog benefits for those with mental illness did not violate the Rehabilitation Act [13]—quite the opposite, in fact. The VA stated that it provides benefits not for particular conditions but for particular purposes, i.e., “to help a veteran manage a visual impairment, a hearing impairment, or a chronic impairment that substantially limits mobility,” and that all veterans receive equal consideration for service dog benefits [13]. Should a mentally disabled veteran have trouble seeing, hearing, or getting around, he or she could very well qualify for a service dog through the VA.

*Great need, but little evidence.* The VA’s reason for not covering service dogs for mental health disabilities is that the agency follows an evidence-based model [15] and published studies or sound clinical evidence supporting the mental health benefits of service dogs is lacking [13]. The testimonials of veterans with PTSD whose lives have been dramatically transformed thanks to the camaraderie and care of a service dog are powerful stories of health and healing. Yet these beneficial experiences, at present, have been supported by anecdotal rather than scientific evidence.

This lack of empirical evidence is not for lack of effort. The VA actually has been working to obtain scientific evidence of the benefits of service dogs for veterans suffering from mental health problems for several years. In 2009, swayed by the personal story of an Iraq war veteran whose service dog helped him overcome PTSD, Senator Al Franken of Minnesota looked into the potential benefits that service dogs can bring to psychologically injured veterans [16]. When he found that research was scarce and that, for most veterans, service dogs were financially inaccessible without monetary support [17], Franken and Senator Johnny Isakson of Georgia introduced the Service Dogs for Veterans Act, calling for a “three-year study to assess the benefits, feasibility, and advisability of using service dogs for the treatment or rehabilitation of veterans with physical or mental injuries or disabilities, including post-traumatic stress disorder” [18].

The implementation of the study, however, has been hampered by numerous setbacks. The research methodology originally included three service dog providers, but by 2012 two had stopped participating in the investigation. Moreover, the entire project was suspended from January to June 2012 after a child was bitten by one of the study dogs

[19], and the study was suspended a second time that year after the VA found that one of the participating hospitals had violated its contract and jeopardized the dogs' health and safety [19]. After a comprehensive redesign of the entire study, a second iteration of it was launched at the end of 2014, with 220 pairs of veterans and service dogs participating in Atlanta, Iowa City, and Portland, Oregon [20].

### **Conclusion**

All hope is not lost in the progress towards understanding the health impact of service dogs on veterans with PTSD. At the end of 2014, the preliminary results of a yearlong study of 75 such veterans conducted by Kaiser Permanente were disseminated to the public and communicated to lawmakers [21]. The Pairing Assistance-Dogs with Soldiers (PAWS) study revealed that service dogs can "significantly reduce symptoms of post-traumatic [stress]...and depression in veterans" [21]. Veterans paired with service dogs reported lower symptoms of PTSD, lower symptoms of depression-related functioning, better interpersonal relationships, less substance abuse, and fewer psychiatric symptoms than veterans without dogs [22].

With this welcome, albeit early, indication of service dogs' health impact on veterans with PTSD, there is now a realistic possibility that the VA will consider changing its stance on the provision of financial resources to this population in need of more assistance. As the agency stated in its final rule determination, "if we ultimately determine that mental health dogs are appropriate treatment tools for mental health impairments, we will amend our regulations to authorize benefits for such dogs" [13]. For war veterans such as Lieutenant Tori Stitt, this type of support from the federal government—and recognition of the sacrifices they have made for the United States—cannot come soon enough.

### **References**

1. The details of Lieutenant Stitt's story recounted here are from Dao J. Loyal companion helps a veteran regain her life after war trauma. *New York Times*. April 28, 2012. [http://www.nytimes.com/2012/04/29/us/loyal-companion-helps-a-veteran-with-post-traumatic-stress-disorder.html?\\_r=0](http://www.nytimes.com/2012/04/29/us/loyal-companion-helps-a-veteran-with-post-traumatic-stress-disorder.html?_r=0). Accessed April 10, 2015.
2. Chandrasekaran R. A legacy of pain and pride. *Washington Post*. March 29, 2014. <http://www.washingtonpost.com/sf/national/2014/03/29/a-legacy-of-pride-and-pain/>. Accessed April 20, 2015.
3. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: American Psychiatric Association; 2013.
4. US Department of Veterans Affairs National Center for PTSD. Understanding PTSD. August 2013. [http://www.ptsd.va.gov/public/understanding\\_ptsd/booklet.pdf](http://www.ptsd.va.gov/public/understanding_ptsd/booklet.pdf). Accessed April 10, 2015.

5. American Psychiatric Association. Posttraumatic stress disorder. 2013. <http://www.dsm5.org/Documents/PTSD%20Fact%20Sheet.pdf>. Accessed April 14, 2015.
6. US Department of Veterans Affairs National Center for PTSD. Treatment of PTSD. <http://www.ptsd.va.gov/public/treatment/therapy-med/treatment-ptsd.asp>. Accessed April 14, 2015.
7. Colin C. How dogs can help veterans overcome PTSD. *Smithsonian Magazine*. July 2012. <http://www.smithsonianmag.com/science-nature/how-dogs-can-help-veterans-overcome-ptsd-137582968/?no-ist>. Accessed April 14, 2015.
8. Froling J. Service dog tasks for psychiatric disabilities. International Association of Assistance Dog Partners. July 30, 2009. [http://www.iaadp.org/psd\\_tasks.html](http://www.iaadp.org/psd_tasks.html). Accessed April 14, 2015.
9. US Department of Veterans Affairs National Center for PTSD. Dogs and PTSD. [http://www.ptsd.va.gov/public/treatment/cope/dogs\\_and\\_ptsd.asp](http://www.ptsd.va.gov/public/treatment/cope/dogs_and_ptsd.asp). Accessed April 14, 2015.
10. Veterans' Benefits, 38 USC sec 1714 (1958).
11. Veterans' Benefits, 38 USC sec 1714 (2002).
12. Veterans' Benefits, 38 USC sec 1714 (2009).
13. Service dogs. *Fed Regist*. 2012;77(172):54368-54382. Codified at 38 CFR sec 17.148.
14. Rehabilitation Act, 29 USC sec 794 (2014).
15. Leading the charge towards evidence-based medicine. *VA Research Currents*. November-December 2008:4-5. [http://www.research.va.gov/resources/pubs/docs/va\\_research\\_currents\\_nov-dec\\_08.pdf](http://www.research.va.gov/resources/pubs/docs/va_research_currents_nov-dec_08.pdf). Accessed April 15, 2015.
16. Nunley A. Service dogs for (some) veterans: inequality in the treatment of disabilities by the Department of Veterans Affairs. *Quinnipiac Health Law*. 2014;17:261-291. [http://www.quinnipiac.edu/prebuilt/pdf/SchoolLaw/HealthLawJournalLibrary/Vol17\\_Issue2\\_2014\\_Nunley.pdf](http://www.quinnipiac.edu/prebuilt/pdf/SchoolLaw/HealthLawJournalLibrary/Vol17_Issue2_2014_Nunley.pdf). Accessed April 21, 2015.
17. Service dogs for veterans. Al Franken: US Senator from Minnesota. <https://www.franken.senate.gov/?p=issue&id=84>. Accessed April 15, 2015.
18. Pub L No 111-84, 123 Stat 2477.
19. Ruiz R. The fight for service dogs for veterans with PTSD. *The Atlantic*. September 26, 2012. <http://www.theatlantic.com/health/archive/2012/09/the-fight-for-service-dogs-for-veterans-with-ptsd/262863/>. Accessed April 15, 2015.
20. Burke MM. Study examines impact of service dogs on veterans with PTSD. *Stars and Stripes*. January 31, 2015. <http://www.stripes.com/news/study-examines-impact-of-service-dogs-on-veterans-with-ptsd-1.327058>. Accessed April 15, 2015.

21. Pedersen T. Service dogs can reduce PTSD symptoms in veterans. *PsychCentral*. December 23, 2014. <http://psychcentral.com/news/2014/12/23/service-dogs-can-reduce-ptsd-symptoms-in-veterans/79009.html>. Accessed April 15, 2015.
22. Kaiser Permanente Research. PAWS Research Project: preliminary results. December 9, 2014. <https://olis.leg.state.or.us/liz/201311/Downloads/CommitteeMeetingDocument/42181>. Accessed April 15, 2015.

**Richard Weinmeyer, JD, MA, MPhil**, is a senior research associate for the American Medical Association Council on Ethical and Judicial Affairs in Chicago. Mr. Weinmeyer received his master's degree in bioethics and his law degree with a concentration in health law and bioethics from the University of Minnesota, where he served as editor in chief for volume 31 of *Law and Inequality: A Journal of Theory and Practice*. He obtained his first master's degree in sociology from Cambridge University. Previously, Mr. Weinmeyer served as a project coordinator at the University of Minnesota Division of Epidemiology and Community Health. His research interests are in public health law, bioethics, and biomedical research regulation.

**Related in the *AMA Journal of Ethics***

[Physician Paternalism and Severe Disability: Strengthening Autonomy through Therapeutic Engagement](#), June 2015

[The Evolving Definition of Posttraumatic Stress Disorder: Legal Ramifications](#), October 2013

[A New Focus on Caring for Survivors of Extreme Violence](#), October 2007

[The "Army of Lost Souls,"](#) January 2009

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 553-557

## POLICY FORUM

### Access to Rehabilitative Care in the Affordable Care Act Era

Steven G. Ullmann, PhD

The Patient Protection and Affordable Care Act of 2010 has certainly caused much discussion and debate in our country since its passage, now more than five years ago. Questions continue to arise in the public discourse as to whether one is “for” or “against” the Affordable Care Act (ACA). Yet when one looks closer at the 2,000-plus pages of the act and 10,000-plus pages of rules, one realizes this is a multi-layered law. One of the areas worthy of exploration and discussion is how the act affects provision and accessibility of rehabilitative care services. That discussion is the purpose of this article.

### A Brief History of Government-Sponsored Health Care Coverage in the United States

It was not until World War II that we began to consider as a society whether medical care should be treated as a right rather than a privilege. Society decided that serving in the military entitled one to health care. Care for those with disabilities acquired during military service was to be provided by the Veterans Administration [1].

Fostered by unions and encouraged by various federal government policies, health insurance coverage expanded significantly. In a mere ten-year period, from 1940 to 1950, the percentage of the US population with health insurance coverage, provided primarily by employers, expanded from 9 percent to 53 percent [2]. Access to medical care, including habilitation and rehabilitation for acute and chronic conditions, was now available to a majority of the population.

Medicare, passed by Congress and signed into law by President Johnson in 1965, expanded health care access to the retired and elderly population and eventually was extended to cover care for those who had certain chronic disabilities. There was to be “equal financial access,” i.e., people in all financial situations would have equal ability to access medical care, and “equal treatment for equal need,” i.e., the provision of services would be the same regardless of individual circumstances [3]. With the passage of Medicare, coverage for those aged 65 and over was to increase from roughly 55 percent to 99 percent essentially overnight [4]. Medicaid was passed at the same time, managed by states but jointly funded by the federal government, with the aim of attaining a “decent minimum” [3] level of care for all—the indigent (those who are poor) and the medically indigent (those who become poor because of their medical situation).

Despite these gains, [patterns of behavior](#) were established that were to repeat themselves. The American Medical Association fought vehemently against Medicare on the grounds that it was “socialized medicine” [5]. Only 26 states established Medicaid programs in the first year [6], despite the availability of significant federal subsidies. It took 17 years for all 50 states to implement Medicaid [6]. All this is much like the story unfolding around the ACA, which was designed to ensure equal access to health care for the US population at large. We are experiencing some of the same debate and raw emotions that we did 50 years ago when the Medicare and Medicaid programs were debated in the halls of Congress. States have been slow to implement the ACA despite the availability of federal funding, and opposition to the underlying aims of the program has been fierce [7]. But the numbers of the uninsured are dropping in the United States [7], from 48 million before the ACA’s passage to 37 million today [8]. We may indeed be beginning to look like other countries in terms of slowly approaching universal coverage. Equal access, as envisioned by those who conceived of Medicare, is perhaps in sight [9]. Health insurance plans are no longer allowed to deny individuals coverage or raise their premiums due to preexisting conditions. Lifetime coverage maximums are no longer legal. In fact, the only variables that can legally affect insurance premiums today are geographic region, use of tobacco, age, the richness of the health care plan benefits, and whether the plan offers individual or family coverage [9].

#### **Does the Affordable Care Act Ensure Equal Access to Care?**

“Equal access” to health care—the intention of the ACA—is not, however, equivalent to “equal financial access” or “equal treatment for equal need,” which served as the basis for the development of Medicare. It is true that individuals or families with incomes below 400 percent of the federal poverty level who purchase health insurance through a federal or state exchange may receive federal subsidies [10]. But there are limitations on what insurance plans provide through these exchanges.

*Barriers to equal access.* The exchanges were created to allow patients “choice,” a mantra of the ACA. This refers to choice of health plans or levels of coverage—bronze, silver, gold, or platinum plans, each successive level providing more benefits and lower deductibles but with a higher monthly premium—as well as choice of clinicians within that insurer’s network. The complexity of such choice is a barrier for the typical person seeking insurance. In one urban community, for example, 91 health plans were available to users of the exchange for 2015 [9]. Each plan comes with a different network of clinicians and different financial aspects: pharmaceutical formularies, costs and provisions for habilitation and rehabilitation, and rules for coverage. Those covered by employer-sponsored insurance do not confront this paralyzing level of complexity.

Added to this complexity is the trend toward increasingly narrow clinician networks, an attempt by health insurance companies to steer policyholders toward those practitioners with lower costs and higher value. Access to care is limited, geographically and

temporally, by restricted networks of clinicians, which can disproportionately affect patients who live in certain places by causing long waits for care in close proximity or time-intensive and expensive travel to obtain care.

Add, further, that thousands of dollars in payments are required by high-deductible health insurance plans before—and by coinsurance after—the coverage actually kicks in, which amounts to a significant financial barrier to access to care that particularly affects those without significant means. That the high costs of health care affect a large number of people is evidenced by their choice of health care plans: 85 percent of the 8 million people who subscribed in the first year of the health insurance exchange offerings chose either a bronze plan (with a deductible upwards of \$4,500 for an individual) or a silver plan (with a deductible of at least \$2,500 for an individual) [11].

Take all this together, and we see that the ACA may have limited success in providing equal access to health care.

*Barriers to habilitation and rehabilitation.* Finally, depending upon the plan chosen, there may be significant limitations on the amount of the habilitation and rehabilitation services covered, and coinsurance requires the patient to pay a significant proportion of the cost. Even though a plan might have limits on out-of-pocket costs to protect the policyholder, that does not mean there will be coverage for unlimited access to habilitation and rehabilitation services. And many patients tend not to look at the details of their benefit plans, leading to a rude awakening about the limits on benefits. All this [limits access to rehabilitation care](#).

In the eyes of many, an injury or significant illness requires immediate attention and may reflect an “inelastic” demand for health care services, in the language of the economist—a demand that is unlikely to be altered significantly by changing prices. Habilitation and rehabilitation, however, tend to not be perceived as requiring immediate attention, and therefore demand is more “elastic.” People without the means to pay for habilitative and rehabilitative care out of pocket may, therefore, put it off, with short- or long-term negative effects on health.

Furthermore, we seek transparency in the marketplace for health care coverage. But when “transparency” amounts to lengthy detailing of extremely complex systems, is it really achieving the intended goals? One may see the following actual language in insurance plan documentation: “Visit limit is a combined limit with Physical, Speech, Massage, Occupational, Cardiac and Respiratory Therapy. Outpatient Rehabilitation and Habilitation Services Visit Limits are a Combined Limit” [9]. Language in another plan indicates the benefits for habilitation and rehabilitation services as follows: “Speech Therapy, Occupational Therapy and Physical Therapy receive a combined maximum of 45 visits, including chiropractic care, sub-acute rehabilitation. Facility use is limited to 21

days per covered person per calendar year. Home Health Care Services is limited to 20 days per covered person per calendar year” [9].

Altogether, low coverage and confusing, overly complex explanations of benefits may be obstructing access to rehabilitation care in the post-ACA United States.

### **Conclusion**

So have we achieved the goals underlying the establishment of Medicare and Medicaid? Equal access, as discussed in the context of the ACA, does not appear to mean the same thing that “equal financial access” did in the 1960s. High-deductible/high-coinsurance plans obstruct access to health care for those with limited financial means. Geographic barriers due to limited clinician networks may also obstruct access to care for residents of certain areas. Equality of access has decidedly not been assured.

Given that 22 states have not expanded their Medicaid programs, it could be argued that we have not even assured a decent minimum of care. In states that have not expanded their Medicaid program, state residents who have incomes below 138 percent of the federal poverty level—a significant proportion of people, since approximately 27 percent of the uninsured nonelderly population have incomes under 100 percent of it [12]—have fallen into the chasm between being able to afford health care and being eligible for Medicaid and/or federal subsidies to reduce health insurance costs.

Laws, rules, and regulations evolve over time. Perhaps legislators and policymakers will realize these shortcomings and make changes—we will see.

### **References**

1. Rostker B. *Providing for the Casualties of War: The American Experience through World War II*. Santa Monica, CA: Rand Corporation; 2013.  
[http://www.rand.org/content/dam/rand/pubs/monographs/MG1100/MG1164/RAND\\_MG1164.pdf](http://www.rand.org/content/dam/rand/pubs/monographs/MG1100/MG1164/RAND_MG1164.pdf). Accessed April 20, 2015.
2. Conover CJ. How private health insurance slashed the uninsured rate for Americans. American Enterprise Institute. September 16, 2011.  
<http://www.aei.org/publication/how-private-health-insurance-slashed-the-uninsured-rate-for-americans/>. Accessed February 27, 2015.
3. Feldstein P. *Health Care Economics*. 7th ed. Clifton Park, NY: Delmar/Cengage Learning; 2011.
4. Social Security Administration. History of SSA during the Johnson Administration 1963-1968. <http://www.socialsecurity.gov/history/ssa/lbjmedicare1.html>. Accessed March 3, 2015.
5. Harry S. Truman Library and Museum. This day in Truman history: November 19, 1945: President Truman’s proposed health program.

- <http://www.trumanlibrary.org/anniversaries/healthprogram.htm>. Accessed February 27, 2015.
6. Oberg CN, Polich CL. Medicaid: entering the third decade. *Health Aff (Millwood)*. 1988;7(4):83-96.
  7. Montanaro D. Obamacare five years later: thriving or on political life support? *NPR*. March 25, 2015.  
<http://www.npr.org/blogs/itsallpolitics/2015/03/25/395293756/obamacare-five-years-later-thriving-or-on-political-life-support>. Accessed April 10, 2015.
  8. Assessing health law's impact at five years. *Kaiser Health News*. March 24, 2015.  
<http://kaiserhealthnews.org/morning-breakout/assessing-health-laws-impact-at-five-years/>. Accessed April 17, 2015.
  9. Healthcare.gov website. <https://www.healthcare.gov/>. Accessed April 17, 2015.
  10. Kaiser Family Foundation. Explaining health care reform: questions about health insurance subsidies. October 27, 2014. <http://kff.org/health-reform/issue-brief/explaining-health-care-reform-questions-about-health>. Accessed April 10, 2015.
  11. US Department of Health and Human Services. ASPE issue brief: the addendum to the health insurance marketplace summary enrollment report for the initial annual open enrollment period. May 1, 2014.  
[http://aspe.hhs.gov/health/reports/2014/MarketPlaceEnrollment/Apr2014/ib\\_2014Apr\\_enrollAddendum.pdf](http://aspe.hhs.gov/health/reports/2014/MarketPlaceEnrollment/Apr2014/ib_2014Apr_enrollAddendum.pdf). Accessed February 27, 2015.
  12. Kaiser Family Foundation. Distribution of the nonelderly uninsured by federal poverty level (FPL).  
<http://www.statehealthfacts.org/comparebar.jsp?ind=136&cat=3>. Accessed March 2, 2015.

**Steven G. Ullmann, PhD**, is the director of the Center for Health Sector Management and Policy and a professor in the School of Business Administration at the University of Miami, Florida.

**Related in the *AMA Journal of Ethics***

[Ethics in Rehabilitation: Access to Prosthetics and Quality Care Following Amputation](#), June 2015

[Service Dogs for Veterans with PTSD](#), June 2015

[Overcoming Inequalities: The Affordable Care Act and Cancer Treatment](#), August 2013

[Implications of the Affordable Care Act for Kidney Transplantation](#), March 2012

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 558-561

## POLICY FORUM

### Veterans Health Administration Policy on Cannabis as an Adjunct to Pain Treatment with Opiates

Michael Krawitz

I am a disabled veteran, but I didn't fall prey to an enemy grenade; my story is much less exciting. Together with my motorcycle, I lost a battle with a coral-packed roadway on a rainy night in 1984 while serving on Guam. I survived thanks to navy doctors on the island to whom I will always be indebted for saving my life.

Over the coming weeks in an army hospital, I would deal with acute pain from my injuries that included shattered and broken bones and damage to parts of my small intestine, which were removed along with my spleen. The worst injury was a broken hip that never did heal. Avascular necrosis set in, leading to a total hip replacement. Over the years I have continued to have pain that only now is deemed long-term and [chronic](#).

I have had some excellent doctors inside and outside the VA who have guided me through many treatment options—dozens, in fact—some involving medications and some involving counseling. I tried many anti-inflammatory and otherwise nonnarcotic pain medications, some with very severe negative side effects, before settling on an opiate medication for my pain.

And then, in the mid-1990s, I discovered something amazing. Although opiates gave me relief from pain and allowed me to have some functionality, the dose I was prescribed for a long flight, for example, caused stomach problems that took days to resolve. It was on a trip abroad that I was first prescribed cannabis as an adjunct to my pain treatment. I found that, with [cannabis](#), I was able to use an amount of opiates small enough to reduce side effects while allowing me to function better than I did when taking the higher dose.

I have discovered I am not alone in finding cannabis helpful in reducing the amount of opiate medication I need to find adequate relief. I met a doctor in California who reported that, since the medical marijuana law there was enacted in 1996, many of his patients have said they were getting better pain relief using less opiates when they combined them with cannabis [1]. Years later, the first double-blind placebo-based cannabis trial results also seemed to support this effect [2], and, even more recently, cannabis's promise in lowering opiate overdose rates has come into focus [3].

One day at the VA hospital, I was handed a “[pain contract](#)” and instructed to sign it—a form my doctor received in a memo that threatened denial of my medication if I didn’t follow the rules outlined therein, including abstaining from all use of marijuana. When I took the document to my attorney I was advised that it couldn’t be a legal contract, since a contract must benefit both parties. And, since I was already receiving my medical care from the VA under federal law, I concluded that the VA couldn’t compel me to sign the document as a condition for receiving treatment. Much to my surprise, however, I was cut off from access to my prescribed pain medication and told that this situation would continue until I signed the form.

My standoff with the VA over the “pain contract” would lead to new national VA policy on medical marijuana and an end to the VA’s use of the document.

The first thing I discovered was a strong disconnect between what the memos on pain management meant to those who were writing them and how they were being perceived by those charged with their implementation. According to the Pain Management Directorate and the VA’s National Center for Ethics in Health Care (VHA Ethics), the memos on pain management were never supposed to be applied indiscriminately to all patients. The national VA officials seemed genuinely concerned that the policy was playing out at the clinic level in the way I described because, according to VHA Ethics, “no patient should be denied opioid therapy for chronic pain when that is otherwise clinically appropriate” [4].

I crafted and mailed a question to the VA’s leadership based upon the ethical standard that pain treatment should never be withheld punitively, to try to elicit a written response that could be used as guidance at the clinic level. The VA Undersecretary of Health’s answer was clear enough that in 2010 I was able to parlay it, through negotiation brought about by media attention, into a new national VA medical marijuana policy drawn from medical ethics concepts [5, 6].

Since the VA’s medical marijuana policy went into effect, the VA has thrown out the old “pain contract” and instituted a policy based upon informed consent to treatment, with a nonpunitive pain agreement that specifically mentions medical marijuana. If you study this new VA directive #1005 [7] and the associated handbook, you will see that drug testing is intended to improve communication between the doctor and patient and the patient’s signature is required because the VA considers long-term opiate use life-threatening enough to require written consent. The associated drug testing is never intended to be used for punishment.

But, given the lack of guidance from VA leadership on what to actually do when confronted with a patient testing positive on the drug test, it is no surprise that many doctors still think it is OK to dramatically alter a patient’s treatment plan for “violating

the rules.” The police are tasked with enforcing society’s rules; medical ethics requires doctors to focus on the needs of the patient [8-9].

The classification of cannabis as a Schedule I drug in the US is based on the assertion that it has no medical value. This is the main reason why [cannabis can’t be prescribed](#) and/or readily accessed for research. Veterans for Medical Cannabis Access supports several bills before Congress to change the schedule number of cannabis, which are only really necessary because the Drug Enforcement Administration has blocked routine changes to the schedule number of marijuana [10]. The VA medical marijuana policy revealed that VA doctors, as federal employees, are prohibited from assisting veterans with paperwork for state medical marijuana programs, so another of our federal efforts is focused on removing this restriction. It is important to note that the act of writing a medical recommendation for cannabis has been determined to be a free speech activity integral to the doctor-patient relationship protected by the US Constitution in *Conant v. Walters* [11]. At the state level, we have been assisting in drafting medical cannabis access laws and ensuring that existing laws cover conditions vets are likely to suffer from, like traumatic brain injury, posttraumatic stress disorder, chronic pain, and cancer. Our goal is simply to make sure all relevant treatment options are made available to the patient [12].

## References

1. California Secretary of State. Proposition 215: Medical use of marijuana. Initiative statute. <http://vote96.sos.ca.gov/bp/215.htm>. Accessed April 28, 2015.
2. Brooks M. Cannabis augments analgesic effect of opioids. *Medscape*. December 13, 2011. <http://www.medscape.com/viewarticle/755388>. Accessed April 28, 2015.
3. Lower opioid overdose death rates associated with state medical marijuana laws [news release]. Chicago, IL: *JAMA*; August 25, 2014. <http://media.jamanetwork.com/news-item/lower-opioid-overdose-death-rates-associated-with-state-medical-marijuana-laws/>. Accessed April 28, 2015.
4. National Center for Ethics in Health Care. Ethical considerations in opioid therapy for chronic pain. April 2005. [http://www.ethics.va.gov/docs/infocus/InFocus\\_20050401\\_Opioid\\_Therapy\\_for\\_Chronic\\_Pain.pdf](http://www.ethics.va.gov/docs/infocus/InFocus_20050401_Opioid_Therapy_for_Chronic_Pain.pdf). Accessed April 28, 2015.
5. Petzel RA. Letter to Michael Krawitz. Department of Veterans Affairs; July 6, 2010. <http://www.veteransformedicalmarijuana.org/files/Undersecretary-Jun6.pdf>. Accessed April 28, 2015.
6. Geppert CA. Legal and clinical evolution of Veterans Health Administration policy on medical marijuana. *Fed Pract*. 2014;31(3):6-12. <http://www.fedprac.com/articles/feature/article/legal-and-clinical-evolution-of-veterans-health-administration-policy-on-medical-marijuana/ec143e5b5c6b3ed4838537da0bbf3b8b/ocregister.html>. Accessed April 28, 2015.

7. Veterans Health Administration. VHA Directive 1005: informed consent for long-term opioid therapy for pain. Department of Veterans Affairs; May 6, 2014. [http://www1.va.gov/vhapublications/ViewPublication.asp?pub\\_ID=3005](http://www1.va.gov/vhapublications/ViewPublication.asp?pub_ID=3005). Accessed April 28, 2015.
8. Veterans Affairs National Pain Management Program; VA National Center for Ethics in Health Care. Taking opioids responsibly for your safety and the safety of others: patient information guide on opioids for chronic pain. [http://www.ethics.va.gov/docs/policy/Taking\\_Opioids\\_Responsibly\\_2013528.pdf](http://www.ethics.va.gov/docs/policy/Taking_Opioids_Responsibly_2013528.pdf). Accessed April 28, 2015.
9. American Medical Association. Opinion 1.02 The relation of law and ethics. *Code of Medical Ethics*. <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion102.page>. Accessed April 28, 2015.
10. Compassionate Access, Research Expansion, and Respect States Act of 2015. S 683, 114th Cong, 1st Sess (2014-2015). <https://www.congress.gov/bill/114th-congress/senate-bill/683/text>. Accessed April 28, 2015.
11. *Conant v Walters*, 309 F3d 629 (9th Cir 2002).
12. Veterans for Medical Cannabis Access. About the VMCA. <http://www.veteransformedicallmarijuana.org/content/about-vmca>. Accessed April 28, 2015.

### Further Reading

Bulletin of Cannabis Reform. Discovery of the cannabinoid receptor system. <http://www.drugscience.org/Petition/C3D.html>. Accessed April 28, 2015.

Grant I, Atkinson JH, Mattison A, Coates TJ; Center for Medical Cannabis Research. Report to the Legislature and Governor of the State of California presenting findings pursuant to SB847 which created the CMCR and provided state funding. February 11, 2010. [http://cmcr.ucsd.edu/images/pdfs/cmcr\\_report\\_feb17.pdf](http://cmcr.ucsd.edu/images/pdfs/cmcr_report_feb17.pdf). Accessed April 28, 2015.

**Michael Krawitz** is executive director of Veterans for Medical Cannabis Access, in which capacity he negotiated the first Veterans Affairs policy on medical marijuana. He is a disabled United States Air Force Veteran and volunteer patient advocate.

### Related in the AMA Journal of Ethics

[Service Dogs for Veterans with PTSD](#), June 2015

[A Clinical Ethics Approach to Opioid Treatment of Chronic Noncancer Pain](#), June 2015

[Physicians, Medical Marijuana, and the Law](#), September 2014

[Medicinal Cannabis and Painful Sensory Neuropathy](#), May 2013

[Chronic Pain Patients and the Biomedical Model of Pain](#), May 2013

[Physicians' Responsibility to Understand Patients' Pain](#), May 2013

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 562-567

## MEDICINE AND SOCIETY

### The Disability Movement's Critique of Rehabilitation's Medical Model: A Rebuttal

John D. Banja, PhD

A few years ago, I received an invitation from the editors of the then-projected fourth edition of *Bioethics*—previously published as the *Encyclopedia of Bioethics*—to revise my 1995 entry on rehabilitation medicine [1]. I accepted the invitation, wrote and submitted the revision, and, in due time, received a review. While most of the review was positive, it nevertheless complained that my essay

tends to individualize the problem (of disability) and to pathologize the disabled person. More contemporary work in bioethics...theorizes disability in terms of the patient's embodied experience in the context of unjust social structures. Disability, that is, is best understood not as a property of individuals but rather of social contexts.

Although my essay was eventually accepted and published, I was perplexed by these comments. Having spent more than 30 years on the faculty of a medical school's department of rehabilitation medicine and now holding the rank of full professor, I felt I knew something about rehabilitation, and I was certainly aware of the "disability as a social construction" trope. My objection to the reviewer's comments was that rehabilitation medicine must, by its very nature, apply its therapeutic know-how to cognitive, behavioral, and affective symptoms of disability onset; otherwise, it wouldn't be rehabilitation medicine.

In this essay, I would like to ponder these questions: If disability is essentially an "embodied experience in the context of unjust social structures," do disability advocates view the rehabilitation effort and the medical model on which it rests as sociocultural mistakes? How can we explain disability advocates' arguments? Because we need to avoid "pathologizing the disabled person," should we forgo rehabilitation's explicitly therapeutic or admittedly "normalizing" attempts to lessen the burdens and discomforts of stroke and musculoskeletal, spinal cord, and brain injury? When I experienced the onset of myasthenia gravis about seven years ago and was significantly (but only temporarily) disabled as a result, if someone had told me my experience was largely one of "unjust social structures," I would have thought him or her mad. But would the disability movement say I would have been wrong to do so?

Have I concocted a *reductio ad absurdum* argument? I don't think so. People with disability and their advocates frequently evince a pronounced discomfort with anything that devalues the experience or phenomenon of disability—including rehabilitation's "normalization" approach to alleviating disability's burdens and discomforts by restoring function through pharmacologic and therapeutic modalities. Even a cursory reading of the disability movement (or disability studies) literature reveals a marked antipathy if not downright contempt toward medical interventional models (like rehabilitation medicine) that attend to disability onset. Such models are repudiated for portraying "disabilities as deficits" that range on a continuum from moderately undesirable to not worth living with. Consider this passage from one of the entries on disability appearing in the fourth edition of *Bioethics* [2]:

The way that disability tends to be discussed within bioethics remains at odds with how it is understood within disability studies and by advocates for disability rights [3]. Tensions between the disability rights perspective and the dominant voices within bioethics tend to arise from or reflect a very basic dispute about the effect of having a significant impairment on one's quality of life [4].... The legacy of the medical model within bioethics...is in the unquestioned idea that...the quality of a life lived with a disability is inherently diminished, and that decisions to end or prevent the existence of a disabled person therefore incontrovertibly reflect sound, well-reasoned judgments [5].

Indeed, some disability advocates roundly criticize Western bioethics for embracing the medical model, especially in emphasizing personal autonomy and condoning the relief of disability's burdens through medical rather than environmental or attitudinal interventions. Worst of all, in the eyes of this community of advocates, is Western bioethics' embrace of personal autonomy, which has occasionally and with only modest bioethical pushback resulted in persons with severe disabilities electing to have life-prolonging treatments withheld or discontinued, resulting in their deaths.

Over the last 30 years, the stories of people like Larry McAfee and Elizabeth Bouvia—two people with profound levels of disability who requested that their life-prolonging treatments be discontinued—have rallied disability advocates, who interpreted their requests to die as capitulations to Western societies' perception that their lives were not worth living [6]. More recently, practices like preimplantation and [prenatal genetic diagnosis](#) that result in selective abortion have drawn the disability movement's ire with their "eliminating disability by eliminating persons with disability" approach [2, 6, 7].

My Emory colleague and noted disability studies scholar Rosemarie Garland-Thomson recently termed this sensibility that disability advocates fiercely oppose "eugenic logic" and opined that:

Eugenic logic tells us that our world would be a better place if disability could be eliminated. Enacted worldwide in policies and practices that range from segregation to extermination, the aim of eugenics is to eliminate disability and, by extension, disabled people from the world [8]... This understanding of disability as somehow detachable from human life rather than essential to it fosters the idea that disability does not have much to do with us unless we have the misfortune of having it descend upon us [9].

In her essay, Garland-Thomson offers a variety of arguments—based on her view that disability brings the intrinsic value of *diversity* to the human experience—to show why disability should be appreciated as a good in itself rather than just protected or maintained at arm's length. She argues that disability enables (1) the creation of meaningful life narratives, especially by contributing to “the cultural work of teaching the nondisabled how to be more human” [10]; (2) knowledge development, especially as that knowledge is processed by an intersection of body and world filtered by the minority epistemic lens of disability; and (3) ethical insight and sensitivity, drawn from an “openness to forces outside of our will as a form of creative and flexible dialectical engagement with the world” [11].

One response to the disability rights opposition to the medical model, however, is that the former tends to conflate two rather different phenomena—(1) the pain and suffering that accompany disability onset, especially as experienced by persons whose disabilities or impairments are acquired, like my myasthenia gravis, and (2) instances in which people are born with congenital blindness or deafness, Tourette's, motor impairments from cerebral palsy, and so forth—and to understand both of them as essential, indeed defining, elements of who they are. Thus, what may count as “impairments” in the medical model, requiring therapeutic intervention—such as cochlear implants for deafness, orthopedic surgeries for limb “deficiencies,” or pre-implantation genetic diagnosis to prevent numerous genetic syndromes resulting in disability—are often characterized by disability advocates as normal variations within the human species [7]. Disability advocates are angered over the propensity toward “normalization” inherent in the medical model because disability for them needs no adjustment or remediation. But I believe that this position is sometimes articulated in too sweeping a fashion, such that the efforts of health care professionals like rehabilitationists to remediate functional loss imposed by some—especially acquired and keenly oppressive and undesirable—disabilities like my myasthenia gravis goes roundly unappreciated.

A second response to the disability rights position is that its arguments often seem the products of “motivated reasoning.” As described by cognitive psychologists over the last two decades, the process of motivated reasoning begins with an individual's having

selected or arrived at a point of view (or conclusion) *prior* to argumentation [12]. The reasoner then proceeds to argue backwards—that is, selectively searching for, constructing, and attending to only those argumentative materials that support his or her position and ignoring or dismissing facts, data, or beliefs to the contrary. The more committed the reasoner is to his or her preferred position, the more unyielding will be the reasoner's argumentative attitude. Motivated reasoning theory thus explains why debates between entrenched ideologues or "true believers" seldom result in the participants changing their minds on the basis of the logical or rational power of the other side's reasoning. Each side has decided on what will count as acceptable and persuasive reasons prior to debate and will predictably refuse to budge from the preferred scripts and explanatory models [12].

Consequently, as persons with disability associate the medical model with an ideology that they believe condones their disappearance from the earth, they advance arguments predicated on the intrinsic value of disability and repudiate instrumentalities like selective abortion and various forms of assisted death as murderous. In my opinion—and possibly that of many able-bodied people and even people with serious ongoing disability—these arguments nevertheless sound hollow. Garland-Thomson's arguments, for example, have an uncomfortable utilitarian ring in justifying the value of disability in terms of its bettering human society. First and foremost, we should be intent on improving the welfare of persons with disability rather than using them for improving others' social consciousness. Alternatively, insisting that prospective parents not abort a fetus with serious disability would seem to impose an unreasonable degree of moral obligation on them by insisting that they and their offspring live lives whose quality they may find acutely and chronically unpleasant [13]. In a related vein, rejecting the request of a person with disability to discontinue or withhold life-prolonging medical treatment because disability advocates believe it transmits a worrisome or politically incorrect message treats that person as an instrument of ideology rather than as an end in him- or herself. And, while human diversity and variation can indeed be salutary, it is hard to imagine that their many manifestations across the globe must include the significant loss of welfare characteristic of many serious disabilities.

I suggest that disability advocates would be much more persuasive by noting, as Garland-Thomson pithily observes, that "disability is the body's response over time to its environment" [9]. Disability is indeed "inherent in our being" [9], as anyone who lives long enough will almost certainly join the community of persons with disability.

Just as I believe disability advocates maintain an unreasonable fear of "eugenic logic," I also believe that the community of (temporarily) able-bodied persons maintains a host of deep-seated but strikingly adolescent fantasies about eternal youth, independence, and rugged individualism that renders the idea of serious functional loss from disability onset unimaginable. That denial is best illustrated by an inability to achieve consensus on what

our socioeconomic policies towards disability care should be or on what justice “owes” to persons with disability, with the result that Americans with disabilities today typically have less money, less education, poorer employment prospects, and less social participation than any other group in our society [14]. Yet, with one billion people in the world experiencing serious disability—about one person in every seven [14]—it seems safe to say that disability will only disappear when the kinds of technologies that transhumanists envision—technologies that represent the transhumanist belief that the human body (whether temporarily able or not) is embarrassingly weak, imperfect, and unreliable—become universally accessible [15].

In the meantime, we will need to figure out how to advance from our adolescent denial of the reality of disability to a mature and realistic acceptance of our inherent finitude and life’s predictably entropic course. Only then will we be able to develop disability policy and cultural attitudes that will be humanly gratifying and dignifying, especially when disability finds and strikes virtually every one of us.

## References

1. Banja J. Rehabilitation medicine. In: Reich WT, ed. *The Encyclopedia of Bioethics*. 2nd ed. New York, NY: MacMillan; 1995:2201-2206.
2. Schick A, Asch A, Wasserman D. Disability: III. Theories of. In: Jennings B, ed. *Bioethics*. 4th ed. Farmington Hills, MI: Macmillan Reference; 2014:867-874.
3. Schick, Asch, Wasserman, 867.
4. Schick, Asch, Wasserman, 868.
5. Schick, Asch, Wasserman, 869.
6. Cohon R. Disability: I. Ethical and societal perspectives. In: Jennings B, ed. *Bioethics*. 4th ed. Farmington Hills, MI: Macmillan Reference; 2014:846-858.
7. Garland-Thomson R. The case for conserving disability. *J Bioeth Inq*. 2012;9(3):339-355.
8. Garland-Thomson, 339-340.
9. Garland-Thomson, 342.
10. Garland-Thomson, 344.
11. Garland-Thomson, 348.
12. Haidt J. The emotional dog and its rational tail: a social intuitionist approach to moral judgment. *Psychol Rev*. 2001;108(4):814-834.
13. Sparrow R. Imposing genetic diversity. *Am J Bioeth*. In press. <https://mc.manuscriptcentral.com/societyimages/uajb/Sparrow.pdf>. Accessed February 24, 2015.
14. Gostin LO, Francis LP. Disability: II. Legal issues. In: Jennings B, ed. *Bioethics*. 4th ed. Farmington Hills, MI: Macmillan Reference; 2014:859-866.
15. Bostrom N. In defense of posthuman dignity. *Bioethics*. 2005;19(3):202-214.

**John D. Banja, PhD**, is a professor in the Department of Rehabilitation Medicine in the medical school and a medical ethicist at the Center for Ethics at Emory University in Atlanta. He is the author of *Medical Errors and Medical Narcissism* (Jones and Bartlett, 2005) and consults frequently on medical malpractice cases.

**Related in the *AMA Journal of Ethics***

[Is Prenatal Genetic Screening Unjustly Discriminatory?](#) January 2006

[The Uncertain Rationale for Prenatal Disability Screening](#), January 2006

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 568-574

## HISTORY OF MEDICINE

### History of Physical Medicine and Rehabilitation and its Ethical Dimensions

Levan Atanelov, MD, MS, Steven A. Stiens, MD, MS, and Mark A. Young, MD, MBA

Physical medicine and rehabilitation (PM&R), or physiatry, is a medical specialty focused on prevention, diagnosis, rehabilitation, and therapy for patients who experience functional limitations resulting from injury, disease, or malformation. Although the specialty is a relatively young one (with beginnings in the early twentieth century), fundamentals of the field originated during ancient times. The history of PM&R crosses many cultures and geographic boundaries.

#### The Origins of Rehabilitation Therapy

The word “therapy” comes from the ancient Hebrew word *refua* (healing) [1]. Rehabilitation therapy, an essential component of the PM&R treatment approach, has a long history. Thousands of years ago the ancient Chinese employed Cong Fu, a movement therapy, to relieve pain; the Greek physician Herodicus described an elaborate system of gymnastic exercises for the prevention and treatment of disease in the fifth century BCE [2]; and the Roman physician Galen described interventions to rehabilitate military injuries in the second century CE. During the Middle Ages, the philosopher-physician Maimonides emphasized Talmudic principles of healthy exercise habits, as well as diet, as preventive medicine in *Medical Aphorisms*, published between 1187-1190; and in 1569 the philologist-physician Mercurialis promoted gymnastics as both a preventive and a rehabilitative method in *The Art of Gymnastics*. In the eighteenth century, Niels Stenson explored the biomechanics of human motion and Joseph Clement Tissot’s 1780 *Medical and Surgical Gymnastics* promoted the value of movement as an alternative to bed rest for patients recovering from surgery, facing neurological conditions, and recuperating after strokes [2]. In the nineteenth century, the concept of neuromuscular re-education was proposed by Fulgence Raymond (1844-1910) [3].

#### The History of Physical Medicine Rehabilitation in the United States

The development of PM&R in the US has origins both in comprehensive rehabilitative programs for polio survivors and veterans and in academic departments and medical centers.

In 1921, Franklin Delano Roosevelt (FDR) developed a high fever and lower extremity paralysis from a polio virus infection. His bout with polio necessitated his rehabilitation at Warm Springs, Georgia, where therapeutic swimming and sun exposure were believed to help him regain leg strength and physical endurance. An avid proponent of rehabilitation,

FDR bought the property at Warm Springs and turned it into a comprehensive rehabilitative center to help others affected with polio regain independence in activities of daily living. The services offered there included heliotherapy, swimming, exercise, training in orthotic use, muscle re-education, massage, and occupational and recreational therapy. Warm Springs, Georgia, is believed by many historians to be the first facility to provide comprehensive rehabilitative care [4].

The first university department of PM&R was founded by Dr. Frank Krusen at Temple University Medical School in 1929. Dr. Krusen acknowledged the critical importance of physical medicine after contracting TB and needing a prolonged stay at a sanatorium, which interrupted his surgical career. Recognizing the intense deconditioning and functional deterioration faced by bedbound patients in the sanatorium, Dr. Krusen decided that physical medicine should address these problems and become a medical specialty with a strong scientific basis. He rigorously studied the effects of physical agents on the human body, used physical therapy to help his patients recover, and published his findings prolifically. In 1935, as a result of his work he was offered a chair in a new department of physical medicine at the Mayo Clinic in Rochester, Minnesota. At the Mayo clinic, Krusen studied the effects of therapeutic exercise and physical modalities like short-wave diathermy and ultraviolet radiation on patients with military-related disabilities, back pain, and postsurgical musculoskeletal complications. In 1941 Dr. Krusen published *Physical Medicine*, the first comprehensive textbook on that topic. He is also credited with coining the term “physiatrist” [5].

During the middle and latter part of the century, improvements in medical care, including the use of antibiotics during World War II, saved the lives of many wounded soldiers, who returned home disabled and needing rehabilitative care [6]. As disabled veterans came to military hospitals, the US established the Army Air Forces Convalescent Training Program in 1942, which, under the direction of Dr. Howard A. Rusk, focused on comprehensive rehabilitative services including physical, neuropsychological, and occupational therapies [3]. Dr. Rusk, who is legendary in the field of PM&R and widely recognized as “the father of comprehensive rehabilitation,” founded in 1951 the world’s first university-affiliated comprehensive rehabilitation center at New York University, later renamed the Howard A. Rusk Institute of Rehabilitation Medicine [6, 7].

Contemporary support for physiatry’s establishment as a medical specialty came from philanthropist Bernard Baruch, who sought to advance the research of his physician father, Simon Baruch, on the use of hydrotherapy for patients with chronic diseases. The Baruch Committee on Physical Medicine was formed in 1943 under Dr. Krusen’s auspices [8, 9] to promote physical medicine—“the employment of the physical and other effective properties of light, heat, cold, water, electricity, massage, manipulation, exercise and mechanical devices for physical and occupational therapy in the diagnosis or treatment of disease” [10]—and rehabilitation—“the restoration of people handicapped

by disease, injury, or malformation as nearly as possible to a normal physical and mental state” [11]—to address the needs of the estimated four million disabled people in 1940 and the expected surge of World War II veterans with disabilities [8]. Large grants were made by the Baruch Committee to several prominent medical centers for research and education in the field of physical medicine, and, in 1947, the American Board of Physical Medicine was established [9].

### **Physical Medicine Rehabilitation Today**

Today, the American Board of Physical Medicine and Rehabilitation defines physiatrists as

nerve, muscle, and bone experts who treat injuries or illnesses that affect how you move... diagnose and treat pain, restore maximum function lost through injury, illness or disabling conditions, treat the whole person, not just the problem area, lead a team of medical professionals, provide non-surgical treatments, [and] explain your medical problems and treatment/prevention plan [12].

As a general rule, many medical specialties focus on the acute management and stabilization of pathologic conditions (e.g., pneumonia or a fractured femur); PM&R also focuses on holistic patient-centered care that addresses [social circumstances](#) (e.g., type of job, hobbies), living space (e.g., number of steps to get into the house, presence of grab bars in the bathroom), and activities of daily living (e.g., proficiency in walking, washing, dressing, cooking, driving). Physiatrists customize treatment plans for patients based on these parameters. The physiatry treatment armamentarium often includes medications, therapeutic exercise, injections, physical modalities, and education.

By emphasizing prevention, diagnosis, and treatment of patients’ functional limitations resulting from many different medical conditions, PM&R helps to maintain and restore optimal function for patients in many spheres of life including the social, emotional, medical, and vocational. Known as the quality-of-life medical specialty, PM&R aims to enhance a person’s functional prognosis through a dynamic team-oriented approach. The physiatrist leads a multidisciplinary team that includes practitioners from physical therapy, occupational therapy, nursing, speech and language pathology, and other specialties. As team leaders, physiatrists champion the rights and autonomy of their patients by maximizing function and optimizing their living situations so that they can contribute to the community in the least restrictive setting. Physiatry’s overarching commitment to optimizing the quality of life and neuromuscular function of an aging society has been recognized internationally.

### **Ethics in PM&R**

With the historical growth and evolution of the field of PM&R summarized above, a variety of ethical and moral issues has emerged. Kirschner et al. [13] identified general

subsets of ethical issues confronted by psychiatrists in contemporary practice and categorized their frequency: 24 percent involved health care reimbursement changes; 17 percent involved conflict among patients, physicians, interdisciplinary team members, and families around goal setting; and 7 percent involved assessing patients' decision-making capacity. Although a comprehensive discussion of these issues is beyond the scope of this article, we have selectively listed a few of the major ethical flashpoints below:

- Scarce resource allocation and the potential for discrimination against disabled people,
- The ethics of accommodating people with disability and chronic neuromuscular disorders, including in medical settings,
- Identifying optimally inclusive nomenclature and terminology (e.g., "physical diversity" rather than "disability"),
- Conflict between the goals of promoting acceptance and accommodation for persons with disability on one hand and securing resources for restoration of functional efficiency and meaningful mission on the other hand,
- The ethics of rehabilitating persons with neurological and behavioral disorders with anosognosia (deficits of awareness), in which maximizing rehabilitation may mean abandoning or overriding patient autonomy [14].

Medical ethics provides a set of moral principles that guide the everyday practice of medicine. Jonsen et al. [15] propose that clinical problems be analyzed in light of four priorities or topics: medical indications, patient preferences (according to the principle of respect for autonomy, assessment of patients' expected quality of life, and context, such as economic constraints, procedures, and laws.

As team leaders, psychiatrists must carefully and judiciously consider each of the above elements when making a decision. Additionally, consultation with the hospital medical ethics committee may be necessary. It may be challenging to reach consensus about a patient's treatment plan because health care clinicians consistently rate the quality of life of patients with disability or chronic illness lower than the patients rate it themselves, fostering disagreement between patient and treatment team [16].

Lewin et al. define patient-centered care as care that shares decisions and interventions with the patient and views the patient as a whole person with social roles, rather than as an impaired organ [17]. The role and ultimate obligation of the psychiatrist as the leader of the interdisciplinary team is to thoroughly know and understand the patient as a person [8]—including his or her interactions with family, employment, community, and environment. The psychiatrist must have sufficient knowledge and experience to predict functional outcomes following rehabilitation for each patient. Sufficient evaluation must be carried out to confirm the diagnosis and prognosis. Optimal communication with the patient, family, and interdisciplinary team must take place throughout the patient's care.

Recently, an analysis model, PCEAM-R—Patient Centered Care Ethics Analysis Model for Rehabilitation—has been developed to guide ethical rehabilitative care, given the complexity of the care team, patient disablement, and a variety of possible interventions. This six-step process for ethical decision making is theoretically grounded in the International Classification of Functioning Disability and Health and has a sufficiently detailed list of questions to provide a comprehensive and balanced assessment of each patient's situation [18]. Responsible psychiatrists may want to consider using such guides to ensure high-quality care.

On an ongoing basis it is also the responsibility of the psychiatrist as a citizen to support policies and laws that promote the independence and maximize the function of people with disabilities in the community [17].

### **Conclusion**

PM&R physicians in their role as staunch advocates for persons with disabilities strive to help people feel and function their best with customized care plans delivered by multidisciplinary teams. The overarching goal is the restoration of optimal patient function in multiple dimensions of life including the vocational, emotional, social, and medical by combining the best of the traditional medical model (“adding years to life”) with the functional approach (“adding life to years”). Its continuing popularity among medical students [19] has been fueled by its stalwart commitment to addressing the quality-of-life requirements of an aging population without surgery. The noble mission of PM&R physicians is perhaps best summarized by the words of inspirational author and educator William Arthur Ward: “A true friend knows your weaknesses but shows you your strengths, feels your fears but fortifies your faith; sees your anxieties but frees your spirit; recognizes your disabilities but emphasizes your possibilities” [20]. The psychiatrist ever strives to achieve this goal.

### **References**

1. Origin of English word therapy. Edenics. <http://edenics.net/english-word-origins.aspx?word=THERAPY>. Accessed on April 24, 2015.
2. Dreeben O. Development of the physical therapy profession. *Introduction to Physical Therapy for Physical Therapist Assistants*. Sudbury, MA: Jones and Bartlett; 2007:3-22.
3. Conti AA. Western medical rehabilitation through time: a historical and epistemological review. *Sci World J*. 2014(2014):432506.
4. Verville RE, Ditunno JF. Franklin Delano Roosevelt, polio, and the Warm Springs experiment: its impact on physical medicine and rehabilitation. *PM R*. 2013;5(1):3-8.
5. Opitz JL, Folz TJ, Gelfman R, Peters DJ. The history of physical medicine and rehabilitation as recorded in the diary of Dr. Frank Krusen: part 1. Gathering momentum (the years before 1942). *Arch Phys Med Rehabil*. 1997;78(4):442-445.

6. O'Young BJ, Young MA, Stiens SA. What is physical medicine and rehabilitation? In O'Young BJ, Young MA, Stiens SA, eds. *Physical Medicine and Rehabilitation Secrets*. 3rd ed. Philadelphia, PA: Mosby/Elsevier; 2008:9-14.
7. Blum N, Fee E, Howard A. Rusk (1901-1989): from military medicine to comprehensive rehabilitation. *Am J Public Health*. 2008;98(2):256-257.
8. Krusen FH. The future of physical medicine with special reference to the recommendations of the Baruch Committee on Physical Medicine. *JAMA*. 1944;125(16):1093-1097.
9. Folz TJ, Opitz JL, Peters DJ, Gelfman R. The history of physical medicine and rehabilitation as recorded in the diary of Dr. Frank Krusen: part 2. Forging ahead (1943-1947). *Arch Phys Med Rehabil*. 1997;78(4):446-450.
10. Krusen, 1093.
11. Folz et al., 447.
12. American Academy of Physical Medicine and Rehabilitation. What is a physiatrist? <http://www.aapmr.org/patients/aboutpmr/Pages/physiatrist.aspx>. Accessed April 30, 2015.
13. Kirschner KL, Stocking C, Wagner LB, Foye SJ, Siegler M. Ethical issues identified by rehabilitation clinicians. *Arch Phys Med Rehabil*. 2001;82(12)(suppl 2):S2-S8.
14. Young MJ. Pathologies of thought and first-person authority. *Philos Psychiatr Psychol*. In press.
15. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. 7th ed. New York, NY: McGraw-Hill; 2010.
16. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med*. 1999;48(8):977-988.
17. Lewin SA, Skea ZC, Entwistle V, Zwarenstein M, Dick J. Interventions for providers to promote a patient-centered approach in clinical consultations. *Cochrane Database Syst Rev*. 2001(4):CD003267.
18. Hunt MR, Ellis C. A patient-centered care ethics analysis model for rehabilitation. *Am J Phys Med Rehabil*. 2013;92(9):818-827.
19. Association of Academic Physiatrists Residents/Fellows Council. PM&R medical student interest group guidebook. [http://c.ymcdn.com/sites/www.physiatry.org/resource/resmgr/medical\\_student\\_interest\\_gro.pdf](http://c.ymcdn.com/sites/www.physiatry.org/resource/resmgr/medical_student_interest_gro.pdf). Accessed April 27, 2015.
20. Zuck RD, ed. *The Speaker's Quote Book*. Grand Rapids, MI: Kregel Academic; 2009:204.

### Further Reading

Stiens SA, O'Young BJ, Young MA. Person-centered rehabilitation: interdisciplinary intervention to enhance patient enablement. In O'Young BJ, Young MA, Stiens SA, eds. *Physical Medicine and Rehabilitation Secrets*. 3rd ed. Philadelphia, PA: Mosby/Elsevier; 2008:118-125.

**Levan Atanelov, MD, MS**, is a fourth-year resident in PM&R at Johns Hopkins University in Baltimore. His interests include telerehabilitation, quality improvement, and early mobility.

**Steven A. Stiens, MD, MS**, is an associate professor in the Department of Rehabilitation Medicine at the University of Washington in Seattle. Dr. Stiens is a spinal cord medicine physician practicing rehabilitation and primary care. His published research is primarily in the area of neurogenic bowel rehabilitation, life care planning, and neurological recovery after spinal cord injury, and his current projects focus on vocational rehabilitation, video simulations for distance learning, and telemedicine.

**Mark A. Young, MD, MBA**, is chair of PM&R at the Workforce & Technology Center, State of Maryland Division of Rehabilitation Services (DORS), Department of Education. He is also a faculty member at Johns Hopkins University School of Medicine in Baltimore and the New York University School of Medicine. His scholarly interests include vocational rehabilitation and technology, pain, and neurologic rehabilitation.

### **Acknowledgement**

The authors wish to graciously acknowledge the help and input of Michael Young, MS-4 at Harvard Medical School, who reviewed the manuscript and offered his insights on the ethics section.

### **Related in the *AMA Journal of Ethics***

[Safety and Ethical Considerations in Discharging Patients to Suboptimal Living Situations](#), June 2015

[Assessing Competency in Physical Medicine and Rehabilitation Residency: The ACGME Milestones Initiative](#), June 2015

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 575

## IMAGES OF HEALING AND LEARNING

### *Multifaceted Nexus*

Kyle T. Amber, MD

This issue of the *AMA Journal of Ethics* examines numerous ethical issues in rehabilitation medicine. Good ethical analysis is not based merely on polarized views but considers all possible views between the extremes. In this image, the framing structures created by multiple angles of a single knee radiograph illustrate the dynamic and flexible nature of the joint itself.



These framing structures, reproduced in different colors in the center, represent two polarized perspectives. The overlaid vibrant colors force the viewer to consider the composite image rather than focusing on either of the two color-contrasted sets of structures. In combination, the structures in *Multifaceted Nexus* depict not only the dynamic nature of the objects in question, but also how single views of an object (or subject) can distort the true clinical and ethical picture.

**Kyle T. Amber, MD**, completed his first year of residency in the Department of Internal Medicine at MacNeal Hospital in Berwyn, Illinois, in 2015, after which he became a resident in dermatology at the University of California, Irvine. His areas of research interest include immunodermatology, medical ethics, and medical humanities.

### **Related in the *AMA Journal of Ethics***

[The Hanging Medical Student: Sacrifice and Authority in Medical Education](#), March 2014

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2015 American Medical Association. All rights reserved.**

**ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 576-592

## Suggested Readings and Resources

Abbey L. Elder abuse and neglect: when home is not safe. *Clin Geriatr Med*. 2009;25(1):47-60.

Accreditation Council for Graduate Medical Education. Milestones. <https://www.acgme.org/acgmeweb/tabid/430/ProgramandInstitutionalAccreditation/NExtAccreditationSystem/Milestones.aspx>. Accessed April 15, 2015.

Akarsu S, Tekin L, Safaz I, Göktepe AS, Yazicioğlu K. Quality of life and functionality after lower limb amputations: comparison between uni- vs. bilateral amputee patients. *Prosthet Orthot Int*. 2013;37(1):9-13.

Albert SM, Rabkin JG, Del Bene ML, et al. Wish to die in end-stage ALS. *Neurology*. 2005;65(1):68-74.

Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med*. 1999;48(8):977-988.

ALS Association. Facts you should know. <http://www.alsa.org/about-als/facts-you-should-know.html>. Accessed February 27, 2015.

American Academy of Physical Medicine and Rehabilitation. About physical medicine and rehabilitation (PM&R). <http://www.aapmr.org/patients/aboutpmr/Pages/default.aspx>. Accessed April 22, 2015.

American Academy of Physical Medicine and Rehabilitation. What is a physiatrist? <http://www.aapmr.org/patients/aboutpmr/Pages/physiatrist.aspx>. Accessed April 30, 2015.

American Board of Physical Medicine and Rehabilitation. New part II examination format. *Diplomat News*. 2005:6. [http://www.abpmr.org/newsletters/documents/summer2005diplomatenews\\_002.pdf](http://www.abpmr.org/newsletters/documents/summer2005diplomatenews_002.pdf). Accessed April 15, 2015.

American Diabetes Association. Fast facts: data and statistics about diabetes. March 2015. <http://professional.diabetes.org/ResourcesForProfessionals.aspx?cid=91777&loc=dorg-statistics>. Accessed March 10, 2015.

American Hospital Association. Fast facts on US Hospitals. January 2015. <http://www.aha.org/research/rc/stat-studies/fast-facts.shtml>. Accessed April 29, 2015.

American Hospital Association. Trendwatch: teaching hospitals: their impact on patients and the future health care workforce. September 2009. <http://www.aha.org/research/reports/tw/twsept2009teaching.pdf>. Accessed April 29, 2015.

American Medical Association. Opinion 1.02 The relation of law and ethics. *Code of Medical Ethics*. <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion102.page>. Accessed April 28, 2015.

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: American Psychiatric Association; 2013.

American Psychiatric Association. Posttraumatic stress disorder. 2013. <http://www.dsm5.org/Documents/PTSD%20Fact%20Sheet.pdf>. Accessed April 14, 2015.

Andolsek K, Padmore J, Hauer KE, Holmboe E. Clinical competency committees: a guidebook for programs. Accreditation Council for Graduate Medical Education; 2015:2. <https://www.acgme.org/acgmeweb/Portals/0/ACGMEClinicalCompetencyCommitteeGuidebook.pdf>. Accessed April 15, 2015.

Antoniou SA, Antoniou GA, Granderath FA, Mavroforou A, Giannoukas AD, Antoniou AI. Reflections of the Hippocratic Oath in modern medicine. *World J Surg*. 2010;34(12):3075-3079.

Apkarian AV, Sosa Y, Sonty S, et al. Chronic back pain is associated with decreased prefrontal and thalamic gray matter density. *J Neurosci*. 2004;24(46):10410-10415.

Ashburn MA, Staats PS. Management of chronic pain. *Lancet*. 1999;353(9167):1865-1869.

Assessing health law's impact at five years. *Kaiser Health News*. March 24, 2015. <http://kaiserhealthnews.org/morning-breakout/assessing-health-laws-impact-at-five-years/>. Accessed April 17, 2015.

Association of Academic Physiatrists Residents/Fellows Council. PM&R medical student interest group guidebook. [http://c.ymcdn.com/sites/www.physiatry.org/resource/resmgr/medical\\_student\\_interest\\_gro.pdf](http://c.ymcdn.com/sites/www.physiatry.org/resource/resmgr/medical_student_interest_gro.pdf). Accessed April 27, 2015.

Ballantyne JC, Fleisher LA. Ethical issues in opioid prescribing for chronic pain. *Pain*. 2010;148(3):365-367.

Banja J. Rehabilitation medicine. In: Reich WT, ed. *The Encyclopedia of Bioethics*. 2nd ed. New York, NY: MacMillan; 1995:2201-2206.

Biddiss E, McKeever P, Lindsay S, Chau T. Implications of prosthesis funding structures on the use of prostheses: experiences of individuals with upper limb absence. *Prosthet Orthot Int*. 2011;35(2):215-224.

Bingel U, Wanigasekera V, Wiech K, et al. The effect of treatment expectation on drug efficacy: imaging the analgesic benefit of the opioid remifentanyl. *Sci Transl Med*. 2011;3(70):70ra14.

Blum N, Fee E, Howard A. Rusk (1901-1989): from military medicine to comprehensive rehabilitation. *Am J Public Health*. 2008;98(2):256-257.

Bockenek WL, Massagli TL, Swing SR, Fischer C; the PMR Milestone Working Group. The development of the physical medicine and rehabilitation milestones. *J Grad Med Educ*. 2014;6(1)(suppl 1):204-206.

Branas CC, MacKenzie EJ, Williams JC, et al. Access to trauma centers in the United States. *JAMA*. 2005;293(21):2626-2633.

Brem H, Tomic-Canic M. Cellular and molecular basis of wound healing in diabetes. *J Clin Invest*. 2007;117(5):1219-1222.

Brooks M. Cannabis augments analgesic effect of opioids. *Medscape*. December 13, 2011. <http://www.medscape.com/viewarticle/755388>. Accessed April 28, 2015.

Bui KM, Raugi GJ, Nguyen VQ, Reiber GE. Skin problems in individuals with lower-limb loss: literature review and proposed classification system. *J Rehabil Res Dev*. 2009;46(9):1085-1090.

Burger H, Marincek C. Return to work after lower limb amputation. *Disabil Rehabil*. 2007;29(17):1323-1329.

Burke MM. Study examines impact of service dogs on veterans with PTSD. *Stars and Stripes*. January 31, 2015. <http://www.stripes.com/news/study-examines-impact-of-service-dogs-on-veterans-with-ptsd-1.327058>. Accessed April 15, 2015.

California Secretary of State. Proposition 215: Medical use of marijuana. Initiative statute. <http://vote96.sos.ca.gov/bp/215.htm>. Accessed April 28, 2015.

Carter WA Jr. Milestone myths and misperceptions. *J Grad Med Educ*. 2014;6(1):18-20.

Cassell EJ. Diagnosing suffering: a perspective. *Ann Intern Med.* 1999;131(7):531-534.

Centers for Disease Control and Prevention. National diabetes fact sheet, 2011. [http://www.cdc.gov/diabetes/pubs/pdf/ndfs\\_2011.pdf](http://www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf). Accessed March 8, 2015.

Centers for Medicare and Medicaid Services. Inpatient rehabilitation therapy services: complying with documentation requirements. July 2012. [http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/Inpatient\\_Rehab\\_Fact\\_Sheet\\_ICN905643.pdf](http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/Inpatient_Rehab_Fact_Sheet_ICN905643.pdf). Accessed March 3, 2015.

Chandrasekaran R. A legacy of pain and pride. *Washington Post.* March 29, 2014. <http://www.washingtonpost.com/sf/national/2014/03/29/a-legacy-of-pride-and-pain/>. Accessed April 20, 2015.

Chou R, Fanciullo GJ, Fine PG, et al; American Pain Society-American Academy of Pain Medicine Opioids Guidelines Panel. Clinical guidelines for the use of chronic opioid therapy in chronic noncancer pain. *J Pain.* 2009;10(2):113-130.

Cigna. Cigna medical coverage policy: lower limb prosthetic devices (including vacuum-assisted socket system and microprocessor/computer-controlled lower limb prostheses). September 15, 2013. [http://www.spsco.com/media/wysiwyg/download/mm\\_0194\\_coveragepositioncriteria\\_lower\\_limb\\_prosthet\\_vass\\_computer\\_control%20copy.pdf](http://www.spsco.com/media/wysiwyg/download/mm_0194_coveragepositioncriteria_lower_limb_prosthet_vass_computer_control%20copy.pdf). Accessed March 11, 2015.

Cohen MJ. Psychosocial aspects of evaluation and management of chronic low back pain. In: Young MA, Lavin RA, eds. *Spinal Rehabilitation*. Philadelphia, PA: Hanley and Belfus; 1995:726-746.

Cohen MJ, Jasser S, Herron PD, Margolis CG. Ethical perspectives: opioid treatment of chronic pain in the context of addiction. *Clin J Pain.* 2002;18(4)(suppl):S99-S107.

Cohon R. Disability: I: Ethical and societal perspectives. In: Jennings B, ed. *Bioethics*. 4th ed. Farmington Hills, MI: Macmillan Reference; 2014:846-858.

Colin C. How dogs can help veterans overcome PTSD. *Smithsonian Magazine.* July 2012. <http://www.smithsonianmag.com/science-nature/how-dogs-can-help-veterans-overcome-ptsd-137582968/?no-ist>. Accessed April 14, 2015.

Compassionate Access, Research Expansion, and Respect States Act of 2015. S 683, 114th Cong, 1st Sess (2014-2015). <https://www.congress.gov/bill/114th-congress/senate-bill/683/text>. Accessed April 28, 2015.

*Conant v Walters*, 309 F3d 629 (9th Cir 2002).

Conover CJ. How private health insurance slashed the uninsured rate for Americans. American Enterprise Institute. September 16, 2011. <http://www.aei.org/publication/how-private-health-insurance-slashed-the-uninsured-rate-for-americans/>. Accessed February 27, 2015.

Conti AA. Western medical rehabilitation through time: a historical and epistemological review. *Sci World J*. 2014(2014):432506.

Cowart D. *Dax's Case: Who Should Decide* [video]. New York, NY: Filmmakers Library; 1984.

Dao J. Loyal companion helps a veteran regain her life after war trauma. *New York Times*. April 28, 2012. [http://www.nytimes.com/2012/04/29/us/loyal-companion-helps-a-veteran-with-post-traumatic-stress-disorder.html?\\_r=0](http://www.nytimes.com/2012/04/29/us/loyal-companion-helps-a-veteran-with-post-traumatic-stress-disorder.html?_r=0). Accessed April 10, 2015.

DaVanzo JE, El-Gamil A, Li JW, Shimer M, Manolov N, Dobson A. Assessment of patient outcomes of rehabilitative care provided in inpatient rehabilitation facilities (IRFs) and after discharge. Vienna, VA: Dobson DaVanzo; 2014. <https://www.amrpa.org/newsroom/Dobson%20DaVanzo%20Final%20Report%20-%20Patient%20Outcomes%20of%20IRF%20v%20SNF%20-%207%2010%2014%20redated.pdf>. Accessed April 9, 2015.

DiFiori JP, Benjamin HJ, Brenner J, et al. Overuse injuries and burnout in youth sports: a position statement from the American Medical Society for Sports Medicine. *Clin J Sport Med*. 2014;24(1):3-20.

Dillie KS, Fleming MF, Mundt MP, French MT. Quality of life associated with daily opioid therapy in a primary care chronic pain sample. *J Am Board Fam Med*. 2008;21(2):108-117.

Dillingham TR, Pezzin LE, MacKenzie EJ. Incidence, acute care length of stay, and discharge to rehabilitation of traumatic amputee patients: an epidemiologic study. *Arch Phys Med Rehabil*. 1998;79(3):279-287.

Dobson A, El-Gamil A, Shimer M, DaVanzo JE. Retrospective cohort study of the economic value of orthotic and prosthetic services among Medicare beneficiaries. Vienna, VA: Dobson DaVanzo; 2013. [http://mobilitysaves.org/docs/Dobson\\_Davanzo\\_Study\\_on\\_Cost\\_Effectiveness.pdf](http://mobilitysaves.org/docs/Dobson_Davanzo_Study_on_Cost_Effectiveness.pdf). Accessed April 14, 2015.

Dougherty PJ, McFarland LV, Smith DG, Reiber GE. Bilateral transfemoral/transtibial amputations due to battle injuries: a comparison of Vietnam veterans with Iraq and Afghanistan servicemembers. *Clin Orthop Relat Res*. 2014;472(10):3010-3016.

Dreeben O. Development of the physical therapy profession. *Introduction to Physical Therapy for Physical Therapist Assistants*. Sudbury, MA: Jones and Bartlett; 2007:3-22.

Durmus D, Safaz I, Adigüzel E, et al. The relationship between prosthesis use, phantom pain and psychiatric symptoms in male traumatic limb amputees. *Compr Psychiatry*. 2015;59:45-53.

Ehde DM, Czerniecki JM, Smith DG, et al. Chronic phantom sensations, phantom pain, residual limb pain, and other regional pain after lower limb amputation. *Arch Phys Med Rehabil*. 2000;81(8):1039-1044.

Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA*. 1992;267(16):2221-2226.

Ephraim PL, MacKenzie EJ, Wegener ST, Dillingham TR, Pezzin LE. Environmental barriers experienced by amputees: the Craig Hospital Inventory of Environmental Factors-Short Form. *Arch Phys Med Rehabil*. 2006;87(3):328-333.

Eslami MH, Zayaruzny M, Fitzgerald GA. The adverse effects of race, insurance status, and low income on the rate of amputation in patients presenting with lower extremity ischemia. *J Vasc Surg*. 2007;45(1):55-59.

Etchells E, Darzins P, Silberfeld M, et al. Assessment of patient capacity to consent to treatment. *J Gen Intern Med*. 1999;14(1):27-34.

Feldstein P. *Health Care Economics*. 7th ed. Clifton Park, NY: Delmar/Cengage Learning; 2011.

Ferrell BA, Ferrell BR. Principles of pain management in older people. *Compr Ther*. 1991;17(8):53-58.

Ferrell BR, Dean G. The meaning of cancer pain. *Semin Oncol Nurs*. 1995;11(1):17-22.  
Fine PG, Mahajan G, McPherson ML. Long-acting opioids and short-acting opioids: appropriate use in chronic pain management. *Pain Med*. 2009;10(suppl 2):S79-S88.

Fish D. The development of coverage policy for lower extremity prosthetics: the influence of the payer on prosthetic prescription. *J Prosthet Orthot*. 2006;18(6):125-129.

Fishbain DA, Cole B, Lewis JE, Gao J, Rosomoff RS. Do opioids induce hyperalgesia in humans? An evidence-based structured review. *Pain Med*. 2009;10(5):829-839.

Fisher ES, Goodman DC, Chandra A. Disparities in health and health care among Medicare beneficiaries: a brief report of the Dartmouth Atlas Project. Robert Wood Johnson Foundation; 2008.

[http://www.dartmouthatlas.org/downloads/reports/AF4Q\\_Disparities\\_Report.pdf](http://www.dartmouthatlas.org/downloads/reports/AF4Q_Disparities_Report.pdf). Accessed April 29, 2015.

Fisher ES, Goodman DC, Chandra A. *Geography Is Destiny: Differences in Health Care among Medicare Beneficiaries in the United States and California*. Oakland, CA: California HealthCare Foundation; 2008.

<http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/G/PDF%20GeographyIsDestiny08.pdf>. Accessed April 28, 2015.

Flor H, Fydrich T, Turk DC. Efficacy of multidisciplinary pain treatment centers: a meta-analytic review. *Pain*. 1992;49(2):221-230.

Folz TJ, Opitz JL, Peters DJ, Gelfman R. The history of physical medicine and rehabilitation as recorded in the diary of Dr. Frank Krusen: part 2. Forging ahead (1943-1947). *Arch Phys Med Rehabil*. 1997;78(4):446-450.

Franklin GM; American Academy of Neurology. Opioids for chronic noncancer pain: a position paper of the American Academy of Neurology. *Neurology*. 2014;83(14):1277-1284.

Fredericson M. On the horizon: defining the future of sports medicine and the role of the physiatrist. *PM R*. 2012;4(10):707-710.

Froling J. Service dog tasks for psychiatric disabilities. International Association of Assistance Dog Partners. July 30, 2009. [http://www.iaadp.org/psd\\_tasks.html](http://www.iaadp.org/psd_tasks.html). Accessed April 14, 2015.

Gailey R, Allen K, Castles J, Kucharik J, Roeder M. Review of secondary physical conditions associated with lower-limb amputation and long-term prosthesis use. *J Rehabil Res Dev*. 2008;45(1):15-29.

Ganzini L, Johnston WS, McFarland BH, Tolle SW, Lee MA. Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med*. 1998;339(14):967-973.

Garcia-Retamero R, Galesic M. How to reduce the effect of framing on messages about health. *J Gen Intern Med*. 2010;25(12):1323-1329.

Garland-Thomson R. The case for conserving disability. *J Bioeth Inq*. 2012;9(3):339-355.

Geppert CA. Legal and clinical evolution of Veterans Health Administration policy on medical marijuana. *Fed Pract*. 2014;31(3):6-12.  
<http://www.fedprac.com/articles/feature/article/legal-and-clinical-evolution-of-veterans-health-administration-policy-on-medical-marijuana/ec143e5b5c6b3ed4838537da0bbf3b8b/ocregister.html>. Accessed April 28, 2015.

Goldberg DS, McGee SJ. Pain as a global public health priority. *BMC Public Health*. 2011;11:770.

Gostin LO, Francis LP. Disability: II. Legal issues. In: Jennings B, ed. *Bioethics*. 4th ed. Farmington Hills, MI: Macmillan Reference; 2014:859-866.

Grachev ID, Fredrickson BE, Apkarian AV. Abnormal brain chemistry in chronic back pain: an in vivo proton magnetic resonance spectroscopy study. *Pain*. 2000;89(1):7-18.

Grisso T, Appelbaum PS. *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. New York, NY: Oxford University Press; 1998.

Gureje O. Psychiatric aspects of pain. *Curr Opin Psychiatry*. 2007;20(1):42-46.

Haidt J. The emotional dog and its rational tail: A social intuitionist approach to moral judgment. *Psychol Rev*. 2001;108(4):814-834.

Halpern J, Arnold RM. Affective forecasting: an unrecognized challenge in making serious health decisions. *J Gen Intern Med*. 2008;23(10):1708-1712.

Ham R, Regan JM, Roberts VC. Evaluation of introducing the team approach to the care of the amputee: the Dulwich study. *Prosthet Orthot Int*. 1987;11(1):25-30.

Harden N, Cohen M. Unmet needs in the management of neuropathic pain. *J Pain Symptom Manage*. 2003;25(5)(suppl):S12-S17.

Harden RN, Oaklander AL, Burton AW, et al; Reflex Sympathetic Dystrophy Syndrome Association. Complex regional pain syndrome: practical diagnostic and treatment guidelines, 4th edition. *Pain Med*. 2013;14(2):180-229.

Harry S. Truman Library and Museum. This day in Truman history: November 19, 1945: President Truman's proposed health program.  
<http://www.trumanlibrary.org/anniversaries/healthprogram.htm>. Accessed February 27, 2015.

Haythornthwaite JA, Menefee LA, Quatrano-Piacentini AL, Pappagallo M. Outcome of chronic opioid therapy for non-cancer pain. *J Pain Symptom Manage*. 1998;15(3):185-194.

Healthcare.gov website. <https://www.healthcare.gov/>. Accessed April 17, 2015.

Henry DE, Chiodo AE, Yang W. Central nervous system reorganization in a variety of chronic pain states: a review. *PM R*. 2011;3(12):1116-1125.

Highsmith MJ, Kahle JT, Bongiorno DR, Sutton BS, Groer S, Kaufman KR. Safety, energy efficiency, and cost efficacy of the C-Leg for transfemoral amputees: a review of the literature. *Prosthet Orthot Int*. 2010;34(4):362-377.

Hobson AR, Aziz Q. Brain imaging and functional gastrointestinal disorders: has it helped our understanding? *Gut*. 2004;53(8):1198-1206.

Holzer LA, Sevelde F, Fraberger G, Bluder O, Kicking W, Holzer G. Body image and self-esteem in lower-limb amputees. *PLoS One*. 2014;9(3):e92943.

Hoover RM, Polson M. Detecting elder abuse and neglect: assessment and intervention. *Am Fam Physician*. 2014;89(6):453-460.

Horgan O, MacLachlan M. Psychosocial adjustment to lower-limb amputation: a review. *Disabil Rehabil*. 2004;26(14-15):837-850.

Hunt MR, Ellis C. A patient-centered care ethics analysis model for rehabilitation. *Am J Phys Med Rehabil*. 2013;92(9):818-827.

Ide M, Watanabe T, Toyonaga T. Sexuality in persons with limb amputation. *Prosthet Orthot Int*. 2002;26(3):189-194.

Jasch C. My journey with ALS: an occupational therapist's story. Rehabilitation Institute of Chicago. <https://lifecenter.ric.org/index.php?tray=content&tid=top441&cid=6830>. Accessed April 20, 2015.

Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. 7th ed. New York, NY: McGraw-Hill; 2010.

Kaiser Family Foundation. Distribution of the nonelderly uninsured by federal poverty level (FPL). <http://www.statehealthfacts.org/comparebar.jsp?ind=136&cat=3>. Accessed March 2, 2015.

Kaiser Family Foundation. Explaining health care reform: questions about health insurance subsidies. October 27, 2014. <http://kff.org/health-reform/issue-brief/explaining-health-care-reform-questions-about-health>. Accessed April 10, 2015.

Kaiser Permanente Research. PAWS Research Project: preliminary results. December 9, 2014. <https://olis.leg.state.or.us/liz/201311/Downloads/CommitteeMeetingDocument/42181>. Accessed April 15, 2015.

Katz MH. Long-term opioid treatment of nonmalignant pain: a believer loses his faith. *Arch Intern Med*. 2010;170(16):1422-1424.

Kirschner KL, Stocking C, Wagner LB, Foye SJ, Siegler M. Ethical issues identified by rehabilitation clinicians. *Arch Phys Med Rehabil*. 2001;82(12)(suppl 2):S2-S8.

Krusen FH. The future of physical medicine with special reference to the recommendations of the Baruch Committee on Physical Medicine. *JAMA*. 1944;125(16):1093-1097.

Kübler A, Winter S, Ludolph AC, Hautzinger M, Birbaumer N. Severity of depressive symptoms and quality of life in patients with amyotrophic lateral sclerosis. *Neurorehabil Neural Repair*. 2005;19(3):182-193.

Lavery LA, van Houtum WH, Ashry HR, Armstrong DG, Pugh JA. Diabetes-related lower-extremity amputations disproportionately affect blacks and Mexican Americans. *South Med J*. 1999;92(6):593-599.

Le Feuvre P, Aldington D. Know pain know gain: proposing a treatment approach for phantom limb pain. *J R Army Med Corps*. 2014;160(1):16-21.

Leading the charge towards evidence-based medicine. *VA Research Currents*. November-December 2008:4-5. [http://www.research.va.gov/resources/pubs/docs/va\\_research\\_currents\\_nov-dec\\_08.pdf](http://www.research.va.gov/resources/pubs/docs/va_research_currents_nov-dec_08.pdf). Accessed April 15, 2015.

Lewin SA, Skea ZC, Entwistle V, Zwarenstein M, Dick J. Interventions for providers to promote a patient-centered approach in clinical consultations. *Cochrane Database Syst Rev*. 2001(4):CD003267.

Limb Loss Task Force/Amputee Coalition. *Roadmap for Preventing Limb Loss in America: Recommendations from the 2012 Limb Loss Task Force*. Knoxville, TN: Amputee Coalition; 2012. <http://www.amputee-coalition.org/wp->

content/uploads/2014/09/lsp\_Roadmap-for-Limb-Loss-Prevention-and-Amputee-Care-Improvement\_241014-092312.pdf. Accessed April 29, 2015.

Ling L, Derstine P, Cohen N. Implementing milestones and clinical competency committees. Accreditation Council for Graduate Medical Education. April 24, 2013. <https://www.acgme.org/acgmeweb/Portals/0/PDFs/ACGMEMilestones-CCC-AssesmentWebinar.pdf>. Accessed April 15, 2015.

Loeser JD. The education of pain physicians. *Pain Med*. 2015;16(2):225-229.

Lower opioid overdose death rates associated with state medical marijuana laws [news release]. Chicago, IL: *JAMA*; August 25, 2014. <http://media.jamanetwork.com/news-item/lower-opioid-overdose-death-rates-associated-with-state-medical-marijuana-laws/>. Accessed April 28, 2015.

Ma VY, Chan L, Carruthers KJ. Incidence, prevalence, costs, and impact on disability of common conditions requiring rehabilitation in the United States: stroke, spinal cord injury, traumatic brain injury, multiple sclerosis, osteoarthritis, rheumatoid arthritis, limb loss, and back pain. *Arch Phys Med Rehabil*. 2014;95(5):986-995.

Mackenzie EJ, Jones AS, Bosse MJ, et al. Health-care costs associated with amputation or reconstruction of a limb-threatening injury. *J Bone Joint Surg Am*. 2007;89(8):1685-1692.

Malone MD, Strube MJ, Scogin FR. Meta-analysis of non-medical treatments for chronic pain. *Pain*. 1988;34(3):231-244.

Manchikanti L, Ailinani H, Koyyalagunta D, et al. A systematic review of randomized trials of long-term opioid management for chronic non-cancer pain. *Pain Physician*. 2011;14(2):91-121.

Martino AM. In search of a new ethic for treating patients with chronic pain: what can medical boards do? *J Law Med Ethics*. 1998;26(4):332-349.

May A. Chronic pain may change the structure of the brain. *Pain*. 2008;137(1):7-15.

McCluskey L. Amyotrophic lateral sclerosis: ethical issues from diagnosis to end of life. *NeuroRehabilitation*. 2007;22(6):463-472.

McFarland LV, Hubbard Winkler SL, Heinemann AW, Jones M, Esquenazi A. Unilateral upper-limb loss: satisfaction and prosthetic-device use in veterans and servicemembers from Vietnam and OIF/OEF conflicts. *J Rehabil Res Dev*. 2010;47(4):299-316.

Meyer TM. Psychological aspects of mutilating hand injuries. *Hand Clin.* 2003;19(1):41-49.

Montanaro D. Obamacare five years later: thriving or on political life support? *NPR.* March 25, 2015.

<http://www.npr.org/blogs/itsallpolitics/2015/03/25/395293756/obamacare-five-years-later-thriving-or-on-political-life-support>. Accessed April 10, 2015.

Morley S, Eccleston C, Williams A. Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain.* 1999;80(1-2):1-13.

National Center for Ethics in Health Care. Ethical considerations in opioid therapy for chronic pain. April 2005.

[http://www.ethics.va.gov/docs/infocus/InFocus\\_20050401\\_Opioid\\_Therapy\\_for\\_Chronic\\_Pain.pdf](http://www.ethics.va.gov/docs/infocus/InFocus_20050401_Opioid_Therapy_for_Chronic_Pain.pdf). Accessed April 28, 2015.

National Limb Loss Information Center. Fact sheet: financial assistance for prosthetic services, durable medical equipment, and other assistive devices. Amputee Coalition of America; 2008. [http://www.amputee-coalition.org/fact\\_sheets/assist\\_orgs.html](http://www.amputee-coalition.org/fact_sheets/assist_orgs.html). Accessed April 29, 2015.

Noble M, Treadwell JR, Tregear SJ, et al. Long-term opioid management for chronic noncancer pain. *Cochrane Database Syst Rev.* 2010;(1): CD006605.

Nunley A. Service dogs for (some) veterans: inequality in the treatment of disabilities by the Department of Veterans Affairs. *Quinnipiac Health Law.* 2014;17:261-291. [http://www.quinnipiac.edu/prebuilt/pdf/SchoolLaw/HealthLawJournalLibrary/Vol17\\_Issue2\\_2014\\_Nunley.pdf](http://www.quinnipiac.edu/prebuilt/pdf/SchoolLaw/HealthLawJournalLibrary/Vol17_Issue2_2014_Nunley.pdf). Accessed April 21, 2015.

O'Young BJ, Young MA, Stiens SA. What is physical medicine and rehabilitation? In O'Young BJ, Young MA, Stiens SA, eds. *Physical Medicine and Rehabilitation Secrets.* 3rd ed. Philadelphia, PA: Mosby/Elsevier; 2008:9-14.

Oberg CN, Polich CL. Medicaid: entering the third decade. *Health Aff (Millwood).* 1988;7(4):83-96.

Olympic Movement. Paralympic Games. <http://www.olympic.org/content/olympic-games/paralympic-games/?tab=paralympic-games>. Accessed April 24, 2015.

Opitz JL, Folz TJ, Gelfman R, Peters DJ. The history of physical medicine and rehabilitation as recorded in the diary of Dr. Frank Krusen: part 1. Gathering momentum (the years before 1942). *Arch Phys Med Rehabil.* 1997;78(4):442-445.

Otto Bock. International C-leg studies. 3rd ed.  
[http://www.ottobock.com/cps/rde/xbcr/ob\\_com\\_en/646B33-GB-01-1003w.pdf](http://www.ottobock.com/cps/rde/xbcr/ob_com_en/646B33-GB-01-1003w.pdf).  
Accessed March 11, 2015.

Owings MF, Kozak LJ, National Center for Health. *Ambulatory and Inpatient Procedures in the United States, 1996*. Hyattsville, MD: National Center for Health Statistics; 1998. Vital and Health Statistics 139. [http://www.cdc.gov/nchs/data/series/sr\\_13/sr13\\_139.pdf](http://www.cdc.gov/nchs/data/series/sr_13/sr13_139.pdf).  
Accessed April 30, 2015.

Pandian G, Hamid F, Hammond M. Rehabilitation of the patient with peripheral vascular disease and diabetic foot problems. In: DeLisa JA, Gans BM, eds. *Rehabilitation Medicine: Principles and Practice*. Philadelphia, PA: Lippincott-Raven; 1998: 1544-1571.

Pappagallo M, Campbell JN. Chronic opioid therapy as alternative treatment for post-herpetic neuralgia. *Ann Neurol.* 1994;35(suppl):S54-S56.

Pasquina PF, Hendershot BD, Isaacson BM. Secondary health effects of amputation. In: *Atlas of Amputations and Limb Deficiencies*. 4th ed. Rosemont, IL: American Academy of Orthopedic Surgeons. In press.

Pasquina PF, Miller M, Carvalho AJ, et al. Special considerations for multiple limb amputation. *Curr Phys Med Rehabil Rep.* 2014;2(4):273-289.

Pedersen T. Service dogs can reduce PTSD symptoms in veterans. *PsychCentral*. December 23, 2014. <http://psychcentral.com/news/2014/12/23/service-dogs-can-reduce-ptsd-symptoms-in-veterans/79009.html>. Accessed April 15, 2015.

Petzel RA. Letter to Michael Krawitz. Department of Veterans Affairs; July 6, 2010. <http://www.veteransformedicalmarijuana.org/files/Undersecretary-Jun6.pdf>.  
Accessed April 28, 2015.

Philippidis A. Top 20 grant-giving disease foundations. *Genetic Engineering and Biotechnology News*. May 28, 2013. <http://www.genengnews.com/insight-and-intelligence/top-20-grant-giving-disease-foundations/77899817/?page=1>. Accessed April 23, 2015.

Portenoy RK. Treatment of cancer pain. *Lancet.* 2011;377(9784):2236-2247.

Pub L No. 111-84, 123 Stat 2477.

Rabkin JG, Goetz R, Factor-Litvak P, et al; The ALS Cosmos Study Group. Depression and wish to die in a multicenter cohort of ALS patients [published online ahead of print December 8, 2014]. *Amyotroph Lateral Scler Frontotemporal Degener*. doi: 10.3109/21678421.2014.980428.

Raichle KA, Hanley MA, Molton I, et al. Prosthesis use in persons with lower- and upper-limb amputation. *J Rehabil Res Dev*. 2008;45(7):961-972.

Raja SN, Haythornthwaite JA, Pappagallo M, et al. Opioids versus antidepressants in postherpetic neuralgia: a randomized, placebo-controlled trial. *Neurology*. 2002;59(7):1015-1021.

Reeve C. *Still Me*. New York, NY: Ballantine Books; 1998.

Rehabilitation Act, 29 USC sec 794 (2014).

Reiber GE, McFarland LV, Hubbard S, et al. Servicemembers and veterans with major traumatic limb loss from Vietnam war and OIF/OEF conflicts: survey methods, participants, and summary findings. *J Rehabil Res Dev*. 2010;47(4):275-297.

Reis JP, Ballerini K, O'Farrell S, et al. Is an appropriate wheelchair becoming out of reach? – Part 2. *PM R*. 2014;6(10):934-944.

Resnik L, Meucci MR, Lieberman-Klinger S, et al. Advanced upper limb prosthetic devices: implications for upper limb prosthetic rehabilitation. *Arch Phys Med Rehabil*. 2012;93(4):710-717.

Roberts TL, Pasquina PF, Nelson VS, Flood KM, Bryant PR, Huang ME. Limb deficiency and prosthetic management. 4. Comorbidities associated with limb loss. *Arch Phys Med Rehabil*. 2006;87(3)(suppl 1):S21-S27.

Rostker B. *Providing for the Casualties of War: The American Experience through World War II*. Santa Monica, CA: Rand Corporation; 2013. [http://www.rand.org/content/dam/rand/pubs/monographs/MG1100/MG1164/RAND\\_MG1164.pdf](http://www.rand.org/content/dam/rand/pubs/monographs/MG1100/MG1164/RAND_MG1164.pdf). Accessed April 20, 2015.

Rousseau P. The ethical validity and clinical experience of palliative sedation. *Mayo Clin Proc*. 2000;75(10):1064-1069.

Rucker-Whitaker C, Feinglass J, Pearce WH. Explaining racial variation in lower extremity amputation: a 5-year retrospective claims data and medical record review at an urban teaching hospital. *Arch Surg*. 2003;138(12):1347-1351.

Ruiz R. The fight for service dogs for veterans with PTSD. *The Atlantic*. September 26, 2012. <http://www.theatlantic.com/health/archive/2012/09/the-fight-for-service-dogs-for-veterans-with-ptsd/262863/>. Accessed April 15, 2015.

Sabalow R, Guerra K. Injured hunter chooses death over paralysis. *USA Today*. November 6, 2013. <http://www.usatoday.com/story/news/nation/2013/11/06/injured-hunter-chooses-death-over-paralysis/3461259/>. Accessed March 5, 2015.

Schick A, Asch A, Wasserman D. Disability: III. Theories of. In: Jennings B, ed. *Bioethics*. 4th ed. Farmington Hills, MI: Macmillan Reference; 2014:867-874.

Sehgal N, Colson J, Smith HS. Chronic pain treatment with opioid analgesics: benefits versus harms of long-term therapy. *Expert Rev Neurother*. 2013;13(11):1201-1220.

Service dogs for veterans. Al Franken: US Senator from Minnesota. <https://www.franken.senate.gov/?p=issue&id=84>. Accessed April 15, 2015.

Service Dogs. *Fed Regist*. 2012;77(172):54368-54382. Codified at 38 CFR sec 17.148.

Sheehan TP, Gondo GC. Impact of limb loss in the United States. *Phys Med Rehabil Clin N Am*. 2014;25(1):9-28.

Social Security Administration. History of SSA during the Johnson Administration 1963-1968. <http://www.socialsecurity.gov/history/ssa/lbjmedicare1.html>. Accessed March 3, 2015.

Sparrow R. Imposing genetic diversity. *Am J Bioeth*. In press. <https://mc.manuscriptcentral.com/societyimages/uajb/Sparrow.pdf>. Accessed February 24, 2015.

Stiggelbout AM, Molewijk AC, Otten W, Timmermans DR, van Bockel JH, Kievit J. Ideals of patient autonomy in clinical decision making: a study on the development of a scale to assess patients' and physicians' views. *J Med Ethics*. 2004;30(3):268-274.

Tobin PJ. Giving my uninformed consent to die. United Spinal Association. November 8, 2013. <http://www.spinalcord.org/giving-my-uninformed-consent-to-die/>. Accessed March 5, 2015.

Torio CM, Andrews RM. Statistical brief #160: national inpatient hospital costs: the most expensive conditions by payer, 2011. Healthcare Cost and Utilization Project. <http://www.hcup-us.ahrq.gov/reports/statbriefs/sb160.pdf>. Accessed April 29, 2015.

Turk DC, Okifuji A. What factors affect physicians' decisions to prescribe opioids for chronic noncancer pain patients? *Clin J Pain*. 1997;13(4):330-336.

Turk DC, Wilson HD, Cahana A. Treatment of chronic non-cancer pain. *Lancet*. 2011;377(9784):2226-2235.

US Department of Health and Human Services. ASPE issue brief: the addendum to the health insurance marketplace summary enrollment report for the initial annual open enrollment period. May 1, 2014. [http://aspe.hhs.gov/health/reports/2014/MarketPlaceEnrollment/Apr2014/ib\\_2014Apr\\_enrollAddendum.pdf](http://aspe.hhs.gov/health/reports/2014/MarketPlaceEnrollment/Apr2014/ib_2014Apr_enrollAddendum.pdf). Accessed February 27, 2015.

US Department of Veterans Affairs National Center for PTSD. Dogs and PTSD. [http://www.ptsd.va.gov/public/treatment/cope/dogs\\_and\\_ptsd.asp](http://www.ptsd.va.gov/public/treatment/cope/dogs_and_ptsd.asp). Accessed April 14, 2015.

US Department of Veterans Affairs National Center for PTSD. Treatment of PTSD. <http://www.ptsd.va.gov/public/treatment/therapy-med/treatment-ptsd.asp>. Accessed April 14, 2015.

US Department of Veterans Affairs National Center for PTSD. Understanding PTSD. August 2013. [http://www.ptsd.va.gov/public/understanding\\_ptsd/booklet.pdf](http://www.ptsd.va.gov/public/understanding_ptsd/booklet.pdf). Accessed April 10, 2015.

Varma P, Stineman MG, Dillingham TR. Epidemiology of limb loss. *Phys Med Rehabil Clin N Am*. 2014;25(1):1-8.

Verville RE, Ditunno JF. Franklin Delano Roosevelt, polio, and the Warm Springs experiment: its impact on physical medicine and rehabilitation. *PM R*. 2013;5(1):3-8.

Veterans Administration Health Care. Taking opioids responsibly for your safety and the safety of others: patient information guide on opioids for chronic pain. [http://www.ethics.va.gov/docs/policy/Taking\\_Opioids\\_Responsibly\\_2013528.pdf](http://www.ethics.va.gov/docs/policy/Taking_Opioids_Responsibly_2013528.pdf). Accessed April 28, 2015.

Veterans for Medical Cannabis Access. About the VMCA. <http://www.veteransformedicalmarijuana.org/content/about-vmca>. Accessed April 28, 2015.

Veterans Health Administration. VHA Directive 1005: informed consent for long-term opioid therapy for pain. Department of Veterans Affairs; May 6, 2014. [http://www1.va.gov/vhapublications/ViewPublication.asp?pub\\_ID=3005](http://www1.va.gov/vhapublications/ViewPublication.asp?pub_ID=3005). Accessed April 28, 2015.

Volkow ND, McLellan TA. Curtailing diversion and abuse of opioid analgesics without jeopardizing pain treatment. *JAMA*. 2011;305(13):1346-1347.

Volpe RL, Crites JS, Kirschner KL. Temporizing after spinal cord injury. *Hastings Cent Rep*. 2015;45(2):8-10.

Von Korff M, Kolodny A, Deyo RA, Chou R. Long-term opioid therapy reconsidered. *Ann Intern Med*. 2011;155(5):325-328.

Wasan AD, Ross EL, Michna E, et al. Craving of prescription opioids in patients with chronic pain: a longitudinal outcomes trial. *J Pain*. 2012;13(2):146-154.

Webster L, St Marie B, McCarberg B, Passik SD, Panchal SJ, Voth E. Current status and evolving role of abuse-deterrent opioids in managing patients with chronic pain. *J Opioid Manag*. 2011;7(3):235-245.

White RB. *Please Let Me Die* [video]. Galveston, TX: University of Texas Medical Branch-TV; 1974.

Whyte AS, Carroll LJ. A preliminary examination of the relationship between employment, pain and disability in an amputee population. *Disabil Rehabil*. 2002;24(9):462-470.

Young MJ. Pathologies of thought and first-person authority. *Philos Psychiatr Psychol*. In press.

Zacny JP. Should people taking opioids for medical reasons be allowed to work and drive? *Addiction*. 1996;91(11):1581-1584.

Ziegler-Graham K, MacKenzie EJ, Ephraim PL, Trivison TG, Brookmeyer R. Estimating the prevalence of limb loss in the United States: 2005 to 2050. *Arch Phys Med Rehabil*. 2008;89(3):422-429.

Zuck RD, ed. *The Speaker's Quote Book*. Grand Rapids, MI: Kregel Academic; 2009:204.

**Copyright 2015 American Medical Association. All rights reserved.  
ISSN 2376-6980**

# American Medical Association Journal of Ethics

June 2015, Volume 17, Number 6: 593-596

## About the Contributors

### Theme Issue Editor

Gaurav Jay Dhiman is a third-year medical student at the University of Miami Leonard M. Miller School of Medicine. After completing his clinical training, he hopes to become a clinical, bioethics, and health policy professor and possibly join a think tank. He has interned for US Senators Dianne Feinstein and Bill Nelson as well as the Center for American Progress.

### Contributors

Kyle T. Amber, MD, completed his transitional year residency in the Department of Internal Medicine at MacNeal Hospital in Berwyn, Illinois, in 2015, after which he became a resident in dermatology at the University of California, Irvine. His areas of research interest include immunodermatology, medical ethics, and medical humanities.

Levan Atanelov, MD, MS, is a fourth-year resident in PM&R at Johns Hopkins University in Baltimore. His interests include telerehabilitation, quality improvement, and early mobility.

John D. Banja, PhD, is a professor in the Department of Rehabilitation Medicine in the medical school and a medical ethicist at the Center for Ethics at Emory University in Atlanta. He is the author of *Medical Errors and Medical Narcissism* (Jones and Bartlett, 2005) and consults frequently on medical malpractice cases.

William L. Bockenek, MD, is a professor in and the chair of the Department of Physical Medicine and Rehabilitation at Carolinas Medical Center/Carolinas Rehabilitation in Charlotte, North Carolina.

Antonio J. Carvalho is a researcher for the Henry M. Jackson Foundation for the Advancement of Military Medicine and its programs at the Walter Reed National Military Medical Center and the Uniformed Services University of the Health Sciences in Bethesda, Maryland. He is involved in research that investigates treatments and therapies to advance the care, recovery, and rehabilitation of those with extremity trauma and traumatic brain injury, and he is interested in the impact of scientific advancements on law and regulation.

Mitchell J. Cohen, MD, is the vice chair for education and an associate professor in the Department of Psychiatry and Human Behavior and the director of the Pain Medicine

Program at Sidney Kimmel College of Medicine at Thomas Jefferson University in Philadelphia. Dr. Cohen has served on committees at national organizations, including the American Pain Society, the American Board of Pain Medicine, the Accreditation Council for Graduate Medical Education, and the National Board of Medical Examiners. His areas of expertise are medical education and pain medicine.

William Filer, MD, is an assistant professor at the University of North Carolina School of Medicine in Chapel Hill, where he serves as the associate director of the Physical Medicine and Rehabilitation Residency Program. His clinical interests include neuromuscular and traumatic brain injury rehabilitation, amputee care, electrodiagnosis, and performing arts medicine.

Michael Fredericson, MD, is a professor and the director of physical medicine and rehabilitation sports medicine and of nonoperative sports medicine fellowships at Stanford University School of Medicine in Stanford, California. He has been a team physician with Stanford Athletics for more than 20 years and has lectured and published extensively on the treatment of sports injuries.

James Hill, MD, MPH, is director of the Physical Medicine and Rehabilitation Residency Program and an assistant professor at the University of North Carolina School of Medicine in Chapel Hill. Dr. Hill is a graduate of the NIH-sponsored Rehabilitation Medicine Scientist Training Program (RMSTP). His research and clinical work focus on the intersection of work and health, including work disability, absenteeism, and return to work after injury and illness.

William C. Jangro, DO, is an instructor in the Department of Psychiatry and Human Behavior, the assistant director and overseer of the curriculum of the Psychiatry Residency Training Program, and an attending physician on the consultation liaison service and the pain medicine program at Sidney Kimmel College of Medicine at Thomas Jefferson University in Philadelphia. He treats patients with chronic pain and evaluates hospitalized medical and surgical patients with psychiatric and behavioral complications.

Kristi L. Kirschner, MD, is on the medical staff of Schwab Rehabilitation Hospital and a faculty member in the Department of Disability and Human Development at the University of Illinois in Chicago. She specializes in neurological rehabilitation and disability ethics.

Eric Kodish, MD, is director of the Center for Ethics, Humanities and Spiritual Care at the Cleveland Clinic in Cleveland, Ohio, where he is also the F. J. O'Neill Professor and chairman of the Department of Bioethics and executive director of the Cleveland Fellowship in Advanced Bioethics. Dr. Kodish has an appointment as professor of pediatrics in the Lerner College of Medicine at Case Western Reserve University.

Martin Kohn, PhD, is director of the Cleveland Clinic's Program in Medical Humanities within the Center for Ethics, Humanities and Spiritual Care and an associate professor in the Lerner College of Medicine at Case Western Reserve University in Cleveland, Ohio. His research interests are in the pedagogical aspects of the medical humanities and in developing performance pieces that engage health care professionals and the public in a dialogue about the nature and future of health care.

Michael Krawitz is executive director of Veterans for Medical Cannabis Access, in which capacity he negotiated the first Veterans Affairs policy on medical marijuana. He is a disabled United States Air Force Veteran and volunteer patient advocate.

Debjani Mukherjee, PhD, is the director of the Donnelley Ethics Program at the Rehabilitation Institute of Chicago and an associate professor of physical medicine and rehabilitation and of medical humanities and bioethics at Northwestern University's Feinberg School of Medicine. Her interests include ethical dilemmas posed by neurological impairments, cultural contexts of medical decisions, and the impact of emotionally demanding cases on clinical staff.

Vu Nguyen, MD, MBA, is an associate professor and the vice chair of academics and the residency program director in the Department of Physical Medicine and Rehabilitation at Carolinas Medical Center/Carolinas Rehabilitation in Charlotte, North Carolina.

Colonel Paul F. Pasquina, USA (Ret), MD, is the inaugural chair of the Department of Physical Medicine and Rehabilitation and director of the Center for Rehabilitation Sciences Research at the Uniformed Services University of the Health Sciences and director of the Physical Medicine and Rehabilitation Residency Training Program at Walter Reed National Military Medical Center in Bethesda, Maryland. His research efforts explore new technologies to enhance the recovery, rehabilitation, and reintegration of those with combat casualties, particularly traumatic brain injury and extremity trauma.

Terrence Patrick Sheehan, MD, is the chief medical officer of Adventist Rehabilitation Hospital in Rockville, Maryland. He is also the division director for rehabilitation medicine at The George Washington University Hospital and an associate professor of rehabilitation medicine in the Department of Neurology at The George Washington School of Medicine in Washington, DC. He has served as the national medical director for of the Amputee Coalition since 2006.

Steven A. Stiens, MD, MS, is an associate professor in the Department of Rehabilitation Medicine at the University of Washington in Seattle. Dr. Stiens is a spinal cord medicine physician practicing rehabilitation and primary care. His published research is primarily in

the area of neurogenic bowel rehabilitation, life care planning, and neurological recovery after spinal cord injury, and his current projects focus on vocational rehabilitation, video simulations for distance learning, and telemedicine.

Adam S. Tenforde, MD, is a physician in Redwood City, California, and a PM&R sports medicine fellow at Stanford University, where he was a former All-American long-distance runner. His clinical and research interests are in management and prevention of overuse and sports injuries in athletes.

Steven G. Ullmann, PhD, is the director of the Center for Health Sector Management and Policy and a professor in the School of Business Administration at the University of Miami, Florida.

Richard Weinmeyer, JD, MA, MPhil, is a senior research associate for the American Medical Association Council on Ethical and Judicial Affairs in Chicago. Mr. Weinmeyer received his master's degree in bioethics and his law degree with a concentration in health law and bioethics from the University of Minnesota, where he served as editor in chief for volume 31 of *Law and Inequality: A Journal of Theory and Practice*. He obtained his first master's degree in sociology from Cambridge University. Previously, Mr. Weinmeyer served as a project coordinator at the University of Minnesota Division of Epidemiology and Community Health. His research interests are in public health law, bioethics, and biomedical research regulation.

Julian Willoughby, MD, MPH, is a third-year resident in the Department of Physical Medicine and Rehabilitation at Carolinas Medical Center/Carolinas Rehabilitation in Charlotte, North Carolina.

Mark A. Young, MD, MBA, is chair of PM&R at the Workforce & Technology Center, State of Maryland Division of Rehabilitation Services (DORS), Department of Education. He is also a faculty member at Johns Hopkins University School of Medicine in Baltimore and the New York University School of Medicine. His scholarly interests include vocational rehabilitation and technology, pain, and neurologic rehabilitation.