AMA Journal of Ethics®

September 2017

Volume 19, Number 9: 843-953

Peer-Reviewed CME Articles Ethics Students Go to the Jail Oliver Schirokauer, Thomas A. Tallman, Leah Jeunnette, Despina Mavrakis, and Monica L. Gerrek	845
Compassionate Release Policy Reform: Physicians as Advocates for Human Dignity Andreas Mitchell and Brie Williams	854
"Teach-to-Goal" to Better Assess Informed Consent Comprehension among Incarcerated Clinical Research Participants Cyrus Ahalt, Rebecca Sudore, Marielle Bolano, Lia Metzger, Anna M. Darby, and Brie Williams	862
Incarceration and Correctional Health Care	
From the Editor Ethics at the Intersection of the Criminal Justice and Health Care Systems Lisa Simon	873
Ethics Cases	
What Are Physicians' Responsibilities to Patients Whose Health Conditions Can Influence Their Legal Proceedings? Commentary by David Beckmann	877
How to Talk with Patients about Incarceration and Health Commentary by Kimberly Sue	885
How Should a Health Care Professional Respond to an Incarcerated Patient's Request for a Particular Treatment? Commentary by Tom Peteet and Matt Tobey	894
What Does Health Justice Look Like for People Returning from Incarceration?	903

Case and Commentary by Lisa Puglisi, Joseph P. Calderon, and Emily A. Wang
Podcast
What Are Clinicians' Responsibilities to Incarcerated Patients? An Interview with Troy Williams, Dan McGuire, and Lisa Puglisi
he Code Says
The AMA Code of Medical Ethics' Opinions Related to Health
Care for Incarcerated People
Annalise Norling
Aedical Education
Medicine and Mass Incarceration: Education and Advocacy in
the New York City Jail System
Jonathan Giftos, Andreas Mitchell, and Ross MacDonald
itate of the Art and Science
Why It's Inappropriate Not to Treat Incarcerated Patients
with Opioid Agonist Therapy
Sarah E. Wakeman

Swift and Certain, Proportionate and Consistent: Key Values	
of Urine Drug Test Consequences for Probationers	931
Amy B. Cadwallader	

Policy Forum

Surgery in Shackles: What Are Surgeons' Obligations to	
Incarcerated Patients in the Operating Room?	939
Sara Scarlet and Elizabeth Dreesen	
Images of Healing and Learning	

Hydrochlorothiazide	947
Artwork and caption by Satyajeet Roy	

About the Contributors

911

913

922

949

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 845-853

PEER-REVIEWED CME ARTICLE: MEDICAL EDUCATION

Ethics Students Go to the Jail

Oliver Schirokauer, PhD, MD, Thomas A. Tallman, DO, MMM, Leah Jeunnette, PhD, Despina Mavrakis, MBA, and Monica L. Gerrek, PhD

Editor's Note: To claim one AMA PRA Category 1 Credit^M for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit^M are available through the <u>AMA Education Center</u>.

Abstract

This article describes an educational initiative in which clinical ethics students, who were either in a bioethics master's degree program or in the fourth year of medical school, spent two days observing health care in an urban jail. Students submitted reflections about their experience, in which they drew attention to concerns about privacy, physical restriction, due care, drug addiction, mistrust, and the conflicting expectations that arise when incarcerated people become patients. The rotation was of great value to the students both because it exposed them to many of the ethical issues that arise in a correctional setting and because it deepened their understanding of various ethical concerns that are pervasive in health care.

Introduction

Results published in 2001 from a national survey that looked at correctional health care education in medical residencies [1], two articles that appeared more recently and discuss the merits and importance of partnerships between academic medical centers and correctional institutions [2, 3], and our own literature and internet searches suggest that there is not widespread placement of health care trainees in correctional facilities. Nevertheless, we found descriptions of programs that provide trainees in various clinical professions—including medicine, nursing, and occupational therapy—the opportunity to learn and practice in a correctional setting [3-10]. All attest to the enormous educational value of the experience. Some of the challenges trainees face and the skills they acquire when rotating in a correctional institution are specific to correctional health care. For instance, they must learn to negotiate the conflicting demands inherent in caring for incarcerated persons while also respecting the need of the institution to maintain order and security through measures such as regimented medication management and restrictions on privacy [4, 5, 11]. Much of what trainees gain from working in correctional

health care, however, is transferable to noncorrectional settings, including the learning that comes from managing a wide range of chronic conditions [2-9], providing care to a diverse and generally underserved population [2, 4, 6-8], and negotiating relationships in which mistrust is a potential factor [4-6, 9, 12]. In this paper, we consider whether there are analogous benefits for clinical ethics students who rotate in a correctional facility.

The health care system we are associated with is the MetroHealth System in Cleveland, Ohio. It oversees the medical division of the Cuyahoga County Corrections Center (CCCC) and is affiliated with Case Western Reserve University School of Medicine, whose bioethics department staffs MetroHealth's Center for Biomedical Ethics (CBME). Each year, bioethics master's students and fourth-year medical students, as part of clinical ethics electives in their respective programs, are given the opportunity to observe many different areas of MetroHealth's main campus, including all of the intensive care units, the emergency department, the skilled nursing facility, and the police department. Last year, when the health care staff at the CCCC communicated to members of the CBME that they were open to having ethics students visit, the center began requiring that any student coming through the CBME spend at least two days at the corrections facility. In what follows, we present the details of this initiative and describe how it exposed students to a host of ethical concerns they did not see elsewhere and simultaneously engaged them in considering ethical issues in health care that extend well beyond the CCCC.

Setting and Rotation

The CCCC is a jail, which means that the persons incarcerated there are awaiting either trial or sentencing. In both 2015 and 2016, the average number of people housed at the facility each day was approximately 2,160, and the average length of stay was approximately 30 days [13]. Health care is provided by a team consisting of physicians (including a psychiatrist and an ob-gyn physician), advanced practice clinicians (certified nurse practitioners and physician assistants), an operations manager, a director of nursing, a nursing supervisor, a paramedic, a dentist, a dental hygienist, a pharmacist, registered nurses, licensed practical nurses, and clinical technicians. The medical unit has a dispensary with examination rooms, a pharmacy, in-house imaging including digital x-rays and ultrasound, and comprehensive laboratory support. A telemedicine program provides weekly access to hospital specialty expertise including cardiology, neurology, infectious disease, and psychology. In general, the medical staff sees between 70 and 100 patients each day. Frequent concerns include chronic disease management, drug and alcohol addiction, behavioral health, and chronic pain.

In the spring of 2017, the first cohort of students, consisting of six bioethics master's students and one medical student, rotated at the CCCC. Under the supervision of the facility's ambulatory director, they visited for two days, one or two students at a time. While there, they were given the opportunity to see the full scope of medical activity

occurring at the jail. Namely, they spent time observing medical encounters with patients including psychiatric appointments, accompanied staff who were seeing patients in their cells or delivering medications throughout the jail, and witnessed telemedicine encounters with off-site practitioners. Following each trip to the CCCC, the students were asked to submit to a faculty preceptor from MetroHealth's CBME an open-ended description of what they had experienced, with a focus on any ethical issues they had identified. Subsequently, they met with fellow students and a faculty preceptor in order to discuss the visit more fully. In addition, four students chose to fulfill a course requirement by submitting a more extensive case study based on what they had seen at the jail.

Themes

From the students' written reports, we identified the six ethical themes described below. We note that what follows is a record of student perspectives and caution that these views are not necessarily accurate accounts of what actually occurs at the jail.

Conflict of duties. An incarcerated person who seeks medical attention in the jail is in the dual position of being both a patient and someone who is incarcerated. Students recognized that the way a health care professional approaches an incarcerated patient might not align with the way the jail does. One example that the students took note of, and that is discussed in the next subsection, is the conflict stemming from the medical staff's responsibility to protect a patient's privacy and the facility's need to keep an eve on all areas of the jail to ensure safety. Another example comes from a student who described the case of an 85-year-old male who was ready to be released by the jail and required skilled nursing. However, because of his past behavior, no facility would take him, placing the medical team in the difficult position of trying to determine to what extent, as health care professionals in a jail and not a hospital, they are responsible for arranging a safe release. As a third example, we quote a student who explicitly commented on her decision to use the word "patient" instead of "inmate," stating, "I am still sympathetic with all of the competing priorities and needs the nurse needs to reconcile: tax payer dollars, the needs of the state.... However, the inmates, when visiting the nurse, become patients and should be treated as such."

Privacy. Multiple students commented that the institutional need for security had a significant impact on the amount of privacy that those incarcerated at the jail are afforded, both inside and outside of the medical areas of the jail. One student, in response to learning about a recent case in which a woman who was showering had a medical emergency that was caught on film by a correctional officer's body camera, expressed significant concern about the possibility that this film would be viewed and the "infringe[ment] on her self-determination" that such a viewing would represent. This student went on to describe the ways confidentiality was compromised in the medical encounters she witnessed and concluded, "Although it is understandable that there

needs to be some kind of supervision from the correctional officers for the safety of the doctors and the staff, it still feels like there could be more protection around patient information."

Physical restriction. The need for safety in the jail and the accompanying use of <u>physical</u> <u>restraints</u> including solitary confinement was a profound concern for students. Two students, for example, were disturbed to learn of an incident that occurred nearly a decade ago in which a patient was put in restraints for an extended period of time and died while still restrained. Solitary confinement was a particularly complex topic, since it is used not only punitively but also at times as a means to ensure the safety of an incarcerated person in protective custody. One student was especially troubled by the case of a patient who revealed to a nurse that he did not feel safe in his pod and was then placed briefly in solitary confinement for protection. The student's lengthy analysis, in which she acknowledged the benefits of solitary confinement in this circumstance and the limited options available to jail staff, nevertheless concluded with an impassioned rejection of the practice on the grounds that its "cruelty" could not be justified.

Due care [14]. Students recorded instances when the care that a patient received appeared to be less comprehensive than that which a patient would get outside of jail. Examples included the absence of <u>opioid substitution therapy</u> for those addicted to opioids, the lack of aggressive pain management, the lack of dietary support for certain chronic conditions, and the decision not to start a psychiatric medication for a patient with depressive symptoms but in no acute danger. Students understood these examples in the context of the jail's limited mandate to ensure only that the health status of an incarcerated person does not deteriorate while in custody, which in turn they understood to be a consequence of limited financial resources. One student also discussed how uncertainty about follow up after an incarcerated person leaves the jail might affect treatment decisions. He noted that initiating a workup that would not be completed may not be good use of funds and that initiating antimicrobial treatment that would not be maintained may result in resistance.

Drug addiction. Almost every student made reference to the prevalence of <u>substance use</u> and addiction among those incarcerated at the jail. Many commented on the challenges that the health care professionals at the jail deal with when caring for patients who have an addiction problem. In particular, students discussed the psychiatric and social difficulties that these patients face, the implications of giving or not giving opioid substitute treatment to incarcerated patients, and the question of how to treat patients who repeatedly need an expensive cardiac valve replacement because their continued intravenous drug use leads to case after case of infective endocarditis. In addition, multiple students noted that the jail under no circumstances will provide opioids to a patient in pain, partly out of a concern that the patient may have a history of addiction and partly out of a concern that the opioid medication might be diverted to an

unintended user. For one student, the unavailability of opioids led to the comment that "it is troubling to think of how many inmates have been forced to suffer because of the fear that they may pose a safety risk by possibly (1) getting addicted or (2) getting someone else addicted."

Mistrust. Many students took note of the complicated social dynamics that exist between the health care professionals working at the jail and the people incarcerated there. They focused, in particular, on the medical staff's concern that patients might be trying to manipulate them. For example, students observed clinicians being wary of patients who might be feigning symptoms or fabricating a story about their history in order to get attention, free medication, or some kind of special treatment such as relocation within the jail. Interestingly, students did not comment on the mistrust that incarcerated patients might have for the medical staff.

Discussion

In our clinical ethics teaching, we ask our students to form and articulate opinions about the values and motivations that influence the choices made by people and institutions involved in health care. To help them shape and organize their thoughts, we encourage them to consider the framing principles of respect for patient autonomy, justice, beneficence, and nonmaleficence [14]. Having students visit the county jail supported this educational process by exposing them to specific and difficult ethical questions and by inducing them to engage with the broader issues and principles associated with these questions. We consider two examples.

Respect for patient autonomy. As a discipline, clinical ethics is deeply concerned with practices that protect patient autonomy, especially in the context of medical decision making. In a jail, autonomy is, of course, intentionally and severely constrained. Being confronted by this reality had a dramatic impact on our students emotionally and stretched their conceptual grasp of the principle of respect for autonomy in two ways.

First, it forced students to inquire about the nature of the autonomy that an incarcerated person retains in jail and to consider under what circumstances such a person's choice should not be respected. For instance, many students accepted that the security and financial requirements of the institution necessitate denying freedom of movement or choice of food to those incarcerated there, but they became uncomfortable when someone's entitlement to care or right to refuse treatment appeared to be compromised. A representative articulation of this stance is given by one student who wrote that "[an] inmate can never make a fully autonomous choice because he is limited in his choices by being in jail and there are certain amounts of control over his actions. However, this does not mean that he cannot make choices about his well-being and health, as individuals know their health status the best."

Second, being in an environment in which autonomy is so constrained put a spotlight on aspects of health care that involve patient autonomy but might not get a lot of attention in other clinical settings. The students' heightened concern about the lack of control incarcerated people have over their private information and their physical circumstances, for example, provided a natural platform from which to examine how privacy can be compromised and patients restrained in other health care settings. Similarly, the students' exposure to instances of mistrust between incarcerated patients and the medical staff presented an opportunity for a preceptor to draw attention to the fundamental role that trust plays in clinical decision making and, in particular, to explore with students how informed consent, shared decision making, and patient-clinician partnerships promote respect for patient autonomy and depend on effective, bidirectional, and trusted communication to do so.

Justice. For our purpose here, we take justice to mean the "fair, equitable, and appropriate distribution of benefits and burdens" [15] among the various members of our society. Although this notion of distributive justice is a prominent principle in bioethics, it can become an afterthought in clinical education courses that largely focus on the dynamics and challenges inherent in the individual encounter. In the jail, however, concerns about justice gain attention for two reasons.

To begin with, like other publicly funded institutions, the jail has limited resources. Students were aware of this and, in fact, discussed their perception that decisions about testing and treatment are at times made not solely on the basis of what is medically optimal but instead on the basis of an assessment that might take into account factors such as nonadherence to treatment, length of stay in the jail, and, especially, expense. This unveiling of the harsh financial, behavioral, and social limitations placed on health care in the jail provided an opportunity for them to consider how the same constraints play a role in how health care is distributed in our society at large.

Additionally, justice became a focus of concern for students when the encounters they witnessed raised questions about patient access to resources outside of the jail. For example, one student, in regard to a patient with posttraumatic stress disorder and depression, wrote:

Although these cannot be used to excuse his crimes, he might not have the same access to health care that others his age from different areas or populations have, and therefore is [sic] never got the proper treatment or stood a chance to attempt to recover and was more at risk to be involved in crime and end up in jail. For this student, as well as the others, meeting incarcerated people with significant health concerns provided a glimpse into health disparities that exist in the greater community.

Conclusion

This paper is a preliminary account of an initiative to have ethics students observe how health care is administered in the county jail. The writing our students produced and the discussions we had with them strongly indicate that the experience had a significant intellectual and emotional impact on them. Students were moved both by the difficult circumstances of the people incarcerated at the jail and by the challenges clinicians face trying to provide care there. Moreover, they struggled to understand both the societal and the personal forces that shaped what they were seeing and to place them in an ethical framework.

Although we consider this first implementation of the rotation to have been successful, we recognize that there is room for improvement and expansion. For example, we believe that our students would be better able to make sense of what they observe if they were given more information up front about how the jail operates (e.g., logistics within the jail, available treatment programs, safety issues), and so we are exploring the idea of having them attend an introductory presentation given by the sergeant responsible for educating new staff at the jail. To further help the students contextualize, process, and expand on what they are seeing at the jail, we intend to develop curricular materials for use between their visits there. We also believe that students would benefit from getting feedback on their writing from the medical staff at the jail and that the clinicians, in turn, would be interested in learning how the students view their visits. We therefore plan to ask members of the medical staff to read and comment on some of the students' written work. Finally, in order to deepen the students' experience, we are considering an increase in the number of required visits to the jail. Our conviction that exposure to correctional health care pushes ethics students to think carefully about the nature of ethical health care in our society has even led us to imagine designing an entire course on health disparities in which the jail figures prominently. Wherever it leads, we view a two-day rotation at the jail as a promising first step.

References

- 1. Kraus ML, Isaacson JH, Kahn R, Mundt MP, Manwell LB. Medical education about the care of addicted incarcerated persons: a national survey of residency programs. *Subst Abuse*. 2001;22(2):97-104.
- 2. Wakeman SE, Rich JD. Fulfilling the mission of academic medicine: training residents in the health needs of prisoners. *J Gen Intern Med*. 2010;25(suppl 2):S186-S188.

- 3. Trestman RL, Ferguson W, Dickert J. Behind bars: the compelling case for academic health centers partnering with correctional facilities. *Acad Med.* 2015;90(1):16-19.
- 4. Alemagno SA, Wilkinson M, Levy L. Medical education goes to prison: why? *Acad Med*. 2004;79(2):123-127.
- 5. Holoyda BJ, Scott CL. Psychiatric education in the correctional setting: challenges and opportunities. *Int Rev Psychiatry*. 2017;29(1):11-20.
- 6. Bouchard MT, Swan BA. Integrating correctional and community health care: an innovative approach for clinical learning in a baccalaureate nursing program. *Nurs Forum*. 2017;52(1):38-49.
- 7. Clarke JG, Cyr MG, Spaulding A. Prisons: learning about women's health and substance abuse. *Acad Med*. 2000;75(5):544.
- 8. Filek H, Harris J, Koehn J, Oliffe J, Buxton J, Martin R. Students' experience of prison health education during medical school. *Med Teach*. 2013;35(11):938-943.
- 9. Kaufman A, Holbrook J, Collier I, Farabaugh L, Jackson R, Johnston T. Prisoner health and medical education. *J Med Educ*. 1979;54(12):925-931.
- 10. Provident IM, Joyce-Gaguzis K. Creating an occupational therapy level II fieldwork experience in a county jail setting. *Am J Occup Ther.* 2005;59(1):101-106.
- 11. Kalra R, Kollisch SG, MacDonald R, Dickey N, Rosner Z, Venters H. Staff satisfaction, ethical concerns, and burnout in the New York City jail health system. *J Correct Health Care*. 2016;22(4):383-392.
- 12. Garland BE, McCarty WP. Job satisfaction behind walls and fences: a study of prison health care staff. *Crim Justice Policy Rev.* 2009;20(2):188-208.
- 13. Cuyahoga County Sheriff's Department. 2016 Annual report.
- 14. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics.* 7th ed. New York, NY: Oxford University Press; 2013.
- 15. Beauchamp, Childress, 250.

Oliver Schirokauer, PhD, MD, is a senior research associate in the Department of Bioethics at Case Western Reserve University (CWRU) in Cleveland, Ohio, where his responsibilities include oversight of the ethics curriculum for CWRU's medical students. He is also a clinical ethicist at the MetroHealth System. He recently launched a clinical program to support patients adjusting to major illness by helping them with communication, information processing, and decision making.

Thomas A. Tallman, DO, MMM, is medical director of the MetroHealth Correctional Health Program at the Cuyahoga County Corrections Center and a faculty member at the Cleveland Clinic Lerner College of Medicine in Cleveland, Ohio. A Navy veteran, he is board certified in emergency medicine and is a certified correctional health professional through the National Commission on Correctional Health Care. His interests include emergency preparedness, disaster medicine, education, and hands-on teaching. **Leah Jeunnette, PhD**, is a senior research associate in the Department of Bioethics at Case Western Reserve University and a clinical ethicist at the MetroHealth System in Cleveland, Ohio. She has interests in clinical ethics consultation, ethics education, and the ethics of fertility preservation.

Despina Mavrakis, MBA, is the ambulatory director of the MetroHealth Correctional Health Program at the Cuyahoga County Corrections Center in Cleveland, Ohio. She is certified in executive coaching, serves on MetroHealth's ethics committee, and has an interest in ethics education.

Monica L. Gerrek, PhD, is an assistant professor in the Department of Bioethics at Case Western Reserve University in Cleveland, Ohio, where she is co-director of the Center for Biomedical Ethics. She is also the co-director of the MetroHealth Institute of Burn Ethics. Her interests include food ethics, the ethics of addiction, and international perspectives on health care.

Related in the AMA Journal of Ethics

The AMA *Code of Medical Ethics*' Opinions Related to Health Care for Incarcerated People, September 2017 Hard Time and Health Care: The Squeeze on Medicine Behind Bars, February 2008 How Should a Health Care Professional Respond to an Incarcerated Patient's Request for a Particular Treatment?, September 2017 Medicine and Mass Incarceration: Education and Advocacy in the New York City Jail System, September 2017 Physician Empathy in Correctional Facilities: Still in Need of Analysis, February 2008 Surgery in Shackles: What Are Surgeons' Obligations to Incarcerated Patients in the Operating Room?, September 2017 What Are Physicians' Responsibilities to Patients Whose Health Conditions Can Influence Their Legal Proceedings?, September 2017 Why It's Inappropriate Not to Treat Incarcerated Patients with Opioid Agonist Therapy, September 2017

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 854-861

PEER-REVIEWED CME ARTICLE : POLICY FORUM

Compassionate Release Policy Reform: Physicians as Advocates for Human Dignity

Andreas Mitchell and Brie Williams, MD, MS

Editor's Note: To claim one AMA PRA Category 1 Credit^{\mathbb{M}} *for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit^{\mathbb{M}} <i>are available through the <u>AMA Education Center</u>.*

Abstract

A rapidly aging correctional population has led to an increasing number of patients with serious progressive and terminal illnesses in correctional settings. "Compassionate release" describes a range of policies offering early release or parole to incarcerated patients with serious or debilitating illnesses. However, in many states that have compassionate release policies, few patients are actually granted release. We describe how the continued incarceration of patients with serious or debilitating illness can constitute a violation of human dignity if appropriate palliative care is unavailable. We argue that, given the importance in medical ethics of upholding dignity, physicians should advocate for the appropriate application and use of compassionate release. We describe several opportunities for physicians to take leadership on this issue.

Introduction

Incarcerated patients are more likely to have severe or debilitating medical illnesses than the general population [1]. More than 4,000 people died in jails and state prisons annually from 2003-2011, with heart disease and cancer being major causes of death [2]. These illnesses disproportionately affect older patients, who make up an increasingly larger share of prison populations. From 1993 to 2013, the 55-and-older population in state prisons more than tripled, increasing from 3 percent to 10 percent [3]. "Compassionate release" policies have been designed to allow some of these patients to be released from prison or jail before sentence completion. However, few patients are actually granted compassionate release [4, 5]. This article provides an overview of ethical principles used to justify compassionate release and explores how physicians can leverage their commitment to upholding ethical principles to advocate for more effective compassionate release policies.

Compassionate Release

For humanitarian, practical, and economic reasons, 47 states and the District of Columbia have some form of early release mechanism for seriously ill or disabled incarcerated patients [6-8]. "Compassionate release" is a broad term used to describe a range of these types of policies (including medical parole, emergency parole, and medical release). Most, if not all, share the requirement for a physician to determine medical eligibility for potential candidates, although medical eligibility differs by jurisdiction [9].

Nationwide, compassionate releases occur relatively infrequently. Out of 2,621 requests for compassionate release during a one-year span in the Federal Bureau of Prisons, only 85 (3.24 percent) were granted [10]. State prison systems are likely to have similar if not lower rates of release [11]. These low rates stem in large part from state and federal policies with restrictive medical and criminological eligibility criteria for release, including mandated short-term "terminal prognosis" and exclusion of nonterminal but debilitating conditions [9, 11]. These policy barriers are compounded by administrative barriers to release such as objections by a victim advocate or prosecutor, concerns about public safety (particularly for those incarcerated for violent crimes), and availability of suitable postrelease community care plans [6, 12].

Compassionate release policies are designed in recognition of the fact that an appropriate level of care for patients with severe or debilitating illnesses is difficult, and sometimes impossible, to achieve in the correctional setting [13, 14]. For instance, the community standard for end-of-life care is to offer patients hospice [15]; however, prison hospices are available only at 69 of 1,719 state correctional facilities [9, 16], and they often require patients to move farther away from family or friends at a time when maintaining social connections is a core component of quality care. Prison hospice programs are costly, straining state allocations for correctional health services, which cannot be billed to Medicare and Medicaid [17]. Consider the film Prison Terminal: The Last Days of Private Jack Hall, which depicts a prison hospice program that was made possible by fundraising rather than budgetary allocation [18]. The film highlights comfort measures provided by incarcerated persons employed to help the patient but depicts relatively little in the way of professional hospice nursing and palliative care. In fact, a few days before his death, the patient is shackled, put in an orange jumpsuit, and taken by ambulance to the nearest emergency room, where he can receive appropriate medical care. Cost and logistical limitations make it very difficult to provide standard-of-care hospice care in prisons, threatening the dignity of the seriously ill and offering a strong rationale for compassionate release policies. Although there are several reasons why the medical community should advocate for evidence-based compassionate release policies—including the high cost of care for these patients—we will focus in this paper on the ethical value of human dignity.

Human Dignity: the Ethical Principle Justifying Use of Compassionate Release Policies

Upholding human dignity—the inherent value or "inner worth" of every person—is a core ethical principle [19, 20]. Each person has dignity, which is not subject to circumstance and persists regardless of the situational context in which a person may find himself, including incarceration. Immanuel Kant operationalized the concept of human dignity as the imperative that people always be treated as ends unto themselves, never solely as means to an end [19, 21]. In this paper, we will refer to "upholding" and "maintaining" dignity, by which we mean respecting human inner worth as identified by Kant.

Although human dignity is frequently considered in medical ethics, its role is interpreted variably. While some consider it to be implicit in the four ethical principles of autonomy, justice, beneficence, and nonmaleficence that make up the core of biomedical ethics [22], others consider it to be distinct. For instance, human dignity stands alone in the first tenet of the American Medical Association (AMA) Principles of Medical Ethics, which states, "A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights" [23]. In palliative care, or the care of patients with serious illness aimed at symptom control rather than cure, maintenance of human dignity is considered a fundamental—and independent—ethical principle [24, 25].

For patients with serious, life-limiting illness, maintenance of human dignity has been defined as the provision (to the extent it is possible) of meaning and purpose, autonomy and control, and attention to spiritual and emotional needs [25, 26]. To optimize such care, Chochinov identifies several tasks of "dignity-conserving care" [25], which include settling relationships, sharing words of love, and preparing a legacy document for loved ones [27-29]. For incarcerated patients—all of whom have a constitutional right to appropriate care [30]—one could argue that the right to dignity conservation during a patient's serious illness is not only an ethical imperative for clinicians [20], but also a constitutionally protected right. In this context, a correctional facility that cannot achieve a patient-centered environment, in which dignity-conserving practices are integrated into care, might not meet an appropriate ethical standard of care for the seriously ill. Compassionate release offers a mechanism to shift those patients to settings that can provide appropriate care.

Physicians' Roles in Advocating for Evidence-Based Compassionate Release Policies

While physicians have professional responsibilities to uphold the dignity of their patients in an exam room, for example, they also have obligations to advocate for policy changes when they observe patient dignity being undermined in specific circumstances, such as incarceration. This professional role is described in the AMA Principles of Medical Ethics as "a responsibility to seek changes in those [legal] requirements which are contrary to the best interests of the patient," as well as "a responsibility to participate in activities contributing to the improvement of the community and the betterment of public health" [23]. Policies that expand access to <u>evidence-based palliative care</u>, including dignityconserving strategies, are consistent with both the best interests of patients and the betterment of public health. As such, physicians are encouraged, if not obligated, to advocate for them.

It is important to note that compassionate release might not always be the best option for an incarcerated person with a serious illness. For some patients, questions about public safety and victims' rights present considerations that compete with early release [9]. However, it bears noting that older age at release is a major factor associated with lower recidivism [31], thus mitigating the potential public safety risks of compassionate release. Additionally, barriers related to discharge planning and community placement can impede the ability of a correctional health care team to develop an appropriate release plan [6]. Even in these cases, physicians can <u>advocate</u> for their patients with serious illness to live in the least restrictive, most patient-centered environment that can be achieved without compromising public safety. For all incarcerated patients who are not suitable for release or who are awaiting an administrative ruling on their petition for compassionate release, attention must be focused on the delivery of high-quality, dignity-conserving care.

Next Steps for Physicians and Professional Medical Societies

There are several ways in which physicians can advocate for seriously ill incarcerated patients.

First, the AMA, the National Commission on Correctional Health Care (NCCHC), and other professional medical societies can study barriers to effective compassionate release policy and offer guidance to correctional physicians about how to address those barriers. In particular, further study could help physicians assess the ability (or inadequacy) of their facility to meet palliative care needs of their patients with serious illnesses and facilitate physicians' roles in encouraging development of the least restrictive, most dignified living environments achievable without compromising public safety. This kind of advocacy effort could involve supporting patients' compassionate release petitions with a professional opinion that the patient needs community palliative care to meet ethical standards of human dignity. Additionally, state and national medical organizations themselves can spearhead efforts to promote evidence-based compassionate release policies by involving the broader medical community in support of high-quality palliative care for incarcerated patients.

Second, palliative care organizations should be called upon to recognize the important site of care that correctional settings represent for many seriously ill patients. Such organizations can press correctional health care systems to adopt palliative care as the standard of care for the seriously ill and to embrace compassionate release as a means

to ensure palliative care for patients who need it. Such care requires attention to physical symptoms, emotional and existential concerns, and resolution with family and friends. The quality guidelines for end-of-life care in correctional settings from the National Hospice and Palliative Care Organization may offer guiding principles for such efforts, in terms of both providing such care in correctional facilities and streamlining considerations for compassionate release [32].

Third, correctional physicians who care for seriously ill and dying patients can systematically evaluate which of their compassionate release petitions have been successful in order to optimize the success of future petitions, focusing on administrative hurdles that impede access to timely assessment and release. With such information, correctional physicians can help develop streamlined pathways to assessment for early release, making it the norm that all incarcerated patients who are rapidly declining in health or functional status or who have a life-limiting illness be assessed. They can also forge connections with clinicians outside incarceration settings to help their patients access housing and other social supports that are required for compassionate release petitions in some states [6]. Additionally, if it appears there are more systematic or bureaucratic barriers affecting implementation of existing compassionate release policies, correctional physicians can share their stories with policymakers and the public, illuminating their patients' needs and firmly establishing themselves as champions of human dignity in the correctional setting.

Conclusion

Physicians have important obligations to participate in public debates involving issues of human dignity. One such issue is compassionate release. Physicians can help generate political momentum toward policy analysis and change, contribute medical expertise toward the structuring of scientifically sound compassionate release policies, and advocate directly for their incarcerated patients. As a simple starting point, state and national professional medical societies can study the barriers to effective compassionate release policy, support correctional physicians in addressing those barriers, and engage their members in advocating for policy change.

References

- 1. Binswanger IA, Krueger PM, Steiner JF. Prevalence of chronic medical conditions among jail and prison inmates in the USA compared with the general population. *J Epidemiol Community Health*. 2009;63(11):912-919.
- Noonan ME. Mortality in local jails and state prisons, 2000-2011: statistical tables. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; August 2013. https://www.bjs.gov/content/pub/pdf/mljsp0011.pdf. Accessed July 28, 2017.
- 3. Carson EA, Sabol WJ. Aging of the state prison population, 1993-2013. US Department of Justice Office of Justice Programs Bureau of Justice Statistics;

May 2016. https://www.bjs.gov/content/pub/pdf/aspp9313.pdf. Accessed July 28, 2017.

- 4. Dubler NN. The collision of confinement and care: end-of-life care in prisons and jails. *J Law Med Ethics*. 1998;26(2):149-156.
- Anno BJ, Graham C, Lawrence JE, Shansky R. *Correctional Health Care: Addressing the Needs of Elderly, Chronically III, and Terminally III Inmates*. Washington, DC: US Department of Justice National Institute of Corrections; 2004. https://s3.amazonaws.com/static.nicic.gov/Library/018735.pdf. Accessed July 28, 2017.
- 6. Maschi T, Leibowitz G, Rees J, Pappacena L. Analysis of US compassionate and geriatric release laws: applying a human rights framework to global prison health. *J Hum Rights Soc Work*. 2016;1(4):165-174.
- Utah Admin Code R671-314 (2017). https://rules.utah.gov/publicat/code/r671/r671-314.htm. Accessed July 31, 2017.
- 8. SC Code Ann sec 24-21-715 (2012). http://www.scstatehouse.gov/code/t24c021.php. Accessed July 31, 2017.
- 9. Williams BA, Sudore RL, Greifinger R, Morrison RS. Balancing punishment and compassion for seriously ill prisoners. *Ann Intern Med.* 2011;155(2):122-126.
- US Department of Justice Office of the Inspector General. The impact of an aging inmate population on the Federal Bureau of Prisons. https://oig.justice.gov/reports/2015/e1505.pdf. Published May 2015. Revised February 2016. Accessed July 28, 2017.
- 11. Williams BA, Ahalt C, Rothman A. For seriously ill prisoners, consider evidencebased compassionate release policies. *Health Affairs Blog*. February 6, 2017. http://healthaffairs.org/blog/2017/02/06/for-seriously-ill-prisoners-considerevidence-based-compassionate-release-policies/. Accessed July 28, 2017.
- Russell MP. Too little, too late, too slow: compassionate release of terminally ill prisoners—is the cure worse than the disease? *Widener J Public Law*. 1993;3(3):799-856.
- 13. Williams BA, Stern MF, Mellow J, Safer M, Greifinger RB. Aging in correctional custody: setting a policy agenda for older prisoner health care. *Am J Public Health*. 2012;102(8):1475-1481.
- 14. Linder JF, Meyers FJ. Palliative care for prison inmates: "don't let me die in prison." *JAMA*. 2007;298(8):894-901.
- 15. Institute of Medicine Committee on Approaching Death: Addressing Key End-of-Life Issues. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: National Academies Press; 2015.
- 16. Hoffman HC, Dickinson GE. Characteristics of prison hospice programs in the United States. *Am J Hosp Palliat Care*. 2011;28(4):245–252.

- 17. Morrissey JP, Dalton KM, Steadman HJ, Cuddeback GS, Haynes D, Cuellar A. Assessing gaps between policy and practice in Medicaid disenrollment of jail detainees with severe mental illness. *Psychiatr Serv.* 2006;57(6):803–808.
- 18. *Prison Terminal: The Last Days of Private Jack Hall* [film]. New York, NY: HBO; 2014.
- Ploch A. Why dignity matters: dignity and the right (or not) to rehabilitation from international and national perspectives. *N Y Univ J Int Law Polit*. 2012;44(3):887-949. http://nyujilp.org/wp-content/uploads/2010/06/44-3_Ploch_Web.pdf. Accessed July 30, 2017.
- 20. Cohn F. The ethics of end-of-life care for prison inmates. *J Law Med Ethics*. 1999;27(3):252-259, 210.
- 21. Kant I. *Groundwork for the Metaphysics of Morals*. Paton HJ, trans. London, UK: Hutchinson University Library; 1972.
- 22. Macklin R. Dignity is a useless concept. *BMJ*. 2003;327(7429):1419-1420.
- 23. American Medical Association. Principles of medical ethics. https://www.amaassn.org/sites/default/files/media-browser/2001-principles-of-medicalethics.pdf. Revised June 2001. Accessed July 18, 2017.
- 24. Abiven M. Dying with dignity. *World Health Forum*. 1991;12(4):375-381; discussion 382-398.
- 25. Chochinov HM. Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *JAMA*. 2002;287(17):2253-2260.
- 26. Kennedy G. The importance of patient dignity in care at the end of life. *Ulster Med* J. 2016;85(1):45-48.
- 27. Chochinov HM, Kristjanson LJ, Breitbart W, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncol.* 2011;12(8):753-762.
- 28. Montross L, Winters KD, Irwin SA. Dignity therapy implementation in a community-based hospice setting. *J Palliat Med*. 2011;14(6):729-734.
- 29. Montross LP, Meier EA, De Cervantes-Monteith K, Vashistha V, Irwin SA. Hospice staff perspectives on dignity therapy. *J Palliat Med.* 2013;16(9):1118-1120.
- 30. *Estelle v Gamble*, 429 US 97 (1976).
- 31. Huebner BM, Berg MT. Examining the sources of variation in risk for recidivism. *Justice Q.* 2011;28(1):146-173.
- 32. National Hospice and Palliative Care Organization. *Quality Guidelines for Hospice and End-of-Life Care in Correctional Settings*. National Hospice and Palliative Care Organization.

https://www.nhpco.org/sites/default/files/public/Access/Corrections/CorrectionsQualityGuidelines.pdf. Published 2009. Accessed July 28, 2017.

Andreas Mitchell is a fourth-year medical student at Harvard Medical School and is also pursuing an MPP at the Harvard Kennedy School of Government in Boston. He has served as co-chair of the student leadership committee of the Harvard Medical School Center for Primary Care and is a student member of the board of the Academic Consortium on Criminal Justice Health, an organization with which he has partnered to create a digital curriculum on criminal justice and health.

Brie Williams, MD, MS, is a professor of medicine in the Division of Geriatrics at the University of California, San Francisco, where she directs the program on criminal justice and health and the Criminal Justice Aging Project. Dr. Williams's work focuses on bringing the science of geriatrics and palliative care to criminal justice reform. She collaborates with colleagues from diverse disciplines, including criminal justice, public safety, and the law, to conduct impact-oriented research and education.

Acknowledgements

Dr. Williams's time is supported in part by the Sojourns Scholars Award from the Cambia Health Foundation, a pilot grant from the National Palliative Care Research Center, and Tideswell at the University of California, San Francisco.

Related in the AMA Journal of Ethics

Advocacy by Physicians for Patients and for Social Change, September 2014 Delivering Care in a Non-Health-Care Space, February 2008 High-Value Palliative Care for Cancer Patients, November 2015 Surgery in Shackles: What Are Surgeons' Obligations to Incarcerated Patients in the Operating Room?, September 2017 What Does Health Justice Look Like for People Returning from Incarceration?, September 2017 Why Prisoners Deserve Health Care, February 2008

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 862-872

PEER-REVIEWED CME ARTICLE: STATE OF THE ART AND SCIENCE

"Teach-to-Goal" to Better Assess Informed Consent Comprehension among Incarcerated Clinical Research Participants

Cyrus Ahalt, MPP, Rebecca Sudore, MD, Marielle Bolano, Lia Metzger, Anna M. Darby, MD, MPH, and Brie Williams, MD, MS

Editor's Note: To claim one AMA PRA Category 1 Credit^M for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit^M are available through the <u>AMA Education Center</u>.

Abstract

Correctional health research requires important safeguards to ensure that research participation is ethically conducted. In addition to having disproportionately low educational attainment and low literacy, incarcerated people suffer from health-related conditions that can affect cognition (e.g., traumatic brain injury, substance use disorders, mental illness). Yet modified informed consent processes that assess participants' comprehension of the risks and benefits of participation are not required by relevant federal guidelines. A push to assess comprehension of informed consent documents is particularly timely given an increase in demand for correctional health research in the context of criminal justice reform. We argue that comprehension assessments can identify persons who should be excluded from research and help those who will ultimately participate in studies better understand the risks and benefits of their participation.

Introduction

With a growing focus on reducing health disparities, researchers and funding organizations, including the National Institutes of Health (NIH) [1], are calling for more research conducted with and on behalf of correctional populations [2-6]. Criminal justice reform is integrally connected to health given the disproportionately high rates of mental illness, substance use disorders, chronic illnesses (e.g., diabetes), and infection disease (e.g., hepatitis C) found in correctional populations [7-10]. In consequence, demand for clinical and behavioral health research with incarcerated populations will likely continue to grow in an effort to better connect incarcerated persons with appropriate and effective care and thus reduce their risk of repeat incarceration. For example, successful evidence-based responses by correctional health systems to the nation's increasingly

dire opioid epidemic portend a growing need for correctional health research. Yet correctional settings are coercive and controlled environments where freedom is—by definition—constrained. It is thus critical that incarcerated persons' decision making about participation in research is thoroughly evaluated to ensure that it is voluntary (i.e., uncoerced) and adequately informed (i.e., understood). This article proposes an intervention to assess and improve participant comprehension of the risks and benefits of research conducted in a correctional setting. To motivate this proposal, we first discuss guidelines for research with incarcerated people and describe common vulnerabilities experienced by this population that we argue warrant the use of comprehension assessment tools to supplement the informed consent process. We then discuss the use of such tools in other vulnerable populations that participate in research and, finally, report previously unpublished data describing the use of one such tool, "teach-to-goal," in a recent study of incarcerated older adults.

The Need for More (Ethical) Research with Incarcerated Populations

Since the Nuremberg Code of 1947, general ethical principles governing human subjects research have required that experiments be necessary, that they be conducted by gualified personnel, and that all research participants give their informed consent prior to enrollment [11]. However, in response to ongoing disturbing and exploitative medical testing in US prisons, the 1979 Belmont Report called for enhanced protections when incarcerated populations engage in clinical research [12-14]. Accordingly, the US Department of Health and Human Services (HHS) Office for Human Research Protections classifies "prisoners" as a special population requiring "additional safeguards" and requires that studies present "no more than minimal risk" [15]. These guidelines also require that studies aim to improve "health or well-being" of "prisoners" as a class and are overseen by institutional review boards (IRBs) with no connection to prisons and with at least one member who is a "prisoner, or a prisoner representative" [15]. Yet beyond the scope of permitted research, HHS guidelines offer little specific guidance to researchers engaging in clinical research with incarcerated populations. Some have questioned whether ethical research with incarcerated persons is possible because the prison environment is inherently coercive and may inexorably undermine participant autonomy [16]. However, the current consensus among researchers supports the fundamental right of vulnerable and historically overlooked populations, including the incarcerated, to participate in research designed to improve their health [17-19].

Despite this ethical imperative, research with incarcerated participants remains limited [2, 3]. Some have speculated that uncertainty surrounding how to design research that meets the particular ethical standards and recommended guidelines for incarcerated research participants—guidelines that do not prescribe specific research practices—is an important reason why research with incarcerated participants remains scarce relative to research with other vulnerable populations [17, 20]. Indeed, a sizeable proportion of

the research that is conducted in correctional facilities does not directly enroll incarcerated people. One review of 374 articles published over a five-year period found that 21 percent were based on administrative records [21]. The dearth of such research greatly limits our understanding of the health concerns of patients in correctional settings and our ability to develop evidence-based health interventions to meet the unique needs of this population.

Comprehension of Informed Consent among Incarcerated People: An Overlooked Vulnerability

To clarify and centralize the key principles for achieving ethical research with incarcerated people, the Institute of Medicine (IOM) included an "Updated Ethical Framework" in its 2006 landmark publication, *Ethical Considerations for Research Involving Prisoners* [21]. A general guide that can be used by researchers and institutional review boards engaged in research with this population, the IOM's ethical framework affirms the ethical importance of ensuring access to research participation for incarcerated persons [21]. In calling for improved access to research for incarcerated persons, the report also emphasizes the responsibility that researchers bear to ensure the right of such persons to engage in autonomous decision making is respected and acknowledges that fulfilling this responsibility may require protective measures that are tailored to the needs of particular incarcerated subpopulations or institutions. These measures include taking appropriate steps to ensure that research participation is not just voluntary, or free from coercion, but also well understood by diverse research cohorts across a range of research settings [21].

Yet, as the authors of the IOM report and others have noted, prior work on the ethics of clinical research with incarcerated populations has disproportionality focused on developing informed consent forms that emphasize protection from coercion and undue influence [21, 22]. This work has resulted in typically long forms that emphasize the independence of research from clinical care or correctional outcome and that clearly explain the extent and limits of the benefits of participation [21]. Conversely, strategies to ensure that consent is adequately informed (i.e., understood) are relatively limited (e.g., lowering the grade level at which forms are written) and warrant additional scrutiny.

The IOM report suggests that tests for comprehension can be appropriate for incarcerated people with poor reading skills [21]. However, incarcerated populations commonly suffer numerous social and health-related vulnerabilities with potentially limiting effects on comprehension, some of which may not be reflected in reading skills. These include low educational attainment and literacy [23, 24], high rates of mental illness and learning disabilities, and health-risk factors related to temporarily or permanently impaired cognition (e.g., substance use, traumatic brain injury) [25-27]. Among older incarcerated persons, age-related conditions such as sensory impairments

(e.g., hearing, vision) and cognitive impairments (including dementia) are disproportionately common and are present at relatively young ages [28-30]. In addition, aspects of incarceration itself have been shown to lead to impairments that can affect comprehension, as in the case of prolonged solitary confinement [31].

Impairments associated with aging are especially important because over the past two decades the number of adults aged 55 and older who were incarcerated has increased at almost 7 times the rate of the overall US prison population [32]; adults aged 55 and older now constitute nearly 10.6 percent of the US prison population [33]. As the correctional population ages, enhanced consent procedures are almost certainly needed because medical conditions affecting cognition, such as early dementia, could easily escape researchers' notice in the context of a carefully scripted and linear conversation, and sensory impairments (such as difficulty with vision or hearing) could have an impact on a research participant's comprehension during the consenting process [34]. Given these common vulnerabilities among older adults who are incarcerated as well as demographic trends that suggest these vulnerabilities will likely increase, adapted consent processes that address increased risk for poor comprehension should be the norm in correctional research methodology.

Teach-to-Goal Consent: A Case Example

Among diverse vulnerable community-based populations (e.g., the old, the mentally ill), modifications to informed consent forms, including lowering the reading level of forms, have been shown to enhance participant comprehension [35-38]. Additional protocols have also been developed and tested in an effort to assess or improve participant comprehension. For example, extended discussion interventions create opportunities for participants to ask questions and gain knowledge about the research being considered. Extended discussion approaches include semistructured interviews with study staff and an additional meeting with a third-party expert, among others [39-41]. Multimedia interventions have also been deployed in an effort to better understand and address participant comprehension, including interactive computer programs that replace informed consent forms and follow-up informational videos [42, 43]. According to two systematic reviews of interventions to improve comprehension in informed consent for research, multimedia interventions lack evidence of effectiveness while extended discussions and a third, less resource-intensive type of protocol—test/feedback interventions—have been shown to be effective [44, 45]. One such test/feedback intervention, an iterative process called teach-to-goal, is often used to assess and address consent comprehension in vulnerable populations with limited literacy [46-48].

In teach-to-goal, potential participants are read a consent form and asked to describe the research procedures or to answer questions about the study. Misperceptions are corrected and the participant's comprehension is assessed again. Those who cannot demonstrate comprehension after several attempts are excluded from the study. Some have argued that this process represents a higher ethical standard of consent [49], and teach-to-goal is promoted by the National Quality Forum and the Agency for Healthcare Quality and Research when research is conducted with populations at disproportionate risk for comprehension-relevant vulnerabilities, such as low literacy [50, 51]. The teachto-goal process is described here because it can be easily incorporated into existing research protocols in the correctional environment, although researchers may make a different choice from the variety of additional protocols discussed above [52].

Three of the authors (CA, MB, and BW) were co-investigators on an epidemiologic study that used teach-to-goal in the informed consent process with 129 initial enrollees older adults in jail who had an average age of 59 years [53]. The teach-to-goal tool comprised nine questions that assessed comprehension of the study's purpose, eligibility criteria, study procedures, the risks associated with participation, and participants' rights. As a result of this enhanced consenting procedure, the investigators excluded 3.1 percent of potential participants who could not answer all questions correctly, even after three tries, but who were otherwise prepared to sign a consent form written at a fifth-grade level that had been read to them aloud, without a time limit, by staff trained and experienced in research with incarcerated people. The exclusion of four participants did not adversely affect the representativeness of our sample with respect to age, although it might have resulted in the underrepresentation of relevant health conditions such as dementia. For studies in which a substantial proportion of participants cannot demonstrate comprehension of the study risks, researchers should consider alternative study designs, such as the use of legally appointed surrogates to give informed consent, to achieve a representative sample.

Perhaps of more notable consequence, the investigators also found that even among those who successfully demonstrated comprehension, fewer than half answered all nine questions correctly on their first attempt (see table 1). This finding suggests that comprehension tests and retests are critical to solidifying important knowledge of the risks and benefits of research participation for those who will ultimately participate. In such cases, the absence of protocols to ensure comprehension would call into question whether participants are truly experiencing "choiceworthy options" [54], effectively undermining the principle of justice that animates the IOM's "Updated Ethical Framework" for research with incarcerated people [21].

Attempts Needed to Correctly	
Answer all Questions	% (No.)
One	45.74 (59)
Тwo	44.19 (57)
Three	6.98 (9)
Could not complete	3.10 (4)

Table 1. Teach-to-Goal outcomes in a study of 129 older jail inmates

Source: Previously unpublished data.

Note: Average age of participants was 59; 125 participants ultimately took part in the study [53].

Conclusion

Clinical research with participants in correctional settings requires important additional safeguards to ensure that research participation is ethical. A teach-to-goal process to assess participant comprehension of the risks and benefits of research participation can help ensure that research participation among incarcerated persons is both voluntary and truly informed. As prior studies have shown, the addition to the informed consent process of test/feedback interventions like teach-to-goal or of extended discussion interventions has measurably benefited vulnerable populations including the mentally ill, those at risk for HIV, older adults, and patients with cancer [47, 55, 56]. Added measures to ensure that research meets the highest ethical standards is perhaps most appropriate for studies with incarcerated persons, who often represent a cross-section of vulnerable populations and are commonly exposed while incarcerated to experiences, such as prolonged solitary confinement, that increase relevant vulnerabilities. Yet such measures are not required by current HHS federal guidelines for research with incarcerated persons.

Given the many vulnerabilities common among the incarcerated, as well as the consensus view that fair access to research is an ethical imperative, researchers have an ethical responsibility to take additional protective measures as needed when enrolling incarcerated persons in research. Previously unpublished data from an epidemiologic study of older jail inmates reported here suggest that a teach-to-goal approach to assessing comprehension can screen out some willing participants who lack the ability to comprehend the risks and benefits of participation and can identify others without adequate comprehension at the outset for the purpose of reviewing areas of misunderstanding and solidifying that knowledge in advance of participation. Future research could investigate the factors that contribute most to poor comprehension among potential research participants. However, given the disproportionately high prevalence of medical and social vulnerabilities among incarcerated persons in general, additional safeguards to ensure comprehension, such as teach-to-goal and others, should be considered when conducting research in any correctional setting.

References

- 1. Beadle MR, Graham GN. Collective action to end health disparities. *Am J Public Health*. 2011;101(suppl):S16-S18.
- 2. Ahalt C, Binswanger IA, Steinman M, Tulsky J, Williams BA. Confined to ignorance: the absence of prisoner information from nationally representative health data sets. *J Gen Intern Med*. 2012;27(2):160-166.
- 3. Ahalt C, Bolano M, Wang EA, Williams B. The state of research funding from the National Institutes of Health for criminal justice health research. *Ann Intern Med.* 2015;162(5):345-352.
- 4. Wang EA, Wildeman C. Studying health disparities by including incarcerated and formerly incarcerated individuals. *JAMA*. 2011;305(16):1708-1709.
- 5. Rich JD, Wakeman SE, Dickman SL. Medicine and the epidemic of incarceration in the United States. *N Engl J Med.* 2011;364(22):2081-2083.
- 6. Ferguson WJ, Cloud D, Spaulding AC, et al. A call to action: a blueprint for academic health sciences in the era of mass incarceration. *J Health Care Poor Underserved*. 2016;27(2A):5-17.
- 7. Fazel S, Baillargeon J. The health of prisoners. *Lancet*. 2011;377(9769):956-965.
- Freudenberg N. Jails, prisons, and the health of urban populations: a review of the impact of the correctional system on community health. *J Urban Health*. 2001;78(2):214-235.
- 9. Greifinger R, ed. *Public Health Behind Bars: From Prisons to Communities*. New York, NY: Springer-Verlag; 2007.
- Dumont DM, Allen SA, Brockmann BW, Alexander NE, Rich JD. Incarceration, community health, and racial disparities. *J Health Care Poor Underserved*. 2013;24(1):78-88.
- 11. Shuster E. Fifty years later: the significance of the Nuremberg Code. *N Engl J Med.* 1997;337(20):1436-1440.
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Resesarch. The Belmont Report: ethical principles and guidelines for the protection of human subjects of research. http://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/. Published April 18, 1979. Accessed July 24, 2017.
- 13. Hornblum AM. They were cheap and available: prisoners as research subjects in twentieth century America. *BMJ*. 1997;315(7120):1437-1441.
- 14. Gostin LO. Biomedical research involving prisoners: ethical values and legal regulation. *JAMA*. 2007;297(7):737-740.
- Additional protections pertaining to biomedical and behavioral research involving prisoners as subjects, 45 CFR 46 (2009). https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/index.html#subpartc. Accessed August 3, 2017.

- 16. Wener R. Not situated to exercise free power of choice: human subject research in prison settings. *Temple J Sci Technol Environ Law.* 2007;26(2):365-385.
- 17. Charles A, Rid A, Davies H, Draper H. Prisoners as research participants: current practice and attitudes in the UK. *J Med Ethics*. 2016;42(4):246-252.
- 18. Siegal HA, Carlson RG, Falck R, Reece RD, Perlin T. Conducting HIV outreach and research among incarcerated drug abusers: a case study of ethical concerns and dilemmas. *J Subst Abuse Treat*. 1993;10(1):71-75.
- 19. Thomas SB, Quinn SC, Butler J, Fryer CS, Garza MA. Toward a fourth generation of disparities research to achieve health equity. *Annu Rev Public Health*. 2011;32:399-416.
- 20. Park SS, Grayson MH. Clinical research: protection of the "vulnerable"? *J Allergy Clin Immunol.* 2008;121(5):1103-1107.
- 21. Gostin LO, Vanchieri C, Pope A, eds; Institute of Medicine. *Ethical Considerations for Research Involving Prisoners*. Washington, DC: National Academies Press; 2007.
- 22. Christopher PP, Garcia-Sampson LG, Stein M, Johnson J, Rich J, Lidz C. Enrolling in clinical research while incarcerated: what influences participants' decisions? *Hastings Cent Rep.* 2017;47(2):21-29.
- 23. Haigler KO, Harlow C, O'Connor P, Campbell A. *Literacy Behind Prison Walls: Profiles of the Prison Population from the National Adult Literacy Survey*. Washington, DC: National Center for Educational Statistics; 1994.
- 24. Kirsch IS, Jungeblut A, Jenkins L, Kolstad A. *Adult Literacy in America: A First Look at the Findings of the National Adult Literacy Survey*. Washington, DC: US Department of Education Office of Educational Research and Development; 1993.
- 25. Moser DJ, Arndt S, Kanz JE, et al. Coercion and informed consent in research involving prisoners. *Compr Psychiatry*. 2004;45(1):1-9.
- 26. Binswanger IA, Krueger PM, Steiner JF. Prevalence of chronic medical conditions among jail and prison inmates in the USA compared with the general population. *J Epidemiol Community Health.* 2009;63(11):912-919.
- 27. Binswanger IA, Redmond N, Steiner JF, Hicks LS. Health disparities and the criminal justice system: an agenda for further research and action. *J Urban Health*. 2012;89(1):98-107.
- 28. Maschi T, Kwak J, Ko E, Morrissey MB. Forget me not: dementia in prison. *Gerontologist.* 2012;52(4):441-451.
- 29. Williams BA, McGuire J, Lindsay RG, et al. Coming home: health status and homelessness risk of older pre-release prisoners. *J Gen Intern Med.* 2010;25(10):1038-1044.
- 30. Fazel S, Hope T, O'Donnell I, Jacoby R. Hidden psychiatric morbidity in elderly prisoners. *Br J Psychiatry*. 2001;179:535-539.
- 31. Haney C. Mental health issues in long-term solitary and "supermax" confinement. *Crime Deling*. 2003;49(1):124-156.

- 32. Human Rights Watch. Old behind bars: the aging prison population in the United States. https://www.hrw.org/report/2012/01/27/old-behind-bars/agingprison-population-united-states. Published January 27, 2012. Accessed August 3, 2017.
- 33. Carson EA, Anderson E. Prisoners in 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/p15.pdf. Accessed July 25, 2017.
- 34. Moye J, Karel MJ, Azar AR, Gurrera RJ. Capacity to consent to treatment: empirical comparison of three instruments in older adults with and without dementia. *Gerontologist.* 2004;44(2):166-175.
- 35. Sugarman J, McCrory DC, Hubal RC. Getting meaningful informed consent from older adults: a structured literature review of empirical research. *J Am Geriatr Soc.* 1998;46(4):517-524.
- 36. Stanley B, Guido J, Stanley M, Shortell D. The elderly patient and informed consent: empirical findings. *JAMA*. 1984;252(10):1302-1306.
- 37. Rikkert MG, van den Bercken JH, ten Have HA, Hoefnagels WH. Experienced consent in geriatrics research: a new method to optimize the capacity to consent in frail elderly subjects. *J Med Ethics*. 1997;23(5):271-276.
- 38. Moser DJ, Reese RL, Hey CT, et al. Using a brief intervention to improve decisional capacity in schizophrenia research. *Schizophr Bull.* 2006;32(1):116-120.
- 39. Aaronson NK, Visser-Pol E, Leenhouts GH, et al. Telephone-based nursing intervention improves the effectiveness of the informed consent process in cancer clinical trials. *J Clin Oncol.* 1996;14(3):984-996.
- 40. Kucia AM, Horowitz JD. Is informed consent to clinical trials an "upside selective" process in acute coronary syndromes? *Am Heart J.* 2000;140(1):94–97.
- Fitzgerald DW, Marotte C, Verdier RI, Johnson WD Jr, Pape JW. Comprehension during informed consent in a less-developed country. *Lancet*. 2002;360(9342):1301-1302.
- 42. Benson PR, Roth LH, Appelbaum PS, Lidz CW, Winslade WJ. Information disclosure, subject understanding, and informed consent in psychiatric research. *Law Hum Behav.* 1988;12(4):455-475.
- 43. Agre P, Rapkin B. Improving informed consent: a comparison of four consent tools. *IRB*. 2003;25(6):1-7.
- 44. Flory J, Emanuel E. Interventions to improve research participants' understanding in informed consent for research: a systematic review. *JAMA*. 2004;292(13):1593-1601.
- 45. Tamariz L, Palacio A, Robert M, Marcus EN. Improving the informed consent process for research subjects with low literacy: a systematic review. *J Gen Intern Med.* 2013;28(1):121-126.
- 46. Kripalani S, Bengtzen R, Henderson LE, Jacobson TA. Clinical research in lowliteracy populations: using teach-back to assess comprehension of informed consent and privacy information. *IRB*. 2008;30(2):13-19.

- 47. Sudore RL, Landefeld CS, Williams BA, Barnes DE, Lindquist K, Schillinger D. Use of a modified informed consent process among vulnerable patients: a descriptive study. *J Gen Intern Med.* 2006;21(8):867-873.
- 48. Stiles PG, Poythress NG, Hall A, Falkenbach D, Williams R. Improving understanding of research consent disclosures among persons with mental illness. *Psychiatr Serv.* 2001;52(6):780-785.
- 49. Wendler D. Can we ensure that all research subjects give valid consent? *Arch Intern Med.* 2004;164(20):2201-2204.
- 50. Shojania KG, Duncan BW, McDonald KM, et al., eds. *Making Health Care Safer: A Critical Analysis of Patient Safety Practices*. Rockville, MD: Agency for Healthcare Research and Quality; 2001. Evidence Report/Technology Assessment 43. https://archive.ahrq.gov/clinic/ptsafety/pdf/ptsafety.pdf. Accessed July 12, 2017.
- Wu HW, Nishimi RY, Page-Lopez CM, Kizer KW. Improving patient safety through informed consent for patients with limited health literacy. Washington, DC: National Quality Forum; 2005. http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=22 090. Accessed July 12, 2017.
- 52. Schenker Y, Fernandez A, Sudore R, Schillinger D. Interventions to improve patient comprehension in informed consent for medical and surgical procedures: a systematic review. *Med Decis Making*. 2011;31(1):151-173.
- 53. Bolano M, Ahalt C, Ritchie C, Stijacic-Cenzer I, Williams B. Detained and distressed: persistent distressing symptoms in a population of older jail inmates. *J Am Geriatr Soc.* 2016;64(11):2349-2355.
- 54. Powers M. Theories of justice in the context of research. In: Kahn JP, Mastroianni AC, Sugarman J, eds. New York, NY: Oxford University Press; 1998:150.
- 55. Wirshing DA, Wirshing WC, Marder SR, Liberman RP, Mintz J. Informed consent: assessment of comprehension. *Am J Psychiatry*. 1998;155(11):1508-1511.
- Coletti AS, Heagerty P, Sheon AR, et al; HIV Network for Prevention Trials Vaccine Preparedness Study. Randomized, controlled evaluation of a prototype informed consent process for HIV vaccine efficacy trials. *J Acquir Immune Defic Syndr*. 2003;32(2):161-169.

Cyrus Ahalt, MPP, is a researcher and policy analyst in the Department of Medicine at the University of California, San Francisco, where he co-directs the program on criminal justice and health and the US-European Criminal Justice Innovation Program. Mr. Ahalt conducts policy-oriented research on the individual and public health consequences of the US criminal justice system.

Rebecca Sudore, MD, is a professor of medicine at the University of California, San Francisco, where she serves as a geriatrician, palliative medicine physician, and clinician investigator and directs the Innovation Center for Action-oriented REsearch in Aging & Palliative Care. Dr. Sudore conducts research to improve advance care planning and medical decision making for diverse, vulnerable older adults.

Marielle Bolano is a fourth-year medical student at the University of California, Davis School of Medicine. She has worked at the University of California, San Francisco Division of Geriatrics as a research assistant to study health needs of older adults in the criminal justice system and as a National Institute on Aging Medical Student Training in Aging Research Fellow. She has a strong interest in geriatrics and is particularly interested in improving access to care for vulnerable older adults, including those in the criminal justice system.

Lia Metzger is an assistant clinical research coordinator for the Division of Geriatrics at the University of California, San Francisco, where she conducts research to identify and assess the health needs of older adults in the criminal justice system. She has a strong interest in geriatrics and palliative medicine and is especially interested in improving health outcomes for vulnerable older adults.

Anna M. Darby, MD, MPH, is a second-year emergency medicine resident at Los Angeles County + USC Medical Center, where she works in the dedicated Jail Emergency Department that serves Los Angeles County. She has worked as a litigation assistant at the Prison Law Office advocating for prisoners' health care needs and as a National Institute on Aging Medical Student Training in Aging Research Fellow at the University of California, San Francisco, doing research on older adults in jail.

Brie Williams, MD, MS, is a professor of medicine in the Division of Geriatrics at the University of California, San Francisco, where she directs the Criminal Justice & Health Program and the Criminal Justice Aging Project. In her work on bringing the science of geriatrics and palliative care to criminal justice reform, she collaborates with colleagues from diverse disciplines, including criminal justice, public safety, and the law, to conduct impact-oriented research and education.

Related in the AMA Journal of Ethics

The AMA Code of Medical Ethics' Opinions Related to Health Care for Incarcerated People, September 2017 The Belmont Report's Misleading Conception of Autonomy, August 2009 Informed Consent: What Must a Physician Disclose to a Patient?, July 2012 The Patient's Piece of the Informed Consent Pie, August 2008 Why Prisoners Deserve Health Care, February 2008

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 873-876

FROM THE EDITOR

Ethics at the Intersection of the Criminal Justice and Health Care Systems

Entering a jail for the first time can be an intimidating experience. The building itself is imposing, the metal detectors beep and ring, and heavy doors slide closed behind you with a bang. Yet the exam rooms look quite the same as any other, the dental chair just as mundane. As a dentist, I find my work there profoundly moving: patients routinely tell me that seeing a dentist is "the only good thing that's happened to me here" or "at least I finally got to see a doctor." Yet as much as I cherish the ability to build relationships with patients in such a potentially dehumanizing environment, the subtext of my patients' words is both striking and tragic. How can we do better for my patients and the 2.1 million other people experiencing incarceration in the United States each day [1]?

People who are incarcerated are the only group in the United States with a constitutionally protected right to health care [2]. Since patients affected by incarceration are also less likely to have access to the health care system prior to their incarceration, medical care in the criminal justice system represents an opportunity to dramatically improve patients' health and connect them with necessary services [3, 4]. Yet patients with a history of incarceration continue to have higher rates of medical, psychiatric, and dental disease; higher mortality; and a shorter life expectancy [5-8].

These facts are even more troubling given the high incarceration rates of people from groups already experiencing inequality in health care access and outcomes, including people of color, people with mental illness, and people with low incomes [8, 9]. The health harms caused by incarceration also impact the communities and family members of incarcerated people, perpetuating health disparities in communities across the nation [9].

The United States incarcerates a higher proportion of its population than any other nation [10], a practice that disproportionately punishes men of color [11]. Attorney General Jeff Sessions recently issued guidance from the Justice Department indicating a turn towards more draconian sentencing policies [12], suggesting that, under the new presidential administration, the small improvement in the incarceration rate that has occurred in the last few years [1] might be lost. Now more than ever, clinicians must be aware of the ways the criminal justice system and the health care system interweave in the lives of our patients and in the structure of our society.

This issue of the *AMA Journal of Ethics* explores the complex ways in which incarceration can influence patients' health and health care both during and after their time in prison or jail, as well as the challenges clinicians face in navigating their responsibilities to these vulnerable patients both in the correctional setting and in the community.

Clinicians in correctional institutions often face institutional barriers that limit their ability to provide care. Sarah E. Wakeman discusses the lack of access to <u>opioid agonist therapy</u> in jails and prisons, which can contribute to suffering during incarceration and high rates of overdose deaths in people recently released from incarceration [8]. Responding to a case about an incarcerated patient who refuses a necessary medication and requests a medication that might be restricted in the correctional setting, Tom Peteet and Matt Tobey discuss how clinicians can build <u>patients' agency</u> within the clinician-patient relationship. Correctional clinicians can also diagnose medical conditions that could affect patients' criminal proceedings; David Beckmann considers a clinician's responsibilities when considering the <u>sharing of medical information</u> with a legal team in the case of a patient diagnosed with mild cognitive impairment. Finally, Cyrus Ahalt, Rebecca Sudore, Marielle Bolano, Lia Metzger, Anna M. Darby, and Brie Williams discuss the importance of researchers assessing participants' comprehension of <u>informed consent</u> in conducting studies with incarcerated populations.

Medical students and residents can care for incarcerated patients even if they do not step foot in a correctional institution when ill patients are transferred to hospitals for additional care [9]. Sara Scarlet and Elizabeth Dreesen discuss the practice of keeping <u>patients in shackles</u> or under guard during surgery and the distress both staff and patients experience in these situations, and Satyajeet Roy contributes a <u>drawing of a shackled patient</u>. And Oliver Schirokauer, Thomas A. Tallman, Leah Jeunnette, Despina Mavrakis, and Monica L. Gerrek describe an <u>educational initiative</u> in which clinical ethics students observe and reflect on health care in an urban jail.

The population of corrections-involved people who are supervised in the community (such as through probation) is more than double the incarcerated population [1]. Amy B. Cadwallader explores the logistical and ethical challenges of mandated <u>urine drug testing</u> in this population and how repeated incarceration can be avoided. And Andreas Mitchell and Brie Williams argue for extending and improving <u>compassionate release policies</u> that permit incarcerated patients with serious or debilitating illnesses to be granted early release or parole.

Given the impact of justice involvement on health outcomes and life expectancy, clinicians outside of the correctional system must also be prepared to approach patients' history of incarceration as an important health risk factor [8]. Lisa Puglisi, Joseph P. Calderon, and Emily A. Wang describe the impact of incarceration on the health of patients returning to their community and strategies that clinicians and the medical

system can implement to <u>empower patients</u> and their communities to improve health. In her commentary on a case about a patient with a history of incarceration who is uncomfortable discussing it with his physician, Kimberly Sue uses the framework of "<u>structural competence</u>" to describe how a physician in a primary care office can approach a history of incarceration while respecting a patient's desire for privacy and work to prevent stigmatization of formerly incarcerated patients within and beyond the clinic.

Education can be one of the most potent tools for improving the ability of medical professionals to provide care for people who have experienced incarceration. Clinicians who are well trained in the health care needs of incarcerated people might be more likely to work in correctional settings and to provide care in their communities that is informed by patients' correctional experiences [13]. Jonathan Giftos, Andreas Mitchell, and Ross MacDonald discuss efforts at the Rikers Island complex in New York City to train health care professionals in the impacts of corrections involvement on health in order to inform clinical practice and advocacy. In the podcast, the interaction between health care and incarceration is explored from multiple perspectives. In particular, Troy Williams discusses his own health care experience at San Quentin State Prison, Dan McGuire describes volunteering at the Suffolk County Jail while attending physician assistant school, and Lisa Puglisi discusses her role as a physician caring for patients with a history of incarceration at a dedicated transitional clinic.

Above all, I hope the multifaceted exploration of correctional health care in this issue of the *AMA Journal of Ethics* highlights the fundamental humanity of patients who experience incarceration. As health care professionals, we have unique opportunities to provide compassionate, affirming care for patients in the justice system while advocating for criminal justice reforms that can improve the health and well-being of our patients, their families, and our communities.

References

- Kaeble D, Glaze L. Correctional populations in the United States, 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/cpus15.pdf. Accessed June 6, 2017.
- Estelle v Gamble, 429 US 97 (1976). https://supreme.justia.com/cases/federal/us/429/97/case.html. Accessed June 27, 2017.
- Conklin TJ, Lincoln T, Tuthill RW. Self-reported health and prior health behaviors of newly admitted correctional inmates. *Am J Public Health*. 2000;90(12):1939-1941.
- 4. Ramaswamy M, Diaz F, Pankey T, Hunt SL, Park A, Kelly PJ. Correlates of preincarceration health care use among women and men in jail. *J Correct Health*

Care. 2015;21(3):286-297.

- Brinkley-Rubinstein L. Incarceration as a catalyst for worsening health. *Health Justice*. 2013;1:3. https://healthandjusticejournal.springeropen.com/articles/10.1186/2194-7899-1-3. Accessed July 28, 2017.
- 6. Binswanger IA, Krueger PM, Steiner JF. Prevalence of chronic medical conditions among jail and prison inmates in the USA compared with the general population. *J Epidemiol Community Health.* 2009;63(11):912-919.
- 7. Kulkarni SP, Baldwin S, Lightstone AS, Gelberg L, Diamant AL. Is incarceration a contributor to health disparities? Access to care of formerly incarcerated adults. *J Community Health.* 2010;35(3):268-274.
- 8. Patterson EJ. The dose-response of time served in prison on mortality: New York State, 1989-2003. *Am J Public Health*. 2013;103(3):523-528.
- 9. Wildeman C, Wang EA. Mass incarceration, public health, and widening inequality in the USA. *Lancet.* 2017;389(10077):1464-1474.
- Walmsley R. World prison population list (tenth edition). London, UK: International Centre for Prison Studies; 2013. http://www.apcca.org/uploads/10th_Edition_2013.pdf. Accessed June 27, 2017.
- 11. Carson EA, Anderson E. Prisoners in 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/p15.pdf. Accessed June 27, 2017.
- US Attorney General. Department charging and sentencing policy. Washington, DC: Office of the Attorney General; May 10, 2017. https://www.justice.gov/opa/press-release/file/965896/download. Accessed June 27, 2017.
- MacDonald R, Kaba F, Rosner Z, et al. The Rikers Island hot spotters: defining the needs of the most frequently incarcerated. *Am J Public Health*. 2015;105(11):2262-2268.

Lisa Simon, DMD

MS-2 Harvard Medical School Boston, Massachusetts

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 877-884

ETHICS CASE

What Are Physicians' Responsibilities to Patients Whose Health Conditions Can Influence Their Legal Proceedings?

Commentary by David Beckmann, MD, MPH

Abstract

Correctional populations are disproportionately affected by conditions that affect cognition, such as psychiatric illness and head trauma. Honoring bioethical principles in the care of such patients can be particularly difficult in the correctional setting. However, the approach should not change markedly because a patient is incarcerated. That is, the same standards of respecting patient autonomy and confidentiality should be maintained, and the fact that correctional populations are already marginalized makes it all the more important for clinicians to honor these principles. Physicians should act in the best interest of their patients; in jails this might include disclosing information to and consulting with a patient's legal defense. However, this step should only be taken with a patient's consent or, in cases in which the patient does not have decision-making capacity, when it seems consistent with a patient's wishes.

Case

Dr. Obaje is a primary care physician who works at a county jail, where most of her patients are undergoing court processes. This afternoon, Jonathan, a 52-year-old man with a known history of poorly controlled type II diabetes and a 20-year history of opioid use, is brought to the jail's medical ward for a routine chronic care visit. This is the first time that Dr. Obaje has met Jonathan since his incarceration four weeks ago. Jonathan's blood sugars have ranged between 80 and 150 since his incarceration, and he does not currently seem to be experiencing any withdrawal symptoms. However, during the appointment, Jonathan struggles to provide a health history, shares tangential information, and repeats some information several times. After Dr. Obaje briefly leaves the room to answer a nurse's question, Jonathan does not appear to remember having met her when she returns.

Based on this memory lapse and Jonathan's history, Dr. Obaje worries that Jonathan could be exhibiting cognitive impairment. Jonathan reports that he has been transiently homeless during the past decade and that during several periods of homelessness he experienced violence, including blows to the head. She asks Jonathan about his mood,

and he confirms that he "often feels down" and states that "sometimes I get so angry, and I'm not sure why." On the Mini-Mental State Examination, Jonathan receives a score of 21 out of 30, and Dr. Obaje diagnoses him with mild cognitive impairment (MCI) [1].

Dr. Obaje refers Jonathan for mental health care not only for treatment but also to rule out reversible causes of cognitive decline. She also asks her mental health colleagues to evaluate how Jonathan's cognitive impairment influences his decision-making capacity and judgment. Dr. Obaje wonders whether information about Jonathan's cognitive symptoms could be important for his legal defense.

Commentary

Medical and mental health clinicians working in the correctional setting are likely to encounter scenarios similar to Dr. Obaje's encounter with Jonathan. Conditions that might be associated with cognitive impairment, such as aging, are common in correctional settings. Between 2-3 percent of people incarcerated in jails are over the age of 55, a proportion that is expected to increase as the population ages [2, 3]. More recent data shows that prison populations are aging, with about 10.5 percent of incarcerated people over the age of 55 [4]. While risk of cognitive impairment is highest for persons over age 65 [5], inmate populations might have more risk factors for dementia and other cognitive impairments, and their prevalence is likely higher in inmate populations than in the general population [3]. In 2002, 19 percent of people incarcerated in jails met criteria for substance use disorder; 15 percent met criteria for other mental health problems; and about half met criteria for both [6]. Any mental illness might have effects on cognition, particularly serious mental illness (SMI) that causes severe functional impairment—such as schizophrenia, bipolar disorder, or major depressive disorder [7]—which is estimated to affect up to 19 percent of men and 42 percent of women incarcerated in jails [8]. The prevalence of traumatic brain injury (TBI) in correctional settings is also likely higher than that of the general population. One study examining patients in prisons with a history of TBI found a prevalence of 35.7 percent [9]. Given that TBI is a risk factor for impulsive behavior [10], it is possible that the prevalence in jails is even higher. Thus, Dr. Obaje's meeting a relatively young patient with cognitive difficulties is not unusual, but it remains a practically and ethically complex situation.

What is key to Dr. Obaje's relationship with Jonathan is that she is his treating clinician, and therefore her primary responsibility is to her patient and his best interests. The same is true of the psychiatrist to whom she refers Jonathan for further diagnostic and treatment management. The concept of patient-centered care—the idea that clinicians should help patients be active, informed participants in their own medical management—is if anything more important in settings where patients are already marginalized. In the correctional setting, where the rights and freedoms of patients are

already severely restricted, fostering patient agency so that patients can make informed decisions (both medical and legal) about their care is essential.

This commentary will consider a number of ethical issues in this case. First, privacy and informed consent will be discussed. Then the application of standard bioethical principles in surrogate decision making and standards of surrogate decision making will be considered in relation to the case. Finally, how clinicians might interact with other third parties, such as legal counsel, forensic evaluators, and correctional staff, will be considered.

Privacy and Informed Consent

Although there are some differences in the care of patients in the correctional setting (such as the duty to inform custody staff about contraband), laws addressing health care communication and privacy, such as the Health Insurance Portability and Accountability Act (HIPAA) of 1996 apply in the same way [11]. In general, without a patient's consent, clinicians may only share medical information to a third party for treatment, payment, or health care operations; disclosure to legal counsel is not included in these criteria. The easiest thing for Dr. Obaje to do is to discuss with Jonathan the possibility of her informing his counsel of her concerns.

However, if Jonathan does not consent—or even if he does—things are a bit more complex. This is because the nature of his illness might impair his ability to give informed consent (either to permit or to forbid the doctors' speaking to his attorneys). What does not substantially change the importance of consent—or, in Jonathan's case, the assessment of his ability to do so—is the fact that Jonathan is incarcerated. There is no legal reason for incarceration to change the process of consent as it relates to medical care.

Assessment of Decision-Making Capacity and Surrogate Decision Making

Regardless of Jonathan's decision, any involved physician should determine if he has decision-making capacity. Capacity is a clinical term applied to a particular decision; a patient might demonstrate capacity by showing that he is able to make a clear and consistent choice, that he understands the situation and relevant information, and that he is able to rationally manipulate relevant information [12]. Determination of capacity is a clinical decision that may be made in any treatment setting and is distinct from determination of competence, which is made by a judge and relates to a person's longitudinal global functioning, although the exact legal definition is variable by jurisdiction [12].

If Dr. Obaje feels that Jonathan does not have decision-making capacity to consent to her communicating with his legal team about his MCI, she must apply the bioethical principles of beneficence and respect for autonomy in deciding what to do. A frequently

invoked standard for decision making in such cases is that of substituted judgement: the clinicians and family members—or the clinicians alone, in incarcerated settings in some states [13]—make a decision based not necessarily on what they feel is best for the patient, but rather on what they believe the patient would have wanted if able to make decisions. In the incarcerated setting, the patient's preference can be difficult to know, but obtaining collateral information from close contacts such as family members might be of use. In Jonathan's case, if close contacts are not available, Dr. Obaje might be in the position of having to decide (based on her own interactions with the patient) what decision he would have made, and acting accordingly. Some patients, for example, might be more averse to the idea of having a mental illness, or of being in a treatment facility that addresses mental or cognitive difficulties, than to a harsher criminal sentence; it is well documented that the stigma of psychiatric illness is magnified in the correctional setting [14] due in part to some correctional officers, who often receive little training in mental illness, treating incarcerated patients with psychiatric illness with disrespect or disregard for their vulnerabilities. If Dr. Obaje has no information about Jonathan's preferences and is unable to predict what decision Jonathan would have made, she cannot apply the standard of substituted judgment and instead should apply the best interest standard. For example, she might determine that she should inform his counsel of her concerns, given the benefits of this course of action to Jonathan (i.e., potentially getting Jonathan into a treatment environment rather than a correctional one).

In making this determination, Dr. Obaje has a potential source of assistance. Dr. Obaje was able to gain consultation from a jail psychiatrist, who might be able to provide additional perspectives as to Jonathan's decision-making capacity. Clinic leadership, such as a mental health director or a medical director in a correctional clinic can also be valuable resources for consultation. Getting information from multiple sources and perspectives might make Dr. Obaje feel more confident in her diagnosis or her course of action. It is worth noting, however, that diagnostic certainty is by no means a prerequisite to sharing potentially relevant information with a patient's legal counsel.

Sharing Protected Health Information

The benefit of Dr. Obaje sharing her concerns with Jonathan's counsel is so that his defense team can argue that his MCI should be taken into account during his trial. One way that a lawyer (or the judge) might introduce this information is through the use of a <u>forensic evaluator</u>. The explicit role of a forensic evaluator is to opine on how the patient's illness or limitations might affect his charges or mitigate sentencing. The roles of treating clinician and forensic evaluator are intentionally kept separate whenever possible to avoid conflicts of interest [15]. Jonathan's attorneys, however, were they made aware of his MCI, might respond by obtaining an independent forensic evaluation to strengthen the legal case that his MCI should be taken into account. It will probably ultimately be the role of someone appointed through his lawyers or the judge—namely,

a forensic evaluator—to determine the appropriateness of any diagnosis and how it should impact legal proceedings and decisions.

While there are no laws requiring clinicians to disclose protected health information to a patient's counsel, the American Bar Association requires that the attorney act as a "zealous advocate" for his or her client [16]. As with any sharing of medical information, Dr. Obaje should reveal the minimum amount necessary to achieve the purposes of the communication. Details that would not affect an attorney's decision to get a forensic evaluator, or which would not be relevant to such an evaluation, should not be shared. Although there is no obligation for her to speak to the defense counsel in this situation, she could disclose information that might help Jonathan if she has his permission; or, in the event that Jonathan lacks decisional capacity, Dr. Obaje should obtain consent from a surrogate decision maker or make a decision based on substituted judgment or his best interests. On the other hand, his council is obligated to consider if involving a forensic evaluator would be in Jonathan's best legal interest.

Finally, there is an additional consideration in decisions about sharing information about Jonathan's mental state. Separately from sharing this information with his defense team, should Dr. Obaje's concerns be shared with the correctional staff? There is reason to believe that her concerns about Jonathan's mental status warrant his being treated differently from other inmates. This is particularly true if any jail or medical staff members believe that Jonathan's condition puts him at increased risk of victimization from other inmates. Mental illness and cognitive impairment are risk factors for being victims of violence from both other inmates and correctional staff [5, 17]. In many correctional settings, this risk of violence can be mitigated by putting the inmate in a different setting (either in the same facility or in a different facility). If this is not possible, Dr. Obaje might explain to correctional staff that Jonathan's condition warrants his receiving extra protection. There is little legal guidance on how she should balance her concerns for her patient's privacy and well-being in her discussions with correctional staff, although some professional guidelines have been proposed [18]. However, the jail itself is legally obligated to afford Jonathan additional protections if he is at increased risk of victimization. The Eighth Amendment of the US Constitution protects incarcerated persons from "cruel and unusual punishments" [19], and in the 1994 case, Farmer v Brennan, the US Supreme Court ruled that prison officials' "deliberate indifference" to the risk of harm violated the constitutional rights of incarcerated persons [20, 21]. (The Due Process Clause of the Fourteenth Amendment has been interpreted to extend these rights to pretrial detainees [22].) In other words, if Jonathan is at increased risk of victimization—even if only from other incarcerated persons—failing to protect him from this increased risk of harm is a violation of his constitutional rights.

Conclusion

This is a complex but realistic scenario similar to situations that physicians working in the correctional setting are likely to encounter. From a legal perspective, a clinician's ethical obligations to a patient with a mental illness or cognitive impairment do not change markedly because he or she is in correctional custody. However, the implications of incarceration should still be considered. Some clinicians might have a tendency to partition the lines between the legal and medical systems as much as possible to avoid overstepping their bounds; this compartmentalization might make physicians in the correctional setting less likely to take actions that might be considered effective advocacy for their patients. However, the alternative must also be considered: patients in correctional custody are stripped of so many of the rights and comforts afforded to our patients in the civilian world that going the extra mile to advocate for an incarcerated person's care might have significant benefits for his or her health care, legal situation, and overall well-being.

In this scenario, Dr. Obaje should explain to Jonathan her belief that he has MCI and that this knowledge could help his legal counsel in defending him. She should ask his permission to share this information; whether or not he provides permission, she should also assess his decision-making capacity to do so. If he has capacity to give consent, his preference should be honored. If he does not, she should try to make a decision based on substituted judgment and tell his attorney that this is what he would have wanted were he not impaired. If he lacks capacity and she is unable to make a substituted judgment due to lack of available information, she should do what is in Jonathan's best interest—which, in this case, means informing his defense counsel.

References

1. Folstein MF, Folstein SE. Rehabilitation measures database: Mini-Mental State Examination.

http://www.rehabmeasures.org/Lists/RehabMeasures/PrintView.aspx?ID=912. Published January 21, 2013. Accessed July 2, 2017.

- James DJ. Profile of jail inmates, 2002. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; July 2004. https://www.bjs.gov/content/pub/pdf/pji02.pdf. Revised October 12, 2004. Accessed June 7, 2017.
- 3. Kuhlmann R, Ruddell R. Elderly jail inmates: problems, prevalence and public health. *Calif J Health Promot*. 2005;3(2):49-60.
- Federal Bureau of Prisons. Inmate age. https://www.bop.gov/about/statistics/statistics_inmate_age.jsp. Updated June 24, 2017. Accessed August 1, 2017.
- 5. Hugo J, Ganguli M. Dementia and cognitive impairment: epidemiology, diagnosis, and treatment. *Clin Geriatr Med.* 2014;30(3):421-442.

- James DJ, Glaze LE. Mental health problems of prison and jail inmates. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; September 2006. https://www.bjs.gov/content/pub/pdf/mhppji.pdf. Revised December 14, 2006. Accessed June 7, 2017.
- 7. Substance Abuse and Mental Health Services Administration (SAMHSA). Mental and substance use disorders. http://www.samhsa.gov/disorders. Updated March 8, 2016. Accessed July 2, 2017.
- 8. Steadman HJ, Osher FC, Robbins PC, Case B, Samuels S. Prevalence of serious mental illness among jail inmates. *Psychiatr Serv.* 2009;60(6);761-765.
- 9. Templer DI, Kasiraj J, Trent NH, et al. Exploration of head injury without medical attention. *Percept Mot Skills*. 1992;75(1):195-202.
- 10. Rochat L, Ammann J, Mayer E, Annoni JM, Van der Linden M. Executive disorders and perceived socio-emotional changes after traumatic brain injury. *J Neuropsychol.* 2009;3(pt 2):213-227.
- 11. Goldstein MM. Health information privacy and health information technology in the US correctional setting. *Am J Public Health*. 2014;104(5):803-809.
- 12. Appelbaum PS, Grisso T. Assessing patients' capacities to consent to treatment. *N Engl J Med.* 1988;319(25):1635-1638.
- Smith MS, Taylor LA, Wake A. Healthcare decision-making for mentally incapacitated incarcerated individuals. *Elder Law J.* 2014;22(1):175-207. http://publish.illinois.edu/elderlawjournal/files/2015/02/Smith.pdf. Accessed July 27, 2017.
- 14. Miller RD, Metzner JL. Psychiatric stigma in correctional facilities. *Bull Am Acad Psychiatry Law.* 1994;22(4):621-628.
- 15. Weinstein HC; American Psychiatric Association. *Psychiatric Services in Jails and Prisons: A Task Force Report of the American Psychiatric Association.* 2nd ed. Washington, DC: American Psychiatric Association Publishing; 2000.
- 16. American Bar Association. Model rules of professional conduct: preamble and scope.https://www.americanbar.org/groups/professional_responsibility/publica tions/model_rules_of_professional_conduct/model_rules_of_professional_co nduct_preamble_scope.html. Published 2016. Accessed June 7, 2017.
- 17. Blitz CL, Wolff N, Shi J. Physical victimization in prison: the role of mental illness. *Int J Law Psychiatry*. 2008;31(5):385-393.
- 18. Candilis PJ. The revolution in forensic ethics: narrative, compassion, and a robust professionalism. *Psychiatr Clin North Am*. 2009;32(2):423-435.
- 19. Eighth Amendment. https://www.gpo.gov/fdsys/pkg/GPO-CONAN-2002/pdf/GPO-CONAN-2002-9-9.pdf. Accessed August 1, 2017.
- 20. *Farmer v Brennan*, 511 US 825 (1994). https://www.law.cornell.edu/supct/html/92-7247.ZS.html. Accessed August 1, 2017.
- 21. Cozad SL. Cruel but not so unusual: *Farmer v Brennan* and the devolving standards of decency. *Pepperdine Law Rev.* 2012;23(1):175-204.

22. Haden JR. Constitutional law: *Bell v Wolfish*—a balk at constitutional protection for pretrial detainees. *Univ Miss Kans City Law Rev.* 1979;48:466.

David Beckmann, MD, MPH, is a fellow in child and adolescent psychiatry at Massachusetts General Hospital and McLean Hospital and a clinical fellow at Harvard Medical School in Boston. He is interested in correctional psychiatry and helped to create a new residency rotation at a Boston jail, where he works as the mental health faculty advisor and preceptor for a student-faculty collaborative clinic.

Related in the AMA Journal of Ethics

The AMA Code of Medical Ethics' Opinions on Patient Decision-Making Capacity and Competence and Surrogate Decision Making, July 2017 The AMA Code of Medical Ethics' Opinions Related to Health Care for Incarcerated People, September 2017 Correctional Mental Health, February 2008 Influence of Psychiatric Symptoms on Decisional Capacity in Treatment Refusal, May 2017 Juvenile Forensic Psychiatric Evaluations, October 2013 "Teach-to-Goal" to Better Assess Informed Consent Comprehension among Incarcerated

Clinical Research Participants, September 2017

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 885-893

ETHICS CASE

How to Talk with Patients about Incarceration and Health

Commentary by Kimberly Sue, MD, PhD

Abstract

The United States has the highest incarceration rate of any nation in the world—more than 700 people per 100,000. For this reason alone, clinicians practicing in the US should be aware of the numerous ways in which incarceration adversely affects the health of individuals, their families, and communities. While we clinicians are taught how to discuss ways that culture, religion, or sexuality can affect health outcomes, we are not instructed on how to talk about incarceration history with patients when it might be affecting their health, as highlighted in the case scenario. Here I present a "structural vulnerability" screen, a theoretical approach that clinics or individuals can take to better understand how structures of power (i.e., mass incarceration) directly and indirectly affect our patients. I also offer practical tips on how to talk to patients about incarceration history and why it matters for good health.

Case

Dr. Wen works at a busy primary care practice in an urban community health center. Today he sees that Luke, a 43-year-old man with a diagnosis of hypertension and major depression, is scheduled for a visit. Luke has missed three visits in the last four months without warning and has not refilled his lisinopril or fluoxetine prescriptions during this time. Dr. Wen mentions this to his medical assistant, Jason, and expresses concern about Luke's blood pressure. Jason happens to live down the street from Luke and tells Dr. Wen, "I heard Luke's been locked up for the past couple of months because of a robbery."

When Luke finally arrives for an appointment, Jason reports his blood pressure is 141/87. When asked by Dr. Wen about his medication supply, Luke states he has been taking lisinopril and fluoxetine as directed until last week, when "my prescription ran out." Aware of the many health risks associated with incarceration—including loss of health insurance, loss of social supports, difficulty obtaining employment upon reentry, and higher rates of chronic disease—Dr. Wen asks Luke if he has recently been incarcerated or detained. Luke looks surprised and then becomes irate, yelling, "That's none of your business! Why are you asking about things that have nothing to do with you?"

Commentary

From an ethical point of view, it is clear that the physician approached this clinical encounter based on knowledge obtained from his medical assistant. In my experience, the majority of clinicians would likely agree that obtaining information about any patient's social situation from an ancillary health care practitioner, an acquaintance, or another patient in the clinic who might know the patient personally or informally from the neighborhood is a violation of the patient's right to privacy unless the patient has signed a release of information from one institution to explicitly communicate health information to another. It is important for the physician to obtain information about incarceration history, ideally from patients themselves.

An interesting question is if Dr. Wen would have suspected that Luke had been incarcerated if his medical assistant Jason did not know of Luke as a neighborhood acquaintance. Like many busy community physicians, he might have just thought Luke was a "no show" and had a staff member call the patient to reschedule. If Dr. Wen had perhaps a suspicion that Luke could have been recently incarcerated, which would explain his missing his appointment, does that feeling merely arise from his stigmatization or stereotyping of patients with a history of incarceration rationalized as knowledge of incarceration risks associated with, for example, neighborhood of origin? What if he had obtained the information from a nurse, physician, or social worker at the jail conveying some health information with the patient's consent prior to his release? This is both a matter of means and a matter of ends: both are important.

It is truly commendable that Dr. Wen does feel empowered to discuss incarceration status with his patient. Many clinicians might feel uncomfortable addressing this experience either out of concern that it might offend the patient given the pervasive social stigma of incarceration or out of general lack of experience with how to frame such a discussion, even if he or she does have a sense of its importance.

Medical anthropologists have theorized two closely related concepts of "structural competence" and "structural vulnerability" that can help clinicians to think through issues of inequalities in health more broadly [1, 2]. The "structural competency" approach argues that we as clinicians need to understand how the political-economic structures of inequality—class, skin color, country of origin, sexuality, gender, legal status, and overall position within the larger social hierarchy—make patients structurally vulnerable to health inequalities, as these forces directly affect and determine a person's life chances and chances of well-being and health. Applying this framework to incarceration in the United States requires understanding that correctional institutions have a long history of reinforcing racial, gender-based, and socioeconomic oppression that disadvantages individuals and their communities [3-5]. For example, there is an important connection between the US criminal justice system and the

physical and mental health of large populations of patients who are affected by these systems [5].

In this essay, I will discuss why incarceration matters for health care practitioners and present data on the relevance of incarceration to health outcomes. I will also introduce a theoretical framework and a screening tool based on it to help clinicians understand how incarceration might directly and indirectly affect their patients' health. Finally, I will present practical strategies for talking to patients about incarceration.

Is Incarceration Status Clinically Relevant?

Incarceration can have many effects on a patient's physical and mental health both during and after incarceration. In many ways, it can be a traumatizing experience that can include patients' physical, emotional, or verbal abuse at the hands of other inmates, staff, or even themselves. Incarceration is also isolating, and many might find it difficult to be apart from their children, significant others, extended family, or friends. In addition, parents who are incarcerated might feel like they are a financial or emotional burden on those in the community who might be taking care of their children.

Given overcrowding in many correctional facilities [6], incarcerated patients might also be at high risk for contracting infectious diseases such as TB, HIV, or other sexually transmitted infections [6-9]. It is widely known that drug use is happening in prisons and jails [10-11] and that patients are at high risk of overdose and other addiction-related harms upon release from prison or jail [12]. Patients also are exposed to high-salt diets and cannot even access a heart-healthy diet should they desire to do so; the high sodium and high fat content of food available in these settings exacerbate conditions such as hypertension, congestive heart failure, and end-stage liver disease [13, 14]. Moreover, patients with <u>mental illness</u> are often untreated and at increased risk of self-harm [15], and prison medical staff members are not uncommonly told to "look the other way" or face subtle punishments themselves [16]. Patients also suffer from health risks related to transitioning back to their communities, including disruptions in medications use and an increased risk of a cardiovascular disease event, drug-related death or overdose, or being a victim of trauma or violence within two weeks of release from prison [17, 18].

In some ways, the health of incarcerated people and people leaving prison is determined by the care they receive at the hands of the municipality or state. One study published over three decades ago found that health care practitioners in prisons were more likely to be older and have completed their medical education and training in other countries and less likely to be board certified or specialized physicians [19]. Increasingly, the health care of prisons and jails is contracted out to for-profit prison health corporations. In 2011, Prison Health Services and three other defendants were sued for inadequate triage and care and for negligence in the 2009 death of an inmate from an untreated infection at the Suffolk County House of Correction in a local Boston jail [20]. Often, medications that are available in the community are not available in correctional formularies. Human Rights Watch published a report on mental health in prisons citing several lawsuits in which severely mentally ill patients were taken off their long-term medications (e.g., olanzapine, clozapine) because they were "off-formulary," which led to patients' poor health outcomes [21]. It is not an infrequent occurrence for patients' medication lists to be discontinued or pared down to what is on formulary in that particular institution, leading to worsening of patients' symptoms or clinical instability [21].

Knowing all of these possible ways that incarceration can affect health allows clinicians to focus and tailor the visit to meet patient's needs. If mental health or drug use is an urgent priority, the clinician can triage appropriately and get the patient immediate access to medications or therapy. In Luke's case, Dr. Wen could prioritize getting him the medication refills he needs and work with him and social services to figure out what he needs most upon getting out of jail, such as getting new identification documents, housing, clothes, or insurance.

Why Take an Incarceration History?

It is important for us clinicians to recognize that incarceration history can be a common feature of urban and rural patients' social experience in the United States. It is so common that Sesame Street recently introduced a character named Alex whose father is incarcerated because 1 in 28 children have an incarcerated parent [22]. Many more people are held in county jail or detention centers, where they await trial, than in prisons, which are correctional institutions for individuals who have been sentenced and convicted of a crime. According to the US Bureau of Justice Statistics, over 1.5 million people were incarcerated in the state or federal prison system in the United States in 2015 [23], and over 10.9 million people were detained in a local jail facility in 2015 [24].

It is critical in applying the structural competence approach to situate the patientphysician relationship in the neighborhood in which the patient lives. Is the neighborhood in which Dr. Wen practices characterized by high rates of incarceration among residents? If so, it is important for Dr. Wen to understand the social burdens of the community in which he practices more globally, including but not limited to higher levels of unemployment, physical violence or trauma, incarceration, racism or xenophobia, limited access to social resources, and low health literacy. These forces converge and can negatively impact health outcomes, as outlined above.

Communication Strategies for Taking a Social History

One way that clinics could address this issue is by implementing a structural vulnerability "checklist" administered by a social worker, medical assistant, registered nurse, nurse practitioner, physician assistant, or physician to screen for a variety of domains of inequality including former incarceration status, access to food, housing insecurity, or

residency status, among other metrics. As my colleagues and I have recently outlined in *Academic Medicine* [25], using such a checklist could engage all patients in a specific health care setting in the screening process in order to decrease their perception of being singled out or stereotyped. This checklist allows clinicians to better identify some patients with significant social and structural needs that we know affect health outcomes—such as homelessness or ongoing experiences of trauma—when patients might not otherwise bring up these needs. Having completed the checklist, the health care practitioner can then address domain areas that are relevant to specific patients, such as referral to social workers to help with housing instability or referral to social service organizations that help provide clothes or services to people leaving prison or jail.

During the visit itself, the clinician could also ask more general, open-ended questions including, "Which barriers have you faced in securing a steady supply of your medication?" "Has anything been going on the in past several months that has prohibited you from making it to the clinic to see me?" "What's been going on in your life?" If a clinician working in a community with high rates of incarceration wants to directly screen for an incarceration history in an initial encounter with a patient, she might ask: "A lot of my patients and their family members have experienced incarceration in the past and this can affect how healthy people and their families are. Has this ever happened to you or to a loved one?" In Dr. Wen's case, he might have apologized to Luke and explained some of the ways in which incarceration can indirectly and directly affect patients' health (e.g., as a result of their not being able to make appointments because of court dates or incarceration or of their overdose or death in the first few days after release from prison or jail).

Responding to and Addressing Stigma

In the interaction between Dr. Wen and Luke, <u>social stigma</u> surrounding incarceration directly affects the level of ease or tension in their clinical encounter. Social psychology might explain Luke's reaction in the case as a response to what he perceives as a situational threat, in which Luke could be trying to maintain psychological well-being in the face of perceived impending discrimination by or the prejudice of Dr. Wen, based on his status as incarcerated or formerly incarcerated [26]. As sociologist Erving Goffman pointed out in his classic 1963 work on stigma, it is "an attribute that is deeply discrediting" by which someone is marked and transformed into a damaged social other [27]. Stigma is an extremely strong social force and it can be difficult to overcome. When people face or perceive themselves as facing the negative gaze of others, they can respond psychologically with self-isolation or internalization of shame, which might manifest in patients not leaving the house for routine HIV clinic appointments or not going to a physician's office because they feel ashamed or fear being lectured to or criticized for being overweight or obese.

Clinicians should always attempt to establish that the clinic is a safe space for patients of all walks of life. Part of that effort involves normalizing the experience of incarceration they learn about from patients and speaking openly and nonjudgmentally about a time in a patient's life that might otherwise be laden with the stamp of a disfiguring social experience. This can be done by asking compassionate, open-ended questions that prioritize the patient's lived experience. In the case of incarceration, one might say, "What was that experience like for you?"

Over time, clinicians can create and nurture a longitudinal relationship in which the patient feels comfortable disclosing past events or life experiences. Helping a patient to feel free to say "no" to discussing incarceration is part of creating a safe space that can equalize an often-unrecognized power differential between a clinician and patient. Luke might not want to talk about his incarceration history today, but he might feel more comfortable at the next visit. Moving on to something that Luke does feel is important can be one way to let the patient lead the conversation.

It is also critical to avoid documenting or asking about why a patient was incarcerated. In the era of electronic health records, the "social history" often gets carried over from chart to chart. This documentation can predispose patients to stigma and unintentional bias regardless of the so-called crime. Is it relevant to the matter at hand whether Luke was "locked up for robbery"? The "minimum necessary" standard with respect to disclosure of protected health information is part of the Health Insurance Portability and Accountability (HIPAA) Privacy Rule [28], which should be invoked to avoid unintentional or intentional bias in the delivery of health care by all current and future clinicians.

Finally, clinicians should feel empowered to <u>advocate</u> on behalf of their patients with their colleagues or within their communities. For example, they might advocate for changing the policies and practices of their home institutions or hospital systems and even for political or legislative changes at the local or state level. Advocating for legislation that could increase the number of jobs for people leaving prison or jail or decrease the administrative or financial costs of being formerly incarcerated (such as probation or parole fees or fees to get new state licenses) all are ways that we physicians can combat upstream structural sources that directly contribute to some of our most vulnerable patients' poor health.

References

- 1. Metzl J, Hansen H. Structural competency: theorizing a new medical engagement with stigma and inequality. *Soc Sci Med.* 2014;103:126-33.
- 2. Quesada J, Hart LK, Bourgois P. Structural vulnerability and health: Latino migrant laborers in the United States. *Med Anthropol.* 2011;30(4):339–362.
- 3. Western B. *Punishment and Inequality in America*. New York, NY: Russell Sage Foundation; 2006.

- 4. Alexander M. *The New Jim Crow: Mass Incarceration in the Age of Colorblindness.* New York, NY: New Press; 2010.
- 5. Mauer M, Chesney-Lind M. *Invisible Punishment: The Colateral Consequences of Mass Imprisonment*. New York, NY: New Press; 2002.
- 6. Dumont DM, Brockmann B, Dickman S, Alexander N, Rich JD. Public health and the epidemic of incarceration. *Annu Rev Public Health*. 2012;33:325-339.
- 7. Golembeski C, Fullilove R. Criminal (in)justice in the city and its associated health consequences. *Am J Public Health*. 2005;95(10):1701-1706.
- Spaulding AC, Seals RM, Page MJ, Brzozowski AK, Rhodes W, Hammett TM. HIV/AIDS among inmates of and releasees from US correctional facilities, 2006: declining share of epidemic but persistent public health opportunity. *PLoS One*. 2009;4(11):e7558.

http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0007558. Accessed June 7, 2017.

- 9. Fazel S, Baillargeon J. The health of prisoners. *Lancet*. 2011;377(9769):956-965.
- 10. Jürgens R, Ball A, Verster A. Interventions to reduce HIV transmission related to injecting drug use in prison. *Lancet Infect Dis.* 2009;9(1):57-66.
- 11. Wright NM, Tompkins CN, Farragher TM. Injecting drug use in prison: prevalence and implications for needle exchange policy. *Int J Prison Health*. 2015;11(1):17-29.
- Binswanger IA, Nowels C, Corsi KF,et al. Return to drug use and overdose after release from prison: a qualitative study of risk and protective factors. *Addict Sci Clin Pract*. 2012;7:3. https://ascpjournal.biomedcentral.com/articles/10.1186/1940-0640-7-3. Accessed August 1, 2017.
- 13. Herbert K, Plugge E, Foster C, Doll H. Prevalence of risk factors for noncommunicable diseases in prison populations worldwide: a systematic review. *Lancet.* 2012;379(9830):1975-1982.
- Centers for Disease Control and Prevention. Under pressure: strategies for sodium reduction in institutionalized environments. https://www.cdc.gov/salt/pdfs/institutional_sodium_reduction_guide.pdf. Published July 17, 2012. Accessed August 1, 2017.
- 15. Fazel S, Hayes AJ, Bartellas K, Clerici M, Trestman R. The mental health of prisoners: a review of prevalence, adverse outcomes and interventions. *Lancet Psychiatry*. 2016;3(9):871-881.
- 16. Press E. Madness. *New Yorker*. May 2, 2016. http://www.newyorker.com/magazine/2016/05/02/the-torturing-of-mentallyill-prisoners. Accessed June 7, 2017.
- 17. Merrall EL, Kariminia A, Binswanger IA, et al. Meta-analysis of drug-related deaths soon after release from prison. *Addiction*. 2010;105(9):1545-1554.
- 18. Binswanger IA, Stern MF, Deyo RA, et al. Release from prison—a high risk of death for former inmates. *N Engl J Med*. 2007;356(2):157-165.
- 19. Lichtenstein RL, Rykwalder A. Licensed physicians who work in prisons: a profile.

Public Health Rep. 1983;98(6):589-596.

- Sacchetti M. Lawsuit filed in death of detainee: jail, infirmary are accused of negligence. *Boston Globe*. May 16, 2011. http://archive.boston.com/news/local/massachusetts/articles/2011/05/16/suit _names_jail_infirmary_in_detainees_2009_death/. Accessed August 31, 2017.
- Human Rights Watch. III-Equipped: US Prisons and Offenders with Mental Illness. New York, NY: Human Rights Watch; 2003. https://www.hrw.org/reports/2003/usa1003/usa1003.pdf. Accessed July 28, 2017.
- Vorwerck M. "Sesame Street" tackles prison in new online resource. USA Today. June 25, 2013. https://www.usatoday.com/story/news/nation/2013/06/25/sesame-streetincarceration/2435185/. Accessed June 7, 2017.
- 23. Kaeble D, Glaze L. Correctional population in the United States, 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/cpus15.pdf. Accessed June 7, 2017.
- 24. Minton TD, Zeng Z. Jail inmates in 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/ji15.pdf. Accessed June 7, 2017.
- 25. Bourgois P, Holmes SM, Sue K, Quesada J. Structural vulnerability: operationalizing the concept to address health disparities in clinical care. *Acad Med.* 2017;92(3):299-307.
- 26. Major B, O'Brien L. The social psychology of stigma. *Annu Rev Psychol.* 2005(56):383-421.
- 27. Goffman E. *Stigma: Notes on the Management of Spoiled Identity.* New York, NY: Simon and Schuster; 1963:3.
- Minimum necessary [45 CFR sec 164.502(b), 164.514(d)]. https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/cove redentities/minimumnecessary.pdf. Published December 3, 2002. Revised April 4, 2003. Accessed June 7, 2017.

Kimberly Sue, MD, PhD, is a resident physician in internal medicine primary care at Massachusetts General Hospital in Boston. Her clinical interests include addiction in primary care as well as optimizing care for people with histories of incarceration. Her ethnographic research examines the intersection of US prison systems, addiction policy, mental health, and drug treatment in Massachusetts at the state women's prison, a Boston jail, and a community-based buprenorphine and naloxone treatment program.

Related in the AMA Journal of Ethics

Advocacy by Physicians for Patients and for Social Change, September 2014

The AMA Code of Medical Ethics' Opinions Related to Health Care for Incarcerated People, September 2017 Correctional Mental Health, February 2008 Federal Privacy Protections: Ethical Foundations, Sources of Confusion in Clinical Medicine, and Controversies in Biomedical Research, March 2016 Stigmatized Patients' Right to Equal Treatment, May 2006 What Does Health Justice Look Like for People Returning from Incarceration?, September 2017

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 894-902

ETHICS CASE

How Should a Health Care Professional Respond to an Incarcerated Patient's Request for a Particular Treatment?

Commentary by Tom Peteet, MD, and Matt Tobey, MD, MPH

Abstract

Incarceration complicates the ethical provision of clinical care through reduction in access to treatment modalities and institutional cultures that value order over autonomy. Correctional care clinicians should expand their guiding principles to consider autonomy and health justice for their patients, which in turn should prompt development of processes and care plans that are patient-centered and account for the inherent restrictions of the setting.

Case

Dr. François is the medical director of a prison where more than 200 women are incarcerated. Over the past week, several nurses have contacted her both in person and through the prison's electronic health record to report that Jane, a woman with insulin-dependent type II diabetes who is incarcerated at the facility, has refused her insulin injections during the past week. Blood sugar measurements taken three times each day have been in the 300 to 500 range. Several of the nurses with whom Dr. François talks face-to-face report they feel anxious about the persistence of Jane's refusal.

Dr. François reads Jane's electronic health record and sees that she experienced a motor vehicle accident five years ago, which resulted in a two-week hospitalization. Jane has chronic neck and back pain as a result of the accident and reported that she was prescribed gabapentin by a primary care clinician in the community to control her pain. Clinicians at the prison are discouraged from prescribing gabapentin unless other pain control options have been tried due not only to this drug's risk for cultivating dependence, but also to the diversion risk within the prison [1]. As a result, Jane has not been prescribed gabapentin at the prison and instead has a prescription for ibuprofen.

Dr. François requests to speak with Jane to try to better understand her situation. When Jane arrives at the prison's medical ward, she tells Dr. François that her pain is unbearable and, specifically, that it keeps her from sleeping or moving comfortably. She states, "I need my gabapentin, this is torture!" When Dr. François asks her about her adherence to her insulin regimen, Jane tells her, "The only thing you people care about is whether I take my insulin. Why doesn't anyone care about my pain?" Dr. François tries to

clarify, "Treating your pain is important, but there are risks to continuing you for too long on gabapentin, so it's important that we work together to try something else for your pain." Jane insists, "I'm not going to take insulin until you give me gabapentin."

Commentary

At any time, two million people are incarcerated in the United States [2]. Health care in correctional settings requires attention to features that might not be present in other health care settings: for example, vulnerable patient populations, custody-driven logistics in the facility, and matters of dignity and fairness [3]. Patients in the correctional setting experience higher rates of chronic medical illnesses, major psychiatric illness, and substance use disorders than their peers [4, 5]. Incarceration itself carries substantial risks to health, including a substantially reduced life expectancy [6]. As in this case, chronic pain is a common complaint managed by correctional health clinicians [7].

A frequently cited tension within clinical guidelines, including the National Commission on Correctional Health Care's guidelines on chronic pain treatment, is the prescription of medications with potential for diversion [8, 9]. The specter of diversion—like gabapentin diversion in this case—looms large over many clinical encounters in the correctional setting, determining the availability of medications, from sleep aids to medications for opioid maintenance to medications for pain. Consider one physician's blog post:

I was recently in a meeting with the commissioner of a certain state's Department of Corrections to give an update on medical services in his prisons and the very first question he asked was about gabapentin. Gabapentin! Think of all the things he could have been concerned about—Hepatitis C for example—and instead, he asked about the security problems caused by gabapentin diversion [10].

Despite the pervasiveness of concern for diversion, little data exists on the extent or health impact of medical diversion in correctional settings [1]. To take one example, in a randomized controlled trial of opioid agonist therapies at a large jail, 7 of 116 men were discontinued on the medications out of concern for diversion over a one-month study period [11]. The health impact of medication diversion is unknown: between 2000 and 2013, 4-9 percent of county jail inmate deaths and 1-2 percent of state prison inmate deaths were attributed to alcohol or drug intoxication, although the source of those substances is not reported, and many deaths are likely not due to medication diversion [12].

Although gabapentin has evidence of benefit in many conditions, including epilepsy and neuropathic pain [13, 14], it is a noncontrolled GABA-ergic medication with potential for diversion, which is central to this case. One early description of gabapentin diversion in a prison was noted in Florida in 2004 [15], and diversion of the drug is widespread in the

community for anxiolysis and euphoria [16, 17]. However, gabapentin, even in massively supratherapeutic blood concentrations, is unlikely to cause death [18], as only rare deaths have been definitively attributed to it [19], and its side effects are primarily related to drowsiness [20]. As an example of the degree of controversy around gabapentin prescribing, a lay publication described widespread diversion of gabapentin and then criticized the restriction of access to it in prisons for an off-label indication (anxiety) [21, 22].

The case implies that diversion and dependence are considerations; although gabapentin dependence has been described [23], we will focus in this commentary on diversion, as we believe the restriction of prescribing to limit diversion underlies the case and represents a central ethical quandary in correctional care. Moreover, we will not focus on the patient's threat of nonadherence as an attempt to bargain for gabapentin. We believe we see such brinksmanship occur in correctional care precisely because of problematic clinical environments and restrictions on liberty inherent in correctional environments, which can be addressed by changing policies to improve patients' experiences. Although we agree with published guidelines on the management of chronic pain in correctional health care [8], we acknowledge that clinical care need not be identical within and outside of correctional settings. Indeed, we argue that the lack of autonomy and frequent injustices in the setting of incarceration should lead clinicians to consider prioritizing principles such as *respect for autonomy* and *justice* over concerns about medication diversion and misuse.

Balancing Patient Considerations against Medication Misuse

In the United States, although health care for incarcerated persons has been deemed a constitutional right [24], care is often explicitly rationed and difficult to access [25]. In the case above, the most salient ethical consideration is the clinician's unstated preference to mitigate the harm of medication misuse and diversion by following strict prescribing practices instead of trying to motivate continuity in the patient's care plan. As alluded to above, there can be legitimate safety and security concerns raised by prescribing medications known to be diverted. In exploring the ethical tradeoff, it is useful to consider how we might weigh respect for an individual patient's autonomy against the risk of harm to others differently within a correctional setting [26]. For example, given the lack of autonomy in prison, perhaps clinicians should offer medical care that prioritizes respect for patient autonomy (e.g., by keeping Jane on gabapentin). Or, perhaps given the injustices involved in care rationed according to unfair criteria, clinicians ought to have a higher threshold for withholding a treatment (e.g., by not stopping Jane's gabapentin upon admission). We propose two hypothetical questions to help us reach a conclusion in this case:

1. *Nonmaleficence versus respect for autonomy*. If gabapentin is known to have diversion appeal and diversion carries some risk of harm to prisoners, but if

continuing it for a single patient supports respect for her autonomy and is clinically appropriate, should gabapentin be prescribed?

2. *Health justice in an unjust setting.* If incarcerated persons often suffer injustices from unfair rationing, for example—should individual clinicians be more inclined to honor patients' care plan preferences?

Nonmaleficence versus Respect for Autonomy

Withholding Jane's gabapentin clearly denies her preference for treatment. At the same time, any single prescription of gabapentin carries risk of diversion and potential harm to others. Considered generally, how should clinicians approach the potential consequences of medication diversion and misuse in correctional settings?

We see no compelling argument for why the diversion of a medication should be demonstrably more problematic in a prison or jail than in a community setting. In fact, given how tightly monitored correctional facilities tend to be, prisons or jails might prove safer settings for the misuse of medications with diversion risk. One may disagree and posit a risk of violence associated with diversion in correctional facilities; however, violence associated with diversion could also occur in community settings. Notably, no data that we know of exist to suggest that diversion occurs at a higher rate or that it is more problematic in correctional settings. Using the numbers from the clinical trial cited above, over a month, perhaps 5 percent of incarcerated recipients diverted opioids [11]; national rates in the community setting in the US and France have been quoted as 0.08 percent and 20 percent, respectively [27].

If not from empirical evidence, whence the concern regarding gabapentin use in correctional settings? First, correctional settings might value order over autonomy. For example, correctional facilities typically are strongly risk averse to potentially fatal, if highly unlikely events, such as life-threatening gabapentin overdose, due to legal liability, although such risk aversion limits evidence-based treatment options for numerous patients [28]. Also, the effort necessary to prevent medication diversion and maintain order can be onerous for facility staff. Despite these concerns, we are troubled by the correctional system's strong tendencies against GABA-ergic medications and, for that matter, against other nonscheduled medications used for mental health care and other conditions. Second, a prescriber might be concerned about gabapentin's off-target effects, such as diminishing anxiety [29] or substance use cravings [30], and a patient's preferring it for that reason. However, it is not clear why such additional benefits could be construed as harmful. If a prescriber suspects that unspoken, off-target benefits might be the motive for a patient's care plan preference, a good solution is a strong patient-clinician relationship and appropriate mental health care. Such relationships might be difficult to cultivate if the focus of care is not patient centered and the clinician's primary concern is medication diversion.

We argue that—in general—clinicians should be circumspect in overriding an incarcerated patient's autonomy even if upholding respect for autonomy carries risk for medication diversion. Specifically, in this case, we believe that a risk of harm from medication diversion or misuse should probably be assumed in order to express respect for this patient's autonomy. We suggest that Dr. François consider prioritizing respect for her patient's autonomy over her concern about diversion and possible harms to others.

Health Justice in a Setting of Liberty Restriction

Jane's case highlights a larger question regarding a clinician's duty to provide just care within a system known for its shortcomings in the care of patients with chronic illness [31]. The barriers to high-quality, patient-responsive care in jails and prisons are endemic in the United States: for-profit health care companies, care rationing, formulary restrictions, restricted access to exercise and nutrition, among others. In such a challenging setting, ethical principles of beneficence, respect for autonomy, and justice often require nuanced evaluation. For instance, a correctional facility might in good faith opt to segregate a person at risk of harming others, although paradoxically, over time, that person's declining mental health due to seclusion might generate more harm than it prevents. In many cases, in our experience, what seems beneficial and expedient in the short term might prove to be harmful over the long term.

When clinicians practice in such an environment, we believe that they must seek a higher standard of upholding beneficence, respect for autonomy, and justice in their patient interactions. Simple rules such as, "gabapentin is not on formulary," are not satisfactory in a setting in which patient concerns about preferred care plans should be approached with nuance and care. The gold standard of just care has been argued to be shared decision making [32]. We suggest here that shared decision making or a similar standard should be employed in every correctional clinical encounter in which there is not a clear-cut care plan. In the final section, we offer recommendations for clinical practice.

From Ethics to Clinical Practice

In this case, Jane reports chronic back and neck pain after a motor vehicle accident. She says that her pain has been improved with gabapentin. In her case, with chronic back and neck pain without an obvious neuropathic component, gabapentin is not recommended as a first-line option, largely due to lack of evidence of benefit [33]. However, at times it is used <u>off label</u>. Other pharmacologic measures (e.g., anti-inflammatories, topical therapies) and nonpharmacologic alternatives (e.g., massage therapy, cognitive-behavioral therapy, physical therapy) might be more effective [34]. However, in our experience, nonpharmacologic measures, in particular, are typically unavailable in correctional settings.

As we have described, arguments exist for prioritizing respect for patient autonomy and health justice in the correctional setting. We therefore suggest that correctional clinicians

openly consider requests like Jane's for continuity in the preferred care plan and work collaboratively with their correctional institution both to distribute medications in ways that reduce the risk of diversion and to offer appropriate, attentive clinical assessment and follow-up.

We wish to conclude by encouraging clinicians to consider several factors that we have witnessed cloud decision making in correctional settings. First, clinicians should be aware of their possible cognitive biases, such as the attribution bias of stereotyping incarcerated patients and the "bandwagon effect" of following restrictive prescribing practices from previous clinicians or other facilities. Second, clinicians should confront their fear that if medication diversion is uncovered, it could reflect poorly on them. Third, because US correctional settings' cultures are typically risk averse and focused on order, clinicians should consider the impact that these factors play in their decision making. Or, stated more positively: How might one's decision making differ in a correctional environment that allows inmates to sunbathe, cook with knives, form a band that performs at music festivals, and play darts [35, 36]?

Conclusion

We propose an ethical test: if prescribing patterns and standards of care differ between community and correctional settings, clinicians and facilities should reflect upon the reasons for the difference. If differences are due to another goal being valued above patient welfare (e.g., decreasing drug diversion, limiting costs, or limiting staff burden), then clinicians should consider whether a change to a more patient-centered approach during clinical encounters or at the facility level could better express respect for patient autonomy and promote health justice.

We acknowledge the difficulties of managing locked facilities safely and the challenges that correctional clinicians face in trying to offer just health care to patients whose liberties are so restricted. However, as we've argued, at minimum, facilities and clinicians should commit to making constant improvement in their care systems to motivate more just care for incarcerated patients.

References

- 1. Pilkinton PD, Pilkinton JC. Prescribing in prison: minimizing psychotropic drug diversion in correctional practice. *J Correct Health Care*. 2014;20(2):95–104.
- Kaeble D, Glaze L. Correctional populations in the United States, 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/cpus15.pdf. Accessed May 30, 2017.
- 3. Allen SA, Wakeman SE, Cohen RL, Rich JD. Physicians in US prisons in the era of mass incarceration. *Int J Prison Health*. 2010;6(3):100-106.

- Maruschak LM, Berzofsky M, Unangst J. Medical problems of state and federal prisoners and jail inmates, 2011-12. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; February 2015. https://www.bjs.gov/content/pub/pdf/mpsfpji1112.pdf. Revised October 4, 2016. Accessed May 30, 2017.
- 5. National Center on Addiction and Substance Abuse. *Behind Bars II: Substance Abuse and America's Prison Population*. New York, NY: National Center on Addiction and Substance Abuse; 2010.
- 6. Patterson EJ. The dose-response of time served in prison on mortality: New York State, 1989-2003. *Am J Public Health*. 2013;103(3):523-528.
- 7. Croft M, Mayhew R. Prevalence of chronic non-cancer pain in a UK prison environment. *Br J Pain*. 2015;9(2):96-108.
- National Commission on Correctional Health Care. Management of chronic pain. http://www.ncchc.org/management-of-chronic-pain. Adopted October 16, 2011. Accessed May 30, 2017.
- State of California Prison Health Care Services. *Pain Management Guidelines*. Sacramento, CA: 2009. http://www.cphcs.ca.gov/docs/careguides/PM_FinalGuidelinesWithAttachment s_03152010.pdf. Published 2009. Accessed May 30, 2017.
- 10. Keller JE. Taming the beast: gabapentin. *Jail Medicine*. December 27, 2015. http://www.jailmedicine.com/taming-the-beast-gabapentin/. Accessed July 11, 2017.
- 11. Magura S, Lee JD, Hershberger J, et al. Buprenorphine and methadone maintenance in jail and post-release: a randomized clinical trial. *Drug Alcohol Depend*. 2009;99(1-3):222-230.
- Noonan M, Rohloff H, Ginder S. Mortality in local jails and state prisons, 2000-2013—statistical tables. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; August 2015. https://www.bjs.gov/content/pub/pdf/mljsp0013st.pdf. Accessed May 30, 2017.
- 13. Marson AG, Al-Kharusi AM, Alwaidh M, et al; SANAD Study Group. The SANAD study of effectiveness of carbamazepine, gabapentin, lamotrigine, oxcarbazepine, or topiramate for treatment of partial epilepsy: an unblinded randomised controlled trial. *Lancet*. 2007;369(9566);1000-1015.
- Gilron I, Bailey JM, Tu D, Holden RR, Weaver DF, Houlden RL. Morphine, gabapentin, or their combination for neuropathic pain. *N Engl J Med*. 2005;352(13):1324-1334.
- 15. Reccoppa L, Malcolm R, Ware M. Gabapentin abuse in inmates with prior history of cocaine dependence. *Am J Addict*. 2004;13(3):321-323.
- 16. Smith RV, Havens JR, Walsh SL. Gabapentin misuse, abuse and diversion: a systematic review. *Addiction*. 2016;111(7):1160-1174.

- 17. Ohio Substance Abuse Monitoring Network. Neurotonin[®] widely sought for illicit use. http://mha.ohio.gov/Portals/0/assets/Research/OSAM-TRI/Neurontin-OSAM-O-Gram_Feb2017.pdf. Published February 2017. Accessed July 18, 2017.
- Klein-Schwartz W, Shepherd JG, Gorman S, Dahl B. Characterization of gabapentin overdose using a poison center case series. *J Toxicol Clin Toxicol*. 2003;41(1):11-15.
- 19. Middleton O. Suicide by gabapentin overdose. *J Forensic Sci.* 2011;56(5):1373-1375.
- Pfizer Canada, Inc. Product monograph: Neurontin[®] (gabapentin). http://www.pfizer.ca/sites/g/files/g10023216/f/201505/NEURONTIN_PM_17 5273_EN_12September2014.pdf. Revised September 12, 2014. Accessed July 11, 2017.
- 21. Ramos N, Allen A. Life and loss on methadone mile. *Boston Globe*. July 16, 2016. https://apps.bostonglobe.com/graphics/2016/07/methadone-mile/. Accessed May 30, 2017.
- Cramer M, Russell J, Rezendes M, Helman S, Wallack T. The desperate and the dead: prisons. *Boston Globe*. November 25, 2016. https://apps.bostonglobe.com/spotlight/the-desperate-and-thedead/series/prisons/. Accessed June 8, 2017.
- 23. Mersfelder TL, Nichols WH. Gabapentin: abuse, dependence, and withdrawal. *Ann Pharmacother.* 2016;50(3):229-233.
- 24. American Civil Liberties Union. Medical and mental health care. https://www.aclu.org/issues/prisoners-rights/medical-and-mental-health-care. Accessed May 30, 2017.
- 25. Restum ZG. Public health implications of substandard correctional health care. *Am J Public Health*. 2005;95(10):1689-1691.
- 26. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 7th ed. New York, NY: Oxford University Press; 2012.
- Whelan PJ, Remski K. Buprenorphine vs methadone treatment: a review of evidence in both developed and developing worlds. *J Neurosci Rural Pract*. 2012;3(1):45-50.
- 28. Nunn A, Zaller N, Dickman S, Trimbur C, Nijhawan A, Rich JD. Methadone and buprenorphine prescribing and referral practices in US prison systems: results from a nationwide survey. *Drug Alcohol Depend*. 2009;105(1-2):83-88.
- 29. Pollack MH, Matthews J, Scott EL. Gabapentin as a potential treatment for anxiety disorders. *Am J Psychiatry*. 1998;155(7):992–993.
- 30. Furieri FA, Nakamura-Palacios EM. Gabapentin reduces alcohol consumption and craving: a randomized, double-blind, placebo-controlled trial. *J Clin Psychiatry*. 2007;68(11):1691-1700.
- 31. Wilper AP, Woolhandler S, Boyd JW, et al. The health and health care of US prisoners: results of a nationwide survey. *Am J Public Health*. 2009;99(4):666-672.

- 32. Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patientcentered care. *N Engl J Med.* 2012;366(9):780-781.
- 33. Chou R, Qaseem A, Snow V, et al; Clinical Efficacy Assessment Committee of the American College of Physicians; American College of Physicians/American Pain Society Low Back Pain Guidelines Panel. Diagnosis and treatment of low back pain: a joint clinical practice guideline from the American College of Physicians and the American Pain Society. *Ann Intern Med.* 2007;147(7):478-491.
- 34. American Society of Anesthesiologists Task Force on Chronic Pain Management; American Society of Regional Anesthesia and Pain Medicine. Practice guidelines for chronic pain management: an updated report by the American Society of Anesthesiologists Task Force on Chronic Pain Management and the American Society of Regional Anesthesia and Pain Medicine. *Anesthesiology*. 2010;112(4):810-833.
- 35. Sterbenz C. An American warden visited a Norwegian prison, and he couldn't believe what he saw. *Business Insider*. October 20, 2014. http://www.businessinsider.com/an-american-warden-visited-a-norwegianprison--and-he-couldnt-believe-what-he-saw-2014-10. Accessed May 30, 2017.
- 36. Benko J. The radical humaneness of Norway's Halden prison. New York Times Magazine. March 26, 2015. https://www.nytimes.com/2015/03/29/magazine/the-radical-humaneness-ofnorways-halden-prison.html?mcubz=1&_r=0. Accessed May 30, 2017.

Tom Peteet, MD, is an internal medicine physician and rural health fellow at Massachusetts General Hospital in Boston. His interests include bioethics, addiction medicine, public health, and correctional medicine.

Matt Tobey, MD, MPH, is an internal medicine physician at Massachusetts General Hospital in Boston. He supervises an interdisciplinary student clinic in a jail, coordinates an academic-rural partnership, and practices primary care. His interests include rural and correctional health.

Related in the AMA Journal of Ethics

The AMA Code of Medical Ethics' Opinions Related to Health Care for Incarcerated People, September 2017 Delivering Care in a Non-Health-Care Space, February 2008 Neurontin and Off-Label Marketing, June 2006 Why Must Pain Patients Be Found Deserving of Treatment?, January 2008

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA. **Copyright 2017 American Medical Association. All rights reserved. ISSN 2376-6980**

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 903-910

ETHICS CASE

What Does Health Justice Look Like for People Returning from Incarceration?

Case and Commentary by Lisa Puglisi, MD, Joseph P. Calderon, CHW, and Emily A. Wang, MD, MAS

Abstract

Access to health care is a constitutional right in the United States correctional system, and many incarcerated adults are newly diagnosed with chronic diseases in prison. Despite this right, the quality of correctional health care is variable, largely unmeasured and unregulated, and characterized by patients' widespread distrust of a health system that is intimately tied to a punitive criminal justice system. Upon release, discontinuity of care is the norm, and when continuity is established, it is often hindered by distrust, discrimination, poor communication, and racism in the health system. In this paper, we will propose best practices in transitioning from correctional- to community-based health care and argue that achieving health equity for people with criminal justice involvement in the United States is not possible without ethical provision of health care.

Case

Mr. C was released two months ago after a four-year prison sentence, shortly after having coronary artery bypass surgery for early onset atherosclerotic heart disease. At 42 years old, he was surprised and scared when his chest pain was diagnosed as a heart attack, necessitating major surgery while he was incarcerated. He was also told that there might be some problems with his kidneys, although he is unclear as to the specifics and does not have a copy of his medical records or his medications. Upon release he was homeless and has been staying with his mother in subsidized housing. This is a source of stress for her; because her son has a felony record, she worries that she is violating housing authority policy and could be evicted.

During his first visit to the community clinic, Mr. C shares with Joe, his community health worker, and subsequently with the health care practitioner that he is fearful of being reincarcerated. He feels weak and has not followed through with cardiac rehabilitation because he doesn't have transportation. His parole officer tells him that if he remains unemployed he will be in violation of his parole. Mr. C's stress has brought on cravings for heroin, which he has not used since being incarcerated. Mr. C's clinician and community health worker wonder if there is anything they can do to help him.

Commentary

This clinical vignette represents a common scenario people find themselves in after release from prison and demonstrates the very difficult decisions they are faced with: Where will I live? Who will hire me if I have a felony record? How do I get my medications refilled? Can I trust my doctor? My doctor recommended buprenorphine to treat my cravings, but will I violate my parole by taking it?

As health care practitioners, we are largely untrained to even ask people about their incarceration history, so would it be reasonable to expect that we have the skills to help patients recently released from prison address their concerns and prioritize and consider their health goals? And, more broadly, what are the duties of the health system at large to interface effectively between patients who are returning to our communities and the criminal justice system from which they came? Before addressing these questions, we will first describe the burden of incarceration and associated illnesses in the United States and describe current norms of transitioning patients from the correctional health system to a community-based health care system.

Incarceration and Health in the United States

Worldwide, the nation that is the largest jailer of its citizens is the United States [1]. As of 2014, there were approximately 2.2 million people in the United States behind bars [2], and in the 15 years prior to 2014 over 11 million people were admitted to jails annually [3]. The number of incarcerated people in the United States has risen dramatically since the mid-1970s to a point at which US incarceration rates dwarf the incarceration rates of any other Western democratic nation [1]. Black and Hispanic men, especially the young and noncollege educated, are incarcerated at relative rates that far exceed their white counterparts [4].

Incarcerated people suffer a greater burden of illness than the general population due to the widespread prevalence of communicable diseases (e.g., HIV, hepatitis C, syphilis), noncommunicable diseases (e.g., hypertension, cancers, asthma), and mental health and substance use disorders [5]. For example, at least 10 percent of incarcerated people are infected with <u>hepatitis C</u>, which has a 1 percent prevalence in the general population [6]. Compounding the problem, an estimated 40 percent of incarcerated people with chronic conditions, like Mr. C, are diagnosed while in prison [7], where acquiring the skills to self-manage chronic disease is difficult given the punitive and restrictive policies of the penal system.

Ultimately, prison health care becomes a critical issue for community health systems, as 95 percent of the incarcerated population is released back to the community [8]. Incarcerated people face serious barriers caring for themselves upon release, such as poor health literacy, limited access to housing and employment, and difficulties continuing their medications and accessing primary care [9]. Even in the 26 states that expanded Medicaid services by 2014 as part of the Affordable Care Act (ACA), many people have their Medicaid enrollment terminated upon incarceration, such that most are released without Medicaid and need to reapply [10]. That said, a growing number of states do enroll certain people in Medicaid upon incarceration or suspend their coverage as opposed to terminating the benefit [11].

These obstacles, along with poorly coordinated transitions of care between the prison and community systems, are thought to be some of the driving factors behind the high risk of death, hospitalization, and worsening health outcomes (e.g., increasing HIV viral load, relapse to substance use, elevated blood pressure) following release [12-15]. Mr. C, however, appears to have received at least a month supply of medication and been connected to primary care prior to release by the Department of Corrections.

Moving the Health System from Blockade to Buttress

Enhanced methods of communication between the correctional and community health systems are essential for improving the health of this population. In contrast to current community standards for hospital discharge planning, for which the Centers for Medicare and Medicaid Services (CMS) clearly outlines recommended practices as a prerequisite to reimbursement [16], prison discharge practices in coordinating care across the country are inconsistent and underfunded [17]. Prison discharge plans range from nonexistent (i.e., no medications, medical records, or primary care appointments), to some planning by community-based organizations, to well-coordinated planning run by prison-based medical discharge planners who arrange for medications, medical records, and scheduling community appointments. Regrettably, without coordinated assistance, in our experience, health records are routinely not given to patients and the cost of obtaining records can be as high as two weeks of wages garnered behind bars.

Even when medical discharge is well planned, returning home from prison for those with chronic medical conditions is difficult. Most people's first priorities are access to food, finding somewhere to live, obtaining employment, reconnecting with families, and meeting the myriad stipulations of probation or parole. As a result, patients like Mr. C are often forced to make "trade-off decisions" that put their health at risk.

So how can health care practitioners and health systems address the medical and social complexities of caring for people just released from prison? We argue that achieving health equity is critical for the ethical provision of health care for the previously incarcerated. In her Gardener's Tale talk, Camara Jones, the physician and epidemiologist, defines health equity as assurance of the conditions for the optimal health for all people and asserts that achieving health equity requires: (1) viewing all persons and populations equally, (2) recognizing and rectifying historical injustices, and (3) providing resources according to need [18]. If we apply this framework to evaluate the provision of health

care for people who return to the community from correctional facilities, we can create an ethically sound path toward health equity.

Assessing the Needs of All Persons and Populations Equally

Assessing the needs of all persons equally is a basic ethical duty of physicians, but we are not achieving this goal for corrections-involved populations. Viewing the previously incarcerated as equal to others in the health system is possible and requires that clinicians start by acknowledging that they might have implicit or explicit bias against criminals—viewing them as dangerous and deserving of incarceration, for example and focusing on some of the modalities that show promise in addressing bias: pursuing egalitarian goals, identifying common identities, counterstereotyping, and perspective taking [19]. Hearing that someone has a criminal record can bring out fears and misconceptions of prison life and of those who commit crimes. We clinicians would like to think we are objective, but we are just as susceptible to being discriminatory based on a criminal record as employers, who have been shown to call back fewer than half as many equally qualified applicants with a fictive criminal record [20]. Although there is no consensus, from our personal experience, we believe it is important to ask patients about their experiences while incarcerated—for instance, their experience with trauma or solitary confinement, which pose individual health risks [21]. But asking details about a patient's crimes is usually not medically relevant, can be emotionally taxing on the clinician, and might promote bias when documented in the medical record. The electronic health record—while meant to be a living and fluid document—can be one that tarnishes a person's reputation and labels him or her as a certain "type of patient." One can instead ask patients how one can best help prevent their reincarceration, which might elicit details about patients' past substance use, poverty, and trauma, all of which are clinically relevant.

Additionally, why, ethically, would we require normative practices for hospital discharge in the general population and not require the same for people leaving correctional facilities? Not providing transition of care from prison to community is unethical because it relegates formerly incarcerated people to unequal treatment. We should, at the very least, provide patients with medical discharge summaries, a minimum supply of medications prior to discharge, and a primary care follow-up appointment. Furthermore, there should be a state-based oversight body that ensures standardized procedures for quality and safe discharges.

Recognize and Rectify Historical Health System Injustices

Health care practitioners and systems must recognize and then rectify historical health system injustices. To start with, we are not currently educating health professionals to care for the population of incarcerated and formerly incarcerated patients; only 22 primary care residencies have any formal training on the health impacts of incarceration [22]. We must develop <u>curricula</u> to educate all health professionals in various stages of

training, develop competencies on caring for the previously incarcerated, confront race and racism and its impact on patient and community health, and train clinicians to work within correctional health care systems without becoming an arm of the penal system.

Rectifying injustices will require long-term, systems-level commitment and change. As part of building trust, facilitating communication, and rectifying historically unequal relationships between universities and hospitals and their surrounding communities, urban health systems—which are often large employers—have opportunities to provide meaningful work to people with a history of incarceration and to develop hiring and workforce development programs directly targeting this population. Realizing these opportunities will require changing current practices in hiring and restrictions in occupational licensing to permit hiring of people with incarceration histories in the health system and the creation of training that will support their success [23]. In the Transitions Clinic Network, of which we are a part, the provision of care for chronically ill people returning home from prison hinges on a team of clinicians led by a community health worker who has a history of incarceration and is specifically trained in the care of recently released people. Employing those with histories of incarceration in health care is critical to building bridges and regaining trust between formerly incarcerated patients and the health care system [24].

Advocate for the Provision of Resources According to Patient and Community Needs

Lastly, we must advocate for the provision of resources according to patient and community needs. We, as community health clinicians, are continually confronted by patients living in extremes of poverty and social deprivation, where the safety-net institutions that exist do not sufficiently support their needs. We bear witness to a host of policies that prohibit people with felony convictions from meeting their basic needs—even after serving the terms of their sentences—and these "collateral consequences" (e.g., bans on food stamp and public housing eligibility, voting restrictions, and criminal record discrimination) have a significant impact on patients' health and well-being [25]. Despite recent gains through the ACA, the areas of greatest need for this population—health insurance coverage, substance use treatment, mental health care, and civic engagement [26]—must be prioritized, advocated for, and financially supported both within and outside of prisons. These resources are critical to people with a history of incarceration becoming active, healthy citizens.

Conclusion

So what can Mr. C's health care practitioner and community health worker do both to help him receive health care that is just and addresses the specific health risks he faces and to help him obtain social services? Mr. C's health care practitioner can develop a plan for early initiation of medication-assisted treatment to <u>prevent opioid relapse</u> and prescribe naloxone to prevent overdose. Furthermore, the health care practitioner and community health worker can speak to his parole officer, with Mr. C's permission, to advocate for the medical necessity and safety of this plan. They can assess Mr. C's health literacy and offer guidance on self-care and medication adherence, with the understanding that he has never had to manage his own medications before. This guidance might involve identifying a convenient pharmacy, reviewing Mr. C's medication labels with him, and teaching him how to take the medication and how to obtain refills. The community health worker can work with the local housing authority (which manages low-rent or rent-free housing) and housing organizations (which assist those who don't otherwise qualify for housing) to advocate for Mr. C, identify housing resources of which he is not likely aware, and help circumvent the barriers and stigma that Mr. C will probably encounter because of his felony record. In each of these circumstances, knowing Mr. C has just returned home from prison provides critical context for understanding how best to create feasible action plans for chronic disease management and obtaining social services.

Until we approach the care of the millions of Americans with a history of incarceration through a health equity lens and acknowledge the role that health systems have in rectifying past and current injustices, we will inadvertently be complicit in perpetuating unethical care, and patients like Mr. C will not be able to achieve the levels of health and well-being they deserve and need to return to the community in a meaningful way.

References

- 1. Wildeman C, Wang EA. Mass incarceration, public health, and widening inequality in the USA. *Lancet.* 2017;389(10077):1464-1474.
- Kaeble D, Glaze L. Correctional populations in the United States, 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/cpus15.pdf. Accessed June 6, 2017.
- Minton TD, Zeng Z. Jail inmates 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/ji15.pdf. Accessed June 7, 2017.
- 4. Western B. *Punishment and Inequality in America*. New York, NY: Russell Sage Foundation; 2006.
- 5. Wilper AP, Woolhandler S, Boyd JW, et al. The health and health care of US prisoners: results of a nationwide survey. *Am J Public Health*. 2009;99(4):666-672.
- 6. Beckman AL, Bilinski A, Boyko R, et al. New hepatitis C drugs are very costly and unavailable to many state prisoners. *Health Aff (Millwood)*. 2016;35(10):1893-1901.
- 7. Wang EA, Hong CS, Shavit S, Sanders R, Kessell E, Kushel MB. Engaging individuals recently released from prison into primary care: a randomized trial. *Am J Public Health*. 2012;102(9):e22-e29.

- 8. Petersilia J. *When Prisoners Come Home: Parole and Prisoner Reentry*. New York, NY: Oxford University Press; 2003.
- 9. Baillargeon J, Giordano TP, Rich JD, et al. Accessing antiretroviral therapy following release from prison. *JAMA*. 2009;301(8):848-857.
- Birnbaum N, Lavoie M, Redmond N, Wildeman C, Wang EA. Termination of Medicaid policies and implications for the Affordable Care Act. *Am J Public Health*. 2014;104(8):e3-e4.
- 11. Patel K, Boutwell A, Brockmann BW, Rich JD. Integrating correctional and community health care for formerly incarcerated people who are eligible for Medicaid. *Health Aff (Millwood)*. 2014;33(3):468-473.
- 12. Meyer JP, Cepeda J, Wu J, Trestman RL, Altice FL, Springer SA. Optimization of human immunodeficiency virus treatment during incarceration: viral suppression at the prison gate. *JAMA Intern Med*. 2014;174(5):721-729.
- 13. Howell BA, Long JB, Edelman EJ, et al. Incarceration history and uncontrolled blood pressure in a multi-site cohort. *J Gen Intern Med*. 2016;31(12):1496-1502.
- 14. Binswanger IA, Stern MF, Deyo RA, et al. Release from prison—a high risk of death for former inmates. *N Engl J Med*. 2007;356(2):157-165.
- 15. Wang EA, Wang Y, Krumholz HM. A high risk of hospitalization following release from correctional facilities in Medicare beneficiaries: a retrospective matched cohort study, 2002 to 2010. *JAMA Intern Med.* 2013;173(17):1621-1628.
- 16. Centers for Medicare and Medicaid Services. Revision to state operations manual (SOM), hospital appendix A—interpretive guidelines for 42 CFR 482.43, discharge planning.https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-13-32.pdf. Published May 17, 2013. Accessed July 31, 2017.
- 17. Flanagan NA. Transitional health care for offenders being released from United States prisons. *Can J Nurs Res.* 2004;36(2):38-58.
- 18. Jones CP. Levels of racism: a theoretic framework and a gardener's tale. *Am J Public Health*. 2000;90(8):1212-1215.
- 19. Stone J, Moskowitz GB. Non-conscious bias in medical decision making: what can be done to reduce it? *Med Educ*. 2011;45(8):768-776.
- 20. Pager D. The mark of a criminal record. Am J Sociol. 2003;108(5):937-975.
- 21. Hagan BO, Wang EA, Aminawung JA, et al; Transitions Clinic Network. History of solitary confinement is associated with post-traumatic stress disorder symptoms among individuals recently released from prison [published online ahead of print March 9, 2017]. *J Urban Health*.
- 22. Min I, Schonberg D, Anderson M. A review of primary care training programs in correctional health for physicians. *Teach Learn Med.* 2012;24(1):81-89.
- 23. National Employment Law Project; National Reentry Resource Center; Council of State Governments Justice Center. The consideration of criminal records in occupational licensing. https://csgjusticecenter.org/wp-

content/uploads/2015/12/TheConsiderationofCriminalRecordsinOccupationalLic ensing.pdf. Accessed July 31, 2017.

- 24. Thill Z, Abare M, Fox A. Thinking outside the box: hospitals promoting employment for formerly incarcerated persons. *Ann Intern Med.* 2014;161(7):524–525.
- 25. Mauer M, Chesney-Lind M, eds. *Invisible Punishment: The Collateral Consequences* of Mass Imprisonment. New York, NY: New Press; 2003.
- 26. Purtle J. Felon disenfranchisement in the United States: a health equity perspective. *Am J Public Health*. 2013;103(4):632–637.

Lisa Puglisi, MD, is an assistant professor of general internal medicine at the Yale School of Medicine in New Haven, Connecticut. She is also co-director of Transitions Clinic Network-New Haven, a clinical program focused on providing postincarceration primary care in partnership with community health workers.

Joseph P. Calderon, CHW, is a community health worker with the Transitions Clinic Network in San Francisco, where he also teaches and trains community health workers. He has a passion for working with diverse and disenfranchised populations, leveraging his personal experience with incarceration to advocate the ideals of social justice and community investment.

Emily A. Wang, MD, MAS, is an associate professor at the Yale School of Medicine in New Haven, Connecticut, and co-founder of the Transitions Clinic Network. She has developed expertise in training formerly incarcerated people to become community health workers and researchers through community-based participatory research methods. Dr. Wang's research focuses on promoting health equity for vulnerable populations, especially people with a history of incarceration.

Related in the AMA Journal of Ethics

Correctional Mental Health, February 2008 Diagnosis and Treatment of Chronic Hepatitis C in Incarcerated Patients, February 2008 Ethics Students Go to the Jail, September 2017 How to Talk with Patients about Incarceration and Health Care, September 2017 Medicine and Mass Incarceration: Education and Advocacy in the New York City Jail System, September 2017

Why It's Inappropriate Not to Treat Incarcerated Patients with Opioid Agonist Therapy, September 2017

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 911-912

THE CODE SAYS

The AMA *Code of Medical Ethics*' Opinions Related to Health Care for Incarcerated People

Annalise Norling

The relationship between clinicians and incarcerated patients provides unique challenges for informed consent, respect for <u>autonomy</u>, and quality health care delivery. The American Medical Association adopted a policy ("Health Care While Incarcerated," H-430.986) that promotes greater access to health care for the incarcerated population. This policy states that the American Medical Association "advocates for adequate payment to health care providers ... to encourage improved access to comprehensive physical and behavioral health care services to juveniles and adults throughout the incarceration process from intake to re-entry into the community" [1]. While the *Code of Medical Ethics* does not speak directly to improved access to health care for incarcerated persons, it does speak to the role of the clinician in protecting patients from medical and health care-related <u>mistreatment</u> in the correctional system.

Opinion 9.7.2, "Court-Initiated Medical Treatment in Criminal Cases" [2], states that "although convicted criminals have fewer rights and protections than other citizens, being convicted of a crime does not deprive an offender of all protections under the law" [3]. Outlined in this opinion are guidelines for physicians providing court-initiated care for incarcerated patients that enable them to uphold their civic responsibility while still respecting the protections to which this population is entitled. These include participating "only if the procedure being mandated is therapeutically efficacious and is therefore undoubtedly not a form of punishment" [4], treating "patients based on sound medical diagnosis, not court-defined behaviors" [4], and choosing to "decline to provide treatment that is not scientifically validated and consistent with nationally accepted guidelines for clinical practice" [4].

Furthermore, the guidance in Opinion 9.7.2 calls for respecting the autonomy and obtaining <u>informed consent</u> from the incarcerated patient, to the best of the physician's ability. The opinion states that a physician must "be able to conclude, in good conscience and to the best of his or her professional judgment, that to the extent possible the patient voluntarily gave his or her informed consent, recognizing that an element of coercion ... is inevitably present" [4]. (Although the *Code of Medical Ethics* provides no guidelines for evaluating consent in correctional settings, specifically, or in situations of state-mandated care, it provides general guidelines for evaluating consent in Opinion 2.1.1 [5].)

Opinion 9.7.3, "Capital Punishment," discusses treatment of incarcerated patients in connection with nonmaleficence. According to this opinion, "as a member of a profession dedicated to preserving life when there is hope of doing so, a physician must not participate in a legally authorized execution" [6]. This guidance implies that incarcerated persons should be treated based on their illnesses and diagnoses, rather than their criminal convictions.

In circumstances in which physicians have the responsibility to provide court-initiated medical treatment for people who are incarcerated, they should confirm that the care they are offering is therapeutic and free from exploitation in the forms of punishment and social control.

References

- American Medical Association. Health care while incarcerated H-430.986. https://policysearch.ama-assn.org/policyfinder/detail/h-430?uri=%2FAMADoc%2FHOD-430.986.xml. Accessed July 28, 2017.
- 2. American Medical Association. Opinion 9.7.2 Court-initiated medical treatment in criminal cases. https://www.ama-assn.org/sites/default/files/mediabrowser/code-of-medical-ethics-chapter-9.pdf. Published 2016. Accessed May 30, 2017.
- 3. American Medical Association, Opinion 9.7.2, 23.
- 4. American Medical Association, Opinion 9.7.2, 24.
- American Medical Association. Opinion 2.1.1 Informed consent. https://www.ama-assn.org/sites/default/files/media-browser/code-ofmedical-ethics-chapter-2.pdf. Published 2016. Accessed July 13, 2017.
- American Medical Association. Opinion 9.7.3 Capital punishment. https://www.ama-assn.org/sites/default/files/media-browser/code-ofmedical-ethics-chapter-9.pdf. Published 2016:24. Accessed May 30, 2017.

Annalise Norling is a fourth-year undergraduate at Loyola University Chicago, where she studies philosophy and biology with a concentration in bioethics. During the summer of 2017, she was an intern for the American Medical Association's Ethics Group.

Related in the AMA Journal of Ethics

How Autonomous Is Medical Decision Making?, August 2009 Surgery in Shackles: What Are Surgeons' Obligations to Incarcerated Patients in the Operating Room?, September 2017 "Teach-to-Goal" to Better Assess Informed Consent Comprehension among Incarcerated Clinical Research Participants, September 2017

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 913-921

MEDICAL EDUCATION

Medicine and Mass Incarceration: Education and Advocacy in the New York City Jail System

Jonathan Giftos, MD, Andreas Mitchell, and Ross MacDonald, MD

Abstract

The United States incarcerates more people than any other country in the world. The scale of mass incarceration ensures that almost all practicing physicians will treat formerly incarcerated patients. Yet the majority of physicians receive little training on this topic. In this paper, we will outline the need for expanded education on the interface between incarceration and health, describe initiatives taking place within the New York City jail system and nationally, and describe future directions for curriculum development. We conclude by highlighting the important role health care workers can play in transforming our criminal justice system and ending mass incarceration.

Introduction

The United States incarcerates more people than any other country in the world [1], with 10.9 million people passing through its jails [2] and an estimated 6.7 million under correctional supervision in 2015 [3]. The scale of this mass incarceration—historically high rates of imprisonment, especially among young men of color [4]—along with the fact that the vast majority of incarcerated patients will return to their communities, ensures that almost all practicing physicians will treat justice-involved patients [5]. While innovators like the Transitions Clinic Network [6] have modeled comprehensive care for patients with a history of incarceration, most returning citizens will find themselves in a health care system that might not appreciate the harms of incarceration or the challenges of reentry.

Furthermore, incarcerated patients are disproportionately burdened by chronic medical problems and are exposed to health risks inherent to incarceration itself. Substance use disorders and severe <u>mental illness</u> are especially common [7, 8], and even short jail incarcerations can confer new morbidity due to violence, forced detoxification, medication interruption, and worsening mental health or self-harm during solitary confinement [9].

While *Estelle v Gamble* established the legal right to health care for incarcerated patients in 1976 [10], this right has not guaranteed access to clinicians with the knowledge,

attitudes, and skills necessary to care for a vulnerable population in a complicated environment. Recruiting and retaining mission-driven health care professionals to work in correctional settings remains a challenge [11].

We believe that concerted education of medical trainees in criminal justice and health can benefit patients and communities by improving community care for formerly incarcerated citizens, attracting talented clinicians to the correctional health workforce, and engaging medical professionals in criminal justice reform efforts.

Unfortunately, the majority of health care workers receive little training on this topic despite the high prevalence of criminal justice exposure in many communities [12, 13]. While select academic health centers have partnered with correctional systems, providing educational experiences in correctional health to nursing, social work, pharmacy and physician trainees, most academic health centers do not maintain such a relationship [14]. One survey found that only 14 percent of residency programs offered lectures or conferences on the care of incarcerated persons, and only 22 percent offered clinical experiences in a correctional facility [15]. Most experiences are offered as electives and not as required rotations [16].

In the Division of Correctional Health Services (CHS) of the New York City (NYC) public hospital system, Health + Hospitals, we have sought to foster an academic approach to the provision of medical care in the NYC jail system. These efforts included the hiring of a director of clinical education to manage the engagement of trainees with the jail system and to improve partnerships with academic health centers. This position has formalized CHS's commitment to public education on criminal justice and health and has led to the creation of new educational initiatives within the NYC jail system.

In this paper, we will review the harms of criminal justice exposure for patients and communities in connection with educational initiatives taking place within the NYC jail system, with a focus on CHS's two-week medical student and resident elective in correctional health. We will then discuss barriers to implementation of such programs and the need for expanded clinician education on the interface between incarceration and health. We conclude by highlighting the important role health care workers can play in transforming our criminal justice system and ending mass incarceration.

Curricular Themes and Implementation

Health risks of incarceration and reentry. Incarceration can have long-lasting effects on health and health-seeking behavior, with the immediate postrelease period considered to be a time of particularly increased health risk [17]. Forced detoxification from heroin during incarceration has been shown to increase overdose risk on reentry, and rapid methadone tapers while incarcerated can lead to subsequent aversion to medication-assisted treatment [18]. The Medicaid Inmate Exclusion Policy (MIEP), which suspends

patients' Medicaid coverage while they are incarcerated, can leave patients uninsured during the transition to the community [19], and clinicians' stigmatization of justice–involved patients can limit patients' engagement with medical care [20]. Discrimination in the labor market, where potential employers screen out persons with a criminal record, can make employment difficult to secure [21]. Many patients struggle to find housing, often unable to return to their families or public housing due to restrictions stemming from their conviction [22]. Last, many patients convicted of a felony—including those on parole—are unable to vote in certain states such as New York [23], leading to disenfranchisement and civic disengagement. Collectively, these social determinants of health directly and indirectly confer health risks on justice–involved patients [24, 25], and an awareness of these factors by clinicians can influence clinical care and advocacy efforts.

In the CHS two-week medical student and resident elective in the NYC jail system which includes guided readings, lectures, jail-based clinical shadowing, and experiences with community-based organizations providing services or advocacy to formerly incarcerated patients—learners develop an appreciation for the health risks of incarceration and reentry while also learning about ongoing efforts to minimize these risks. Such efforts include comprehensive reentry support services; overdose prevention through counseling, initiation of methadone or buprenorphine, and naloxone training for families; development of transitions clinics [26]; and promotion of justice–friendly hiring [27].

Social determinants of health. Not all communities are affected equally by the harms of criminal justice exposure [13]. Social determinants of health, such as <u>race and class</u>, also affect one's risk of arrest and incarceration by way of specific criminal justice policies. For example, the use of monetary bail increases the likelihood of pretrial detention and its associated health risks, such as infectious disease, violence, or interruption in medical care, for low-income people [28-30]. Certain law enforcement activities, such as the New York City Police Department's "stop, question, and frisk" policy, are associated with mental health risks for those targeted [31] and, along with schools' zero tolerance policies [32], increase criminal justice exposure for communities of color [31-33]. Lastly, the criminalization of addiction [34] increases the likelihood that patients with substance use disorders will experience incarceration and its associated health risks.

To better understand these risks, we connect learners participating in the CHS correctional health elective to organizations engaged in related organizing and advocacy work. Educational partners include Voices of Community Activists and Leaders (VOCAL-NY), Drug Policy Alliance, the Bronx Defenders, and the Osborne Association. Our trainees learn how interventions such as bail reform (e.g., reducing use of pretrial detention, elimination of cash bail), drug policy reform (e.g., decriminalization of substance use or possession), Law Enforcement Assisted Diversion (LEAD[®]) [35], and

assisted outpatient treatment [36] can mitigate harms of criminal justice exposure for low-income patients with substance use disorders or mental illness. During one elective, medical students observed arraignments at Kings County Criminal Court, met with the Brooklyn Community Bail Fund (a nonprofit organization that pays bail for low-income people), and then observed medical intakes in the jail system. These experiences allowed learners to observe the relationship between poverty and pretrial detention, with its attendant health risks, while highlighting the potential for community bail funds (or, ultimately, bail reform) to mitigate those risks. Community partners are critical to educational efforts, as they help trainees see connections between criminal justice policy and their patients' health, potentially informing trainees' subsequent advocacy.

CHS offers trainees the opportunity to rotate through its jail-based clinics on Rikers Island, either for a one-time visit or as part of a longer elective in correctional health. During these experiences, learners review the triple aims of correctional health: patient safety, population health, and human rights [37]. They observe as clinician educators provide patient care, including medical intakes; <u>chronic care</u> visits; and specialized addiction, mental health, and HIV care. Dual loyalty—the impact of the security setting on health care delivery—and efforts to mitigate its impact are explored [38]. Efforts to reduce the harms of incarceration, including prearraignment health screening, medication-assisted treatment for patients with opioid use disorders, clinical alternatives to punitive segregation, and the use of electronic health records to track violence and injuries are essential topics. The relationship between jail and community is also emphasized. Jails represent part of the institutional circuit [8, 39]—along with inpatient drug treatment programs, emergency rooms, and psychiatric hospitals—for patients with substance use disorders and unstable housing. As such, CHS has hosted addiction specialists and emergency room physicians from community hospitals so that learners might better understand the jail experience and its impact on patients' health.

Barriers to Implementation

Implementing educational experiences in correctional health presents unique challenges. Security concerns inherent to correctional settings can present logistical barriers to access for trainees. During a rotation with CHS, the student coauthor needed to meet his preceptor near public transit, drive onto the grounds of the jail complex, wait for daily security clearance, and be escorted through facilities by a corrections officer. Such restrictions to access and movement create a barrier to entry for trainees interested in correctional health.

A shortage of mentors represents another barrier. The student coauthor on this paper came to New York City—where CHS has a faculty member dedicated to education—in part because he had difficulty finding faculty mentors at his home institution. These challenges have been described previously and are likely to be experienced at other institutions implementing similar programs [40]. Higher requisite faculty-to-student

ratios, coupled with the shortage of faculty mentors, can leave systems struggling to support student interest.

The need for unique systems knowledge represents another barrier. Providing care for justice–involved patients requires navigating the intersection of two complex systems: the health care system and the criminal justice system. Doing so effectively requires knowledge and skills that can take years to learn. This learning process is further complicated by criminal justice policy that varies from one city or state to another. One must be familiar with Medicaid policy to participate in discharge planning, and a basic knowledge of criminal procedure (e.g., timing of court dates, implications of charges or parole for drug treatment) is often necessary to make a treatment plan for jail-incarcerated patients [41]. Without a foundation of such knowledge, trainees can find themselves overwhelmed in justice–related training environments.

Future Directions

Three key elements are rapidly converging in this field: a critical mass of students interested in the health effects of mass incarceration, the development of novel curricula to meet this need, and digital technologies enabling rapid dissemination of educational material. While experiential learning remains at the center of these educational initiatives, technology allows for the expanded reach of educational efforts to more learners without stretching scarce faculty resources.

In addition to his being a participant in the CHS curriculum, the student co-authoring this paper is the co-creator of a separate correctional health curriculum for medical students. This online student curriculum features a collection of curated didactic videos by nationally renowned faculty on salient topics related to criminal justice and health [42], and it has served as a foundation for students nationwide to create similar electives. Already, this digital curriculum has inspired two similar curricula that we know of for medical residents at the University of Washington and Brown University and has generated partnerships with institutions across the country.

Conclusion

As our country wrestles with its response to complex social problems like poverty, institutional racism, and structural violence, there is growing bipartisan consensus (with the exception of some from within the Trump administration [43]) that mass incarceration is a failed experiment and that an alternative path must be pursued. In New York, the governor, the mayor of New York City, and an independent commission convened by the New York City Council and the advocacy community have called for the closure of Rikers Island and the transformation of our city jail system [44]. As this process unfolds, it will be critical for mission–driven health care workers to remain involved, both as providers of compassionate clinical care for patients wherever they might be, and as advocates calling for public health approaches to community problems.

Expanding education for medical trainees on criminal justice and health will be critical to this important effort.

References

- Walmsley R. World prison population list (fifth edition). London, UK: Home Office Research, Development and Statistics Directorate; 2003. http://www.apcca.org/uploads/5th_Edition_2004.pdf. Accessed June 8, 2017.
- 2. Minton TD, Zeng Z. Jail inmates 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/ji15.pdf. Accessed June 7, 2017.
- 3. Kaeble D, Glaze L. Correctional populations in the United States, 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/cpus15.pdf. Accessed May 30, 2017.
- 4. Wildeman C. Mass incarceration. *Oxford Bibliographies*. http://www.oxfordbibliographies.com/view/document/obo-9780195396607/obo-9780195396607-0033.xml. Updated April 24, 2012. Accessed July 24, 2017.
- Hughes T, Wilson DJ. Reentry trends in the US. US Department of Justice Office of Justice Programs Bureau of Justice Statistics. https://www.bjs.gov/content/reentry/reentry.cfm. Updated July 31, 2017. Accessed July 31, 2017.
- Transitions Clinic Network website. http://transitionsclinic.org/. Accessed May 30, 2017.
- Maruschak LM. Medical problems of prisoners. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; April 2008. https://www.bjs.gov/content/pub/pdf/mpp.pdf. Accessed May 30, 2017.
- MacDonald R, Kaba F, Rosner Z, et al. The Rikers Island hot spotters: defining the needs of the most frequently incarcerated. *Am J Public Health*. 2015;105(11):2262–2268.
- 9. Kaba F, Lewis A, Glowa-Kollisch S, et al. Solitary confinement and risk of selfharm among jail inmates. *Am J Public Health*. 2014;104(3):442–447.
- 10. Estelle v Gamble, 429 US 97 (1976).
- Venters H. A three-dimensional action plan to raise the quality of care of US correctional health and promote alternatives to incarceration. *Am J Public Health*. 2016;106(4):613–614.
- 12. Shah MP, Edmonds-Myles S, Anderson M, Shapiro ME, Chu C. The impact of mass incarceration on outpatients in the Bronx: a card study. *J Health Care Poor Underserved*. 2009;20(4):1049–1059.
- 13. New York City Department of Health and Mental Hygiene. NYC community health profiles. https://www1.nyc.gov/site/doh/data/data-publications/profiles.page. Accessed June 8, 2017.

- Trestman RL, Ferguson W, Dickert J. Behind bars: the compelling case for academic health centers partnering with correctional facilities. *Acad Med*. 2015;90(1):16-19.
- Kraus ML, Isaacson JH, Kahn R, Mundt MP, Manwell LB. Medical education about the care of addicted incarcerated persons: a national survey of residency programs. *Subst Abus*. 2001;22(2):97–104.
- 16. Min I, Schonberg D, Anderson M. A review of primary care training programs in correctional health for physicians. *Teach Learn Med.* 2012;24(1):81–89.
- 17. Binswanger IA, Stern MF, Deyo RA, et al. Release from prison—a high risk of death for former inmates. *N Engl J Med.* 2007;356(2):157–165.
- Maradiaga JA, Nahvi S, Cunningham CO, Sanchez J, Fox AD. "I kicked the hard way. I got incarcerated." Withdrawal from methadone during incarceration and subsequent aversion to medication assisted treatments. *J Subst Abuse Treat*. 2016;62:49–54.
- 19. Morrissey JP, Dalton KM, Steadman HJ, Cuddeback GS, Haynes D, Cuellar A. Assessing gaps between policy and practice in Medicaid disenrollment of jail detainees with severe mental illness. *Psychiatr Serv.* 2006;57(6):803–808.
- 20. Marlow E, White MC, Chesla CA. Barriers and facilitators: parolees' perceptions of community health care. *J Correct Health Care*. 2010;16(1):17–26.
- 21. Stoll MA, Bushway SD. The effect of criminal background checks on hiring ex-offenders. *Criminol Public Policy*. 2008;7(3):371-404.
- 22. Baptiste N. After incarceration, what next? *American Prospect*. January 26, 2016. http://prospect.org/article/after-incarceration-what-next. Accessed July 2017.
- 23. Chung J. Felony disenfranchisement: a primer. The Sentencing Project. May 10, 2016. http://www.sentencingproject.org/publications/felony-disenfranchisement-a-primer/_Accessed July 2017.
- 24. Schnittker J, John A. Enduring stigma: the long-term effects of incarceration on health. *J Health Soc Behav.* 2007;48(2):115–130.
- 25. Marmot MG, Stansfeld S, Patel C, et al. Health inequalities among British civil servants: the Whitehall II study. *Lancet.* 1991;337(8754):1387-1393.
- 26. Wang EA, Hong CS, Samuels L, Shavit S, Sanders R, Kushel M. Transitions Clinic: creating a community-based model of health care forrecently released California prisoners. *Public Health Rep.* 2010;125(2):171–177.
- 27. Thill Z, Abare M, Fox A. Thinking outside the box: hospitals promoting employment for formerly incarcerated persons. *Ann Intern Med.* 2014;161(7):524–525.
- Stevenson M. Distortion of justice: how the inability to pay bail affects case outcomes. https://www.law.upenn.edu/cf/faculty/mstevens/workingpapers/Stevenson%2 OJob%20Market%20Paper%20Jan%202016.pdf. Published January 2016. Accessed July 27, 2017.
- 29. Pinto N. The bail trap. *New York Times Magazine*. August 13, 2015.

https://www.nytimes.com/2015/08/16/magazine/the-bail-trap.html. Accessed July 2017.

30. Open Society Foundations. Pretrial Detention and Health: Unintended Consequences, Deadly Results. https://www.opensocietyfoundations.org/sites/default/files/ptd-health-

20111103.pdf. Published 2011. Accessed July 2017.

- 31. Geller A, Fagan J, Tyler T, Link BG. Aggressive policing and the mental health of young urban men. *Am J Public Health*. 2014;104(12):2321–2327.
- 32. Heitzeg NA. Education or incarceration: zero tolerance policies and the school to prison pipeline. *Forum Public Policy*. 2009(2). http://files.eric.ed.gov/fulltext/EJ870076.pdf. Accessed June 8, 2017.
- 33. Gelman A, Fagan J, Kiss A. An analysis of the New York City police department's "stop-and-frisk" policy in the context of claims of racial bias. *J Am Stat Assoc*. 2007;102(479):813-823.
- 34. Mollman M, Mehta C. Neither justice nor treatment: drug courts in the United States. Physicians for Human Rights; June 2017. http://physiciansforhumanrights.org/assets/misc/phr_drugcourts_report_singl epages.pdf. Accessed July 31, 2017.
- 35. Beckett K. Seattle's law enforcement assisted diversion program: lessons learned from the first two years. Ford Foundation; March 21, 2014. https://fordfoundcontent.blob.core.windows.net/media/2543/2014-leadprocess-evaluation.pdf. Accessed June 8, 2017.
- Swartz MS, Wilder CM, Swanson JW, et al. Assessing outcomes for consumers in New York's assisted outpatient treatment program. *Psychiatr Serv.* 2010;61(10):976–981.
- 37. MacDonald R, Parsons A, Venters HD. The triple aims of correctional health: patient safety, population health, and human rights. *J Health Care Poor Underserved*. 2013;24(3):1226–1234.
- 38. Glowa–Kollisch S, Graves J, Dickey N, et al. Data–driven human rights: using dual loyalty trainings to promote the care of vulnerable patients in jail. *Health Hum Rights*. 2015;17(1):e124–e135.
- 39. Hopper K, Jost J, Hay T, Welber S, Haugland G. Homelessness, severe mental illness, and the institutional circuit. *Psychiatr Serv.* 1997;48(5):659-665.
- 40. Haley HL, Ferguson W, Brewer A, Hale J. Correctional health curriculum enhancement through focus groups. *Teach Learn Med.* 2009;21(4):310–317.
- 41. Tomasino V, Swanson AJ, Nolan J, Shuman HI. The Key Extended Entry Program (KEEP): a methadone treatment program for opioid-dependent inmates. *Mt Sinai J Med*. 2001;68(1):14-20.
- 42. Mitchell A, Randall J, Aziz-Bose R, Reichberg T, Stern M, Ferguson W. Criminal justice health digital curriculum: lessons at one year. Poster presented at: 10th Academic and Health Policy Conference on Correctional Health; March 16-17, 2017; Atlanta, GA.

- 43. Ford M. Jeff Sessions reinvigorates the drug war. *Atlantic*. May 12, 2017. https://www.theatlantic.com/politics/archive/2017/05/sessions-sentencingmemo/526029/<u>.</u> Accessed July 2017.
- 44. Independent Commission on New York City Criminal Justice and Incarceration Reform. A More Just New York City. https://assets.documentcloud.org/documents/3533809/Independent-Commission-on-New-York-City-Criminal.pdf. Accessed June 8, 2017.

Jonathan Giftos, MD, is the director of clinical education for the NYC Health + Hospitals Division of Correctional Health Services in New York City, where he teaches and provides clinical care to incarcerated patients in the New York City jail system. He is also a clinical instructor of medicine at the Albert Einstein College of Medicine and a voluntary attending physician in the Bronx Transitions Clinic at Montefiore's Comprehensive Health Care Center.

Andreas Mitchell is a fourth-year medical student at Harvard Medical School and is also pursuing a master's degree in public policy at the Harvard Kennedy School of Government in Boston. He has served as co-chair of the student leadership committee of the Harvard Medical School Center for Primary Care and is a student member of the board of the Academic Consortium on Criminal Justice Health, an organization with which he has partnered to create a digital curriculum on criminal justice and health.

Ross MacDonald, MD, is the chief medical officer for the NYC Health + Hospitals Division of Correctional Health Services in New York City. He is also an assistant professor of medicine at New York University School of Medicine and the author of numerous articles on correctional health and human rights.

Related in the AMA Journal of Ethics

The AMA Code of Medical Ethics' Opinions Related to Health Care for Incarcerated People, September 2017 #BlackLivesMatter: Physicians Must Stand for Racial Justice, October 2015 Correctional Mental Health, February 2008 Diagnosis and Treatment of Chronic Hepatitis C in Incarcerated Patients, February 2008 Ethics Students Go to the Jail, September 2017 Physician Empathy in Correctional Facilities: Still in Need of Analysis, February 2008 Why It's Inappropriate Not to Treat Incarcerated Patients with Opioid Agonist Therapy, September 2017

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 922-930

STATE OF THE ART AND SCIENCE

Why It's Inappropriate Not to Treat Incarcerated Patients with Opioid Agonist Therapy

Sarah E. Wakeman, MD

Abstract

Due to the criminalization of drug use and addiction, opioid use disorder is overrepresented in incarcerated populations. Decades of evidence supports opioid agonist therapy as a highly effective treatment that improves clinical outcomes and reduces illicit opioid use, overdose death, and cost. Opioid agonist therapy has been both studied within correctional facilities and initiated prerelease. It has been found to be beneficial, yet few incarcerated persons receive this evidence-based treatment. In addition to not offering treatment initiation for those who need it, most correctional facilities forcibly withdraw stable patients from opioid agonist therapy upon their entry into the criminal justice system. This approach limits their access to evidence-based health care and results in negative outcomes for individuals, communities, and society.

Introduction

Drug overdose is now the leading cause of death for Americans under age 50 [1]. In 2015 alone, there were 52,404 drug overdose deaths in the US, 63.1 percent of which involved an opioid [2]. Due to the criminalization of drug use and addiction, the prevalence of opioid use is overrepresented in incarcerated populations. Among noninstitutionalized Americans aged 12 or older, the 2014 National Survey on Drug Use and Health estimates that 1.8 percent currently engage in nonmedical use of prescription pain relievers or heroin; in contrast, 12 percent of jail inmates report using opioids regularly [3, 4]. The rising tide of deaths due to opioid overdose has been called an epidemic by the Department of Health and Human Services [5]. An epidemic, defined as an outbreak of disease that spreads rapidly and affects many people, is by definition driven by an illness. That the current opioid crisis is due to a medical condition rather than a moral failing or criminal behavior is an important distinction when shaping a response; people with an illness must be treated, not punished.

Increasingly, this sentiment is echoed in comments by leaders in government and law enforcement, many of whom have used the phrase, "We're not going to arrest out way out of" the crisis of opioid overdose deaths [6]. There are a growing number of police-led diversion efforts, such as the "Angel" program in Massachusetts, which connects patients directly to detoxification or rehabilitation programs [7]. While the changing language and new diversion programs are promising, many people with <u>substance use</u> <u>disorders</u> still experience incarceration for drug-related charges. In jails and federal and state prisons combined, in 2015 there were 469,545 Americans imprisoned for drug-related offenses [8], and in 2010 there were 1,638,846 drug-related arrests, 82 percent of which were for simple possession [9]. A prospective cohort study of current and former people who inject drugs in Baltimore found that 57 percent experienced at least one incarceration episode during a median follow-up period of 6.75 years and that 67percent of those experiencing incarceration reported multiple episodes [10]. And a 2004 study estimated that 440,000 people with opioid use disorder are detained in jails annually [11].

Treatment within correctional facilities for opioid use disorder, when it occurs, rarely resembles evidence-based treatment recommendations, and few patients are even seen by a trained professional [12]. Here, I review the evidence supporting the effectiveness of opioid agonist treatment for opioid use disorder and the lack of access to this therapy in correctional facilities. I will then discuss some reasons for limited access to opioid agonist therapy in correctional facilities and the ethical implications of withholding this treatment.

Clinical Evidence Base for Opioid Agonist Therapy

The most effective treatment for opioid use disorder involves maintenance treatment with the opioid agonist medications methadone and buprenorphine [13-15]. Opioid agonist therapy has been both studied as a treatment within correctional facilities and initiated prerelease in numerous US and international settings [16]. Treatment with buprenorphine or methadone has been found to be beneficial, reducing in-prison risk behavior and increasing postrelease treatment retention while reducing ongoing opioid use, overdose, and death [17]. Protection from fatal overdose is particularly important for those experiencing incarceration, as the risk of death from overdose for those within two weeks of release from prison is 129 times higher than that of community residents [18]. The risk of all-cause mortality among people with opioid use disorder is 2-3 times lower while on opioid agonist therapy than while off it [19]. This treatment is potentially lifesaving not only prior to release but also during incarceration. Among incarcerated people, the hazard of all-cause in-prison death during the first four weeks of incarcerated people, the hazard of all-cause in-prison death during the first four weeks of incarcerated people.

Objections to Opioid Agonist Therapy

Despite the evidence, access to these treatments is limited [11, 12]. Reasons for not offering opioid agonist therapy include concerns about <u>diversion</u> and philosophical objection to the notion of agonist therapy—viewing it as a substitution and thus not as legitimate as abstinence-based recovery [21]. In addition to not initiating treatment for

those who need it, most correctional facilities forcibly withdraw stable patients from opioid agonist therapy upon entry into the criminal justice system [22]. This approach has been shown to decrease community treatment entry [23]. It also functions to detract people with a history of incarceration from engaging in treatment due to fear of subsequent forced withdrawal [24].

The lack of access to opioid agonist therapy in criminal justice settings is due in large part to negative attitudes among correctional staff and leadership about the use of these medications [25]. In a 2008 survey of prison medical directors, the most frequently cited reason for not offering opioid agonist therapy was that they preferred drug-free detoxification [26]. In a study of attitudes towards methadone initiation in prison, a staff member commented, "Why would you re-addict someone after we've cleaned them up?" [27]. A widely held misunderstanding that these medications are "replacement addictions" is a potent driver of stigma [14]. And it is patently false. Addiction is defined by the American Society of Addiction Medicine as compulsive drug use despite harmful consequences [28]. Taking a daily prescribed medication that improves functioning, health, and quality of life, while reducing other drug use and death, does not meet this definition. People taking opioid agonist therapy depend on a daily medication to keep their disease in remission, the same way that people with diabetes, hypertension, hyperlipidemia, hypothyroidism, and nearly every chronic medical condition do. Unfortunately, this persistent stigma against opioid agonist therapy has very real policy implications, as evidenced by the responses of correctional staff cited above. Given the strength of the evidence supporting opioid agonist therapy, incarcerated patients' lack of access to it raises questions about whether the care for people with addiction experiencing incarceration is truly equivalent to the care provided to the general community [29].

Clinical Evidence for Opioid Antagonist Therapy

Few US correctional facilities allow opioid agonist therapy; however, a growing number are supportive of antagonist therapy with extended-release naltrexone. The opioid antagonist naltrexone is the third medication that has been FDA-approved for opioid use disorder and can be considered for people with less severe opioid use disorder and a high likelihood of abstinence [30]. The ongoing crisis of deaths, coupled with the stigma of opioid agonist therapy, has presented a remarkable opportunity for dissemination of extended-release naltrexone and profit for the company manufacturing it [31].

The evidence supporting extended-release naltrexone is weaker than the evidence for opioid agonist therapy. The one US randomized controlled trial conducted with people on probation or parole did show that extended-release naltrexone was more effective than no medication [32]. In this study, opioid-free participants with a stated goal of treatment that did not include opioid agonist or partial agonist treatment were randomized to extended-release naltrexone or to no medication. A relapse event was detected in 43

percent of those in the intervention arm compared to 64 percent in the control arm. In follow-up out to 54weeks after naltrexone was stopped, there were no differences between the two groups, with 46 percent of participants in both groups having opioid-positive toxicology.

While these findings support ongoing treatment with extended-release naltrexone as a relapse prevention intervention among a carefully selected patient population, they do not support the broad adoption of this medication as the only pharmacological option for people with opioid use disorder in the criminal justice system. As Kevin Fiscella, an addiction specialist who advises the National Commission on Correctional Health Care, opined, "When we have two agents that work [methadone and buprenorphine], why would you not use them? I can't imagine anywhere else in medicine where anyone would use an unproven agent instead of a proven one" [21]. Recent journalism has explored the reasons for such broad support of extended-release naltrexone in the face of relatively little empirical evidence. What was uncovered was an extensive and expensive lobbying effort by the company Alkermes, which makes an extended-release naltrexone. This company's effort appears to have largely targeted criminal justice systems and seems to have used correctional staffs' distaste for opioid agonist therapy to its advantage:

That [extended-release naltrexone] has no street value and no potential for abuse has helped the drug shake some of the skepticism directed toward medication-assisted treatment. For the last several years, the company has marketed the drug heavily to people in the criminal justice system, convincing judges and corrections officials to offer [this drug] to inmates and parolees [31].

As a testament to the effectiveness of this strategy, the brand name of this drug and variations on it now appear in more than 70 bills and laws in 15 states [31].

Ethical and Legal Considerations

In 1976, the US Supreme Court ruling in *Estelle v Gamble* found that deliberate indifference to a prisoner's serious illness constitutes cruel and unusual punishment, violating the Eighth Amendment [33]. Importantly, this ruling has advanced the quality of correctional health care for most medical conditions though not necessarily for the <u>treatment of addiction</u> [34]. An ethical challenge unique to physicians working within criminal justice settings is that the patient's well-being is not the sole driver of treatment. Physicians working within correctional facilities are caught in a "dual loyalty conflict" wherein the punitive aspect of the correctional facilities' mission and the best interest of their patients often oppose each other [35]. These ethical conflicts are present not only within jails and prisons but also in drug courts. A 2013 survey found that only 34 percent of US drug courts report permitting initiation of opioid agonist therapy in some circumstances, including continuation of treatment for those on agonist therapy [36]. In a study of clinicians who work with drug courts, respondents felt that the reason judges don't allow methadone is because of their personal biases against methadone as a valid treatment. One clinician commented, "Methadone always has this stigma associated with it.... People can't think of it as medicine" [37]. The clinical implications of these biases can be grim. A judge in New York ordered a defendant taken off of methadone treatment, stating that it does not enable a person "to actually rid him or herself of the addiction." The man subsequently died from overdose [38].

The combination of preferential use of opioid antagonist therapy despite its limited scientific support in comparison with methadone and buprenorphine, the lack of access to opioid agonist therapy initiation for those who need it, and the forced withdrawal of stable patients upon entry into the criminal justice system is ethically concerning. This approach ignores <u>respect for patient autonomy</u>, limits access to evidence-based health care, and results in negative outcomes for individuals, communities, and society. The example of drug court judges mandating withdrawal from successful opioid agonist therapy raises additional concerns in situations in which a judge is making life-or-death clinical decisions. It also highlights how treatment for addiction is approached differently from any other medical illness. Imagine if a judge required that a person with diabetes stop insulin therapy and instead be treated with diet and exercise because he or she didn't "believe" in medication treatment for diabetes.

Conclusion

In light of the scientific evidence, withholding effective medical treatment with opioid agonist therapy from people with addiction is ethically questionable in any context. To do so during a public health crisis that disproportionately affects people experiencing incarceration is unconscionable. Truly addressing the crisis of opioid-related deaths as an epidemic will require strategies guided by science, not ideology. Ongoing practices of incarcerating people for drug-related crimes in the first place deserve scrutiny. In the meantime, those under any form of correctional supervision should be encouraged to start, and should not be prevented from starting, potentially lifesaving opioid agonist treatment. Physicians have a role in advocating for change in both the criminalization of addiction and access to evidence-based, community standards of care for people under correctional supervision. In the face of growing evidence of the deadly impact of the status quo, there is arguably a moral imperative to advocate for such change.

References

Katz J. Drug deaths in America are rising faster than ever. *New York Times*. June 5, 2017. https://www.nytimes.com/interactive/2017/06/05/upshot/opioid-epidemic-drug-overdose-deaths-are-rising-faster-than-ever.html?_r=0. Accessed June 13, 2017.

- 2. Rudd RA, Seth P, David F, Scholl L. Increases in drug and opioid-involved overdose deaths—United States, 2010-2015. *MMWR Morb Mortal Wkly Rep.* 2016;65(5051):1445-1452.
- Substance Abuse and Mental Health Services Administration (SAMHSA). Behavioral health trends in the United States: results from the 2014 National Survey on Drug Use and Health. HHS publication SMA 15-4927. https://www.samhsa.gov/data/sites/default/files/NSDUH-FRR1-2014/NSDUH-FRR1-2014.pdf.Published September 2015. Accessed August 2, 2017.
- 4. Chandler RK, Finger MS, Farabee D, et al. The SOMATICS Collaborative: introduction to a National Institute on Drug Abuse cooperative study of pharmacotherapy for opioid treatment in criminal justice settings. *Contemp Clin Trials.* 2016; 48:166-172.
- 5. US Department of Health and Human Services Office of the Surgeon General. *Facing Addiction in America: The Surgeon General's Report on Alcohol, Drugs, and Health.* Washington, DC: US Department of Health and Human Services; November 2016. https://addiction.surgeongeneral.gov/surgeon-generalsreport.pdf. Accessed August 2, 2017.
- Arsenault C. Natick chiefs: "we're not going to arrest our way out of the opioid epidemic." *Natick Patch*. July 31, 2016. https://patch.com/massachusetts/natick/natick-chiefs-were-not-going-arrestour-way-out-opioid-epidemic. Accessed July 19, 2017.
- Schiff DM, Drainoni ML, Bair-Merritt M, Weinstein Z, Rosenbloom D. A police-led addiction treatment referral program in Massachusetts. *N Engl J Med*. 2016;375(25):2502-2503.
- The Sentencing Project. Trends in US Corrections. http://sentencingproject.org/wp-content/uploads/2016/01/Trends-in-US-Corrections.pdf. Updated June, 2017. Accessed July 18, 2017.
- 9. Federal Bureau of Investigation. Crime in the United States, 2010. https://ucr.fbi.gov/crime-in-the-u.s/2010/crime-in-the-u.s.-2010/personsarrested. Accessed August 2, 2017.
- 10. Genberg M, Astemborski J, Vlahov D, Kirk GD, Mehta SH. Incarceration and injection drug use in Baltimore, Maryland. *Addiction*. 2015;110(7):1152-1159.
- 11. Fiscella K, Pless N, Meldrum S, Fiscella P. Alcohol and opiate withdrawal in US jails. *Am J Public Health*. 2004;94(9):1522-1524.
- 12. Mumola CJ. Substance abuse and treatment, state and federal prisoners, 1997. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; January 1999. http://csdp.org/research/satsfp97.pdf. Accessed June 19, 2017.
- 13. Bart G. Maintenance medication for opiate addiction: the foundation of recovery. *J Addict Dis.* 2012;31(3):207-225.
- 14. Volkow ND, Frieden TR, Hyde PS, Cha SS. Medication-assisted therapies tackling the opioid-overdose epidemic. *N Engl J Med*. 2014;370(22):2063-2066.

- World Health Organization. Guidelines for the Psychosocially Assisted Pharmacological Treatment of Opioid Dependence. Geneva, Switzerland: World Health Organization; 2009. http://www.who.int/substance_abuse/publications/opioid_dependence_guideli nes.pdf. Accessed on June 19, 2017.
- Wakeman SE, Rich JD. Addiction treatment within US correctional facilities: bridging the gap between current practice and evidence-based care. J Addict Dis. 2015;34(2-3):220-225.
- 17. Hedrich D, Alves P, Farrell M, Stöver H, Møller L, Mayet S. The effectiveness of opioid maintenance treatment in prison settings: a systematic review. *Addiction*. 2012;107(3):501-517.
- 18. Binswanger IA, Stern MF, Deyo RA, et al. Release from prison—a high risk of death for former inmates. *N Engl J Med*. 2007;356(2):157-165.
- 19. Sordo L, Barrio G, Bravo MJ, et al. Mortality risk during and after opioid substitution treatment: systematic review and meta-analysis of cohort studies. *BMJ*. 2017;357:j1550.

http://www.bmj.com/content/357/bmj.j1550.long. Accessed June 19, 2017.

- Larney S, Gisev N, Farrell M, et al. Opioid substitution therapy as a strategy to reduce deaths in prison: retrospective cohort study. *BMJ Open*.
 2014;4(4):e004666. http://bmjopen.bmj.com/content/4/4/e004666. Accessed August 2, 2017.
- 21. Vestal C. At Rikers Island, a legacy of medication-assisted opioid treatment. *Stateline*. May 23, 2016. http://www.pewtrusts.org/en/research-andanalysis/blogs/stateline/2016/05/23/at-rikers-island-a-legacy-of-medicationassisted-opioid-treatment. Accessed on June 19, 2017.
- 22. Fiscella K, Moore A, Engerman J, Meldrum S. Jail management of arrestees/inmates enrolled in community methadone maintenance programs. *J Urban Health.* 2004; 81(4):645-654.
- 23. Rich JD, McKenzie M, Larney S, et al. Methadone continuation versus forced withdrawal on incarceration in a combined US prison and jail: a randomised, open-label trial. *Lancet*. 2015;386(9991):350-359.
- 24. Maradiaga JA, Nahvi S, Cunningham CO, Sanchez J, Fox AD. "I kicked the hard way. I got incarcerated." Withdrawal from methadone during incarceration and subsequent aversion to medication assisted treatments. *J Subst Abuse Treat*. 2016;62:49-54.
- 25. Friedmann PD, Hoskinson R Jr, Gordon M, et al; Mat Working Group of CJ-DATS. Medication-assisted treatment in criminal justice agencies affiliated with the criminal justice-drug abuse treatment studies (CJ-DATS): availability, barriers, and intentions. *Subst Abus*. 2012;33(1):9-18.
- 26. Nunn A, Zaller N, Dickman S, et al. Methadone and buprenorphine prescribing and referral practices in state and federal prisons: results from a nationwide survey. *Drug Alcohol Depend*. 2009;105(1-2):83-88.

- 27. McKenzie M, Nunn A, Zaller ND, Bazazi AR, Rich JD. Overcoming obstacles to implementing methadone maintenance therapy for prisoners: implications for policy and practice. *J Opioid Manag.* 2009;5(4):224.
- American Society of Addiction Medicine. Definition of addiction. https://www.asam.org/quality-practice/definition-of-addiction. Adopted April 11, 2011. Accessed June 14, 2017.
- Larney S, Dolan K. A literature review of international implementation of opioid substitution treatment in prisons: equivalence of care? *Eur Addict Res.* 2009;15(2):107-112.
- 30. Substance Abuse and Mental Health Services Administration (SAMHSA). Clinical use of extended-release injectable naltrexone in the treatment of opioid use disorder: a brief guide. http://store.samhsa.gov/shin/content/SMA14-4892R/SMA14-4892R.pdf. Revised February 2, 2015. Accessed June 19, 2017.
- 31. Harper J, Allen B, Wroth C. A drugmaker tries to cash in on the opioid epidemic, one state law at a time. *NPR*. June 12, 2017. http://www.npr.org/sections/health-shots/2017/06/12/523774660/adrugmaker-tries-to-cash-in-on-the-opioid-epidemic-one-state-law-at-a-time. Accessed on June 14, 2017.
- 32. Lee JD, Friedmann PD, Kinlock TW, et al. Extended-release naltrexone to prevent opioid relapse in criminal justice offenders. *N Engl J Med*. 2016;374(13):1232-1242.
- Rosenfeld J. The origin of prisoner's rights: *Estelle v Gamble* 429 US 97; 75-929 (1976). *Natl Law Rev.* September 16, 2016. http://www.natlawreview.com/article/origin-prisoner-s-rights-estelle-v-gamble-429-us-97-75-929-1976. Accessed June 19, 2017.
- 34. Taxman FS, Perdoni ML, Harrison LD. Drug treatment services for adult offenders: the state of the state. *J Subst Abuse Treat*. 2007;32(3):239-254.
- 35. Allen SA, Wakeman SE, Cohen RL, Rich JD. Physicians in US prisons in the era of mass incarceration. *Int J Prison Health*. 2010;6(3):100-106.
- 36. Matusow H, Dickman SL, Rich JD, et al. Medication assisted treatment in US drug courts: results from a nationwide survey of availability, barriers and attitudes. *J Subst Abuse Treat*. 2013;44(5):473-480.
- Csete J, Catania H. Methadone treatment providers' views of drug court policy and practice: a case study of New York State. *Harm Reduct J.* 2013;10:35. https://harmreductionjournal.biomedcentral.com/articles/10.1186/1477-7517-10-35. Accessed August 2, 2017.
- 38. Szalavitz M. Every drug court should allow methadone treatment. *New York Times*. July 20, 2015. https://www.nytimes.com/2015/07/20/opinion/every-drug-court-should-allow-methadone-treatment.html. Accessed August 2, 2017.

Sarah E. Wakeman, MD, is the medical director for the Massachusetts General Hospital Substance Use Disorder Initiative in Boston, where she is also program director of the

Addiction Medicine Fellowship, medical director of the Addiction Consult Team, and cochair of the Opioid Task Force. She is also an assistant professor of medicine at Harvard Medical School and a clinical lead of the Partners Healthcare Substance Use Disorder Initiative. Her research interests include evaluating models for integrated substance use disorder treatment in general medical settings, recovery coaching, physician attitudes and preparedness related to substance use disorder, and screening for substance use in primary care.

Related in the AMA Journal of Ethics

Addiction, 12-Step Programs, and Evidentiary Standards for Ethically and Clinically Sound Treatment Recommendations: What Should Clinicians Do?, June 2016 The AMA *Code of Medical Ethics*' Opinions Related to Health Care for Incarcerated People, September 2017 Communicating with Patients about Harmful Behaviors, January 2008 How Should a Health Care Professional Respond to an Incarcerated Patient's Request for a Particular Treatment?, September 2017 Shared Responsibility: Massachusetts Legislators, Physicians, and An Act Relative to Substance Use Treatment, Education, and Prevention, September 2016 Teaching about Substance Abuse, January 2008

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 931-938

STATE OF THE ART AND SCIENCE

Swift and Certain, Proportionate and Consistent: Key Values of Urine Drug Test Consequences for Probationers

Amy B. Cadwallader, PhD

Abstract

Traditionally, urine drug testing (UDT) in the correctional population (both prison and community corrections) has been infrequent, is scheduled, and has a high possibility of delayed results. Of practical relevance is that scheduled testing is ineffective for identifying drug misuse. Of ethical relevance is that consequences of positive scheduled tests can be unpredictable—in the form of overly severe punishment or a lack of treatment options—and that the scheduled testing paradigm is a poor way to change behaviors. More innovative programs now use a UDT paradigm with more frequent, random testing providing rapid results and certain, swift consequences and addiction treatment when warranted or requested. Studies have shown these new programs—the foundation of which is frequent, random UDTs—to significantly reduce drug use, criminal recidivism, and incarceration.

Introduction

One central goal of the probation system is to help probationers make a positive, productive return to society by providing rehabilitation, including fostering recovery from drug addiction that might otherwise lead to recidivism. Probation supervision is intended to provide an alternative to incarceration; the probationer agrees to comply with a set of terms, and a probation officer is assigned to monitor the enforcement of those terms with the authority to report violations to a court for possible sanctions. Most offenders in the probation population are subject to prolonged supervision of several years or longer and most probation terms, regardless of the offense, drug-related or not, include urine drug testing (UDT) [1, 2]. UDT is an objective tool to detect the presence of nonprescribed or illicit drugs and to confirm the presence of prescribed drugs [3]. A probationer's aberrant UDT, usually positive for nonprescribed or illicit drugs, is typically considered a technical violation of agreed-upon probation terms and can result in return to prison. An innovative method of probation enforcement using frequent, random UDT providing rapid results that lead to swift and certain consequences is meant to motivate probationer compliance and lead to improved outcomes. This innovative method, in contrast to other forms of probation in which UDT is generally infrequent and scheduled, will be discussed.

Ongoing Practical and Ethical Challenges of Administering Probation UDT Programs

Managing heavy caseloads and scheduling UDTs has been, and continues to be, a challenge for detecting drug misuse in the probation population. Studies have documented probation officers overwhelmed with caseloads, some with officer-to-probationer ratios of 150:1, even as high as 180:1; heavy caseloads are clinically and ethically relevant because they are an impediment to keeping up with or detecting violations [2, 4, 5].

In current, traditional probation scenarios, UDT of probationers is generally too infrequent to be useful; once every month is a common UDT pattern used [1]. Testing weekly on an unpredictable schedule at the onset of UDT and moving to less frequent testing after a period of abstinence is recommended by the American Society of Addiction Medicine; UDT less frequently than once a month is not recommended for effective detection of violations or identification of drug misuse [6]. One study of probation populations in California revealed that UDT once a week produces an approximate 35 percent chance of detecting an incidence of drug use, while twice-aweek UDT increases that chance to greater than 80 percent. In contrast, monthly UDT has less than a 10 percent chance of detecting an incidence of drug use [1]. Another study evaluating UDT statistics in a general population noted that, with monthly UDT, it could take up to 13 months to detect aberrant drug use in a person [7]. Additionally, in many programs, testing is often publically scheduled in advance, which defeats the purpose of random UDT. Infrequent testing and public scheduling are ineffective both for the intended purpose of motivating behavior changes among probationers and for identifying probationers' drug misuse.

In addition to probation officers' heavy caseloads and scheduling of UDTs, there are other practical problems with the UDT of probationers. Test results can be sent to a contract laboratory but come back too slowly (weeks later, for example) or be reviewed too late by busy probation officers in order to implement meaningful sanctions intended to promote behavior change [6]. Meaningful or not, sanctions themselves are rare and many positive UDTs go unreported [8]. For some offenders who fail multiple UDTs and are reported, judges can be averse to sentencing the offenders for what they consider mild infractions. There are jurisdictions that have "drug courts" in lieu of traditional probation scenarios, in which judges mandate treatment and addiction services to offenders who fail multiple UDTs, and other newer, innovative probation programs, such as the Hawaii's Opportunity Probation with Enforcement (HOPE) program, which relies on UDT coupled with swift and certain consequences (to be discussed further below). These are special programs that are funded through individual state legislation or policy efforts. To be clear, what is being referred to here is a judge's punitive response to an offender who has violated agreed-upon terms of probation. When judges do levy sanctions, there can be variation and inconsistency in those sanctions [5, 8]. In some

cases, sanctions—months, or even years, in prison for one or more failed UDTs—might be more severe than legal professionals, correctional workers, probationers, and health care professionals, for example, might believe are warranted for the positive UDT infraction(s), particularly when treatment could be a more appropriate course of action [2].

Some probation programs test as little as 5 percent of the offender population, with a month or more turnaround for each individual test and inconsistent implementation of the testing [8, 9]. With programs failing to provide random drug testing, consistent punishment for failed UDTs, or access to treatment if needed, it is perhaps not surprising that approximately one-fourth of probationers fail the terms of their supervision programs [10]. Additionally, the national recidivism rate is estimated to be 40 percent, either for committing a new crime or for violating the terms of probation or release, which includes the technical violation of a positive UDT [11].

Intensive Supervision Probation and Random UDT

In an attempt to manage some of the challenges of traditional probation, every state in the United States implemented intensive supervision probation (ISP) for some high-risk probationers by 1990. Criteria for a probationer to be included in an ISP program vary by jurisdiction, but commonalities among programs include convictions for drug or drug-related offenses. In ISP programs, supervision of the probationer should be more than routine, with a higher frequency of random UDT for probationers and decreased caseloads for officers, allowing increased individual attention [2]. However, a study of ISP implementation in three California counties showed that probationers in ISP in one county were not tested randomly and that arrests for positive tests were no more likely for those in ISP than for those in routine probation [2].

Unfortunately, ISP has prioritized surveillance over rehabilitation, so resources have been utilized for monitoring and incarcerating persons for technical violations of probation terms and insufficient attention has been devoted to treating probationers for <u>substance</u> <u>use disorders</u> [2]. Because of the high prevalence of drug use among probationers, the emphasis that ISP places on technical violations of agreed-upon probation terms has been questioned [2].

Point-of-Care Urine Drug Testing As an Alternative to Standard Probation

In the past several years, more innovative programs have been implemented that utilize a UDT paradigm with frequent UDT coupled with certain, meaningful consequences, including <u>addiction treatment</u> when warranted or requested. Studies have shown that these new programs founded on frequent, random UDT significantly reduce drug use, criminal recidivism, and incarceration compared to standard probation scenarios [4, 8, 12-15]. In these programs, the UDTs are administered with "point-of-care" (POC) testing devices. POC tests are typically noninstrumented devices such as dip cards or cups with imbedded color-changing test strips that can be administered easily and onsite [3]. POC devices offer rapid results within minutes of being administered and allow for immediate consequences to be levied, as opposed to waiting days or weeks for laboratory results to be returned and interpreted. Although some limitations exist with POC testing devices, programs generally have access to laboratories with analytical testing procedures for confirming results that are contested by the probationer [3].

Hawaii's Opportunity Probation with Enforcement (HOPE) Program

Hawaii's Opportunity Probation with Enforcement (HOPE) program was one of the first programs to utilize swift and certain sanctions coupled to rapid UDT and is regarded by some as a successful model of this new approach for offender management [16]. HOPE is a community supervision strategy for substance-misusing probationers, which relies on a regimen of regular, random UDT, and swift and certain, but modest and proportionate (as little as two days in jail) [17] responses to violations to motivate probationer compliance [8]. The stated goals of HOPE are reductions in drug use, new crimes, and incarceration. HOPE began as a pilot program with 34 participants in 2004 and has expanded since then to include over 2,200 probationers in Hawaii as of 2015 [4].

HOPE process. The HOPE program begins with a formal "warning hearing" where probationers, often in a group in open court, are told that success is within their own control and that any violations will result in sanctions that can include a brief jail stay. HOPE's requirements for probationers with a history of drug use, who represent the vast majority of the caseload, include random UDT six times a month for the first several months and a requirement for probationers to call a hotline each weekday morning to determine if they are to be drug tested that day. Probationers who fail a UDT are arrested immediately (swift and certain response to the violation) and appear before a judge within hours or days for a modification of the terms of their probation; each successive violation results in an escalated response. Treatment for substance use disorder is reserved for the small percentage of probationers who request it or for those probationers who consistently fail tests [18].

HOPE research. A yearlong randomized controlled trial of the HOPE model revealed that HOPE probationers were 55 percent less likely to be arrested for a new crime, 72 percent less likely to use drugs, 61 percent less likely to miss appointments with their probation officer, and 53 percent less likely to have their probation revoked than probationers in "probation as usual" who did not receive random UDT but who did have scheduled appointments with a probation officer, typically once per month, during which UDTs could be administered [5, 19]. In a 10-year follow-up study evaluating whether the improvements in criminal justice outcomes after HOPE intervention persist long term after probation, HOPE probationers performed better than probationers under routine supervision; HOPE participants were less likely to commit new crimes and be returned to prison and more likely to receive early termination from probation [4]. Both probationers and probation officers who participated in the study supported the HOPE program. Probation officers believed it made them more effective at their jobs, and probationers appreciated the consistency and defined rules as opposed to the sporadic nature of testing and sanctions under the previous probation paradigms [4, 5].

Spreading HOPE

Several replication sites have been started in locations throughout the United States and additional jurisdictions are considering similar programs. Examples include SWIFT (Supervision With Intensive enForcemenT), PACE (Probation Accountability and Certain Enforcement), and WISP (Washington Intensive Supervision Program). SWIFT in Tarrant County, Texas, began at approximately the same time as HOPE with no knowledge of the program, is very similar to HOPE, and is experiencing outcomes similar to HOPE's [15]. PACE in Alaska was modeled after HOPE; preliminary results closely resembled those of HOPE, and it is being implemented across the state [12]. WISP in Washington State, a parolee version of HOPE targeting high-risk offenders, began as a small experimental pilot. Early reported success resulted in state-level action; legislation implementing the program statewide made WISP the largest program utilizing swift and certain sanctions and random UDT in the United States [13].

Importantly, in each jurisdiction, the model requires tailoring the program to the needs of each location and a coordinated effort [18, 20]. Circumstances vary from one jurisdiction to another, and implementation should be customized to meet the requirements of probationers, probation officers, and probation programs in that area. It is essential that efforts are coordinated in order for the local partners to identify probation violations, maintain consistency of program implementation, and respond to violations with swift and certain, but proportionate and appropriate, sanctions.

Some of the common messaging themes for success that have emerged from HOPE [16] emphasize fairness and consistency for the probationer and include the following:

- Clearly defined messages to probationers—that success is within their own control, that consequences are defined in a contract, and that violations will be followed by swift, certain responses—improves compliance.
- 2. Weekly randomized UDT, which can both aid in behavior change and help in identifying drug misuse, is an objective and useful tool for enforcing agreed-upon contract terms. The availability of treatment is paramount for those who are unable to comply on their own or for those who seek it.
- 3. Assurance of swift and certain levying of sanctions cultivates the probationers' sense of reliability and fairness.
- 4. Clear rules that are consistently implemented cultivate a reputation for follow through.

5. Coordination among all partners involved in the program caseload—including but not limited to probationers, local law enforcement professionals, judges, prosecutors, public defenders, and organizations such as jails, treatment facilities, and UDT laboratories—is critical.

Conclusion

Programs such as HOPE are innovative in their reliance upon core values, such as fairness, that concretely connect behaviors and consequences. There is a growing body of evidence to suggest that the use of objective tools, such as UDT, coupled with an approach that embraces swift, certain, proportionate, consistent consequences, is foundational to whether and when sanctions are perceived as fair and can aid in successful reintegration of those who are released from prison [4, 8, 12-15]. The evidence presented thus far suggests that prioritizing values over process can lead to the development and implementation of programs with better outcomes and offers support for introducing new methods and policy changes in the probation system.

References

- Kleiman MAR, Tran TH, Fishbein P, Magula MT, Allen W, Lacy G. Opportunities and barriers in probation reform: a case study in drug testing and sanctions. Berkeley, CA: California Policy Research Center; 2003. http://escholarship.org/uc/item/0238v37t#page-1. Accessed August 2, 2017.
- 2. Petersilia J, Turner S. Evaluation of intensive probation in California. *J Crim Law Criminol.* 1991; 82(3):610-658.
- 3. American Medical Association Council on Science and Public Health. Urine drug testing. https://www.ama-assn.org/sites/default/files/media-browser/2016-interim-csaph-report-1.pdf. Published 2016. Accessed June 9, 2017.
- Hawken A, Kulick J, Smith K, et al. HOPE II: a follow-up to Hawai 'i's HOPE evaluation. US Department of Justice; May 17, 2016. https://www.ncjrs.gov/pdffiles1/nij/grants/249912.pdf. Accessed June 9, 2017.
- Hawken A, Kleiman M. Managing drug involved probationers with swift and certain sanctions: evaluating Hawaii's HOPE. US Department of Justice; December 2009. https://www.ncjrs.gov/pdffiles1/nij/grants/229023.pdf. Accessed June 9, 2017.
- American Society of Addiction Medicine. Drug testing: a white paper of the American Society of Addiction Medicine (ASAM). https://www.asam.org/docs/default-source/public-policy-statements/drugtesting-a-white-paper-by-asam.pdf. Published October 2013. Accessed June 9, 2017.
- Wawrzyniak K, DiBenedetto D, Kulich R, Porter R. Impact of urine drug toxicology (UDT) frequency on uncovering aberrant behaviors with chronic opioid therapy: implications of delay in time of discovery. Paper presented at: 31st Annual Meeting of the American Academy of Pain Medicine; March 19-22, 2015;

National Harbor, MD. http://www.painmed.org/2015posters/abstract-206/. Accessed August 2, 2017.

- Hawken A, Davenport S, Kleiman M. Managing drug-involved offenders. US Department of Justice; July 2014. https://www.ncjrs.gov/pdffiles1/nij/grants/247315.pdf. Accessed June 9, 2017.
- Taxman FS, Reedy DC, Moline KI, Ormond M, Yancey C. Strategies for the druginvolved offender: testing, treatment, sanctions (BTC), and offender outcomes after 4 years of implementation. University of Maryland Center for Applied Policy Studies Bureau of Governmental Research; January 2003. http://msa.maryland.gov/megafile/msa/speccol/sc5300/sc5339/000113/0020 00/002219/unrestricted/20063158e.pdf. Accessed June 9, 2017.
- Kaeble D, Bonczar TP. Probation and parole in the United States, 2015. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2016. https://www.bjs.gov/content/pub/pdf/ppus15.pdf. Revised February 2, 2017. Accessed June 9, 2017.
- 11. Pew Center on the States. State of recidivism: the revolving door of America's prisons. Washington, DC: Pew Charitable Trusts; April 2011. http://www.pewtrusts.org/~/media/legacy/uploadedfiles/pcs_assets/2011/pe wstateofrecidivismpdf.pdf. Accessed June 9, 2017.
- 12. Carns TW, Martin S. Anchorage PACE probation accountability with certain enforcement: a preliminary evaluation of the Anchorage pilot PACE project. Alaska Judicial Council; September 2011. http://www.aic.ctate.ak.us/reports/pace2011.pdf_Accessed_lupe_0_2017
 - http://www.ajc.state.ak.us/reports/pace2011.pdf. Accessed June 9, 2017.
- Hamilton Z, van Wormer J, Kigerl A, Campbell C, Posey B. Evaluation of Washington State Department of Corrections (WADOC) swift and certain (SAC) policy process, outcome and cost-benefit evaluation. Washington State University Institute for Criminal Justice; August 31, 2015. https://wsicj.wsu.edu/wp-content/uploads/sites/436/2015/11/SAC-Final-Report_2015-08-31.pdf. Accessed June 9, 2017.
- Harrell A, Roman J, Bhati A, Parthasarathy B. The impact evaluation of the Maryland Break the Cycle initiative. Urban Institute Justice Policy Center; June 2003. http://www.urban.org/sites/default/files/publication/59331/410807-The-Impact-Evaluation-of-the-Maryland-Break-the-Cycle-Initiative.PDF. Accessed June 9, 2017.
- Stevens-Martin KD. The supervision with immediate enforcement (SWIFT) court: tackling the issue of high-risk offenders and chronic probation violators. *Corrections Today*. September/October 2014:74-77. http://www.aca.org/aca_prod_imis/Docs/Corrections%20Today/2014%20Articl es/Sept%20Articles/Martin.pdf. Accessed June 9, 2017.
- 16. Hawken A. The Message from Hawaii: HOPE for probation. *Perspectives*. 2010:36-49.

- Hawken A, Kleiman M. Washington intensive supervision program. Swift Certain Fair Resource Center; December 9, 2011. http://www.scfcenter.org/resources/Research/201112%20Washington%20Inte nsive%20Supervision%20Program%20Evaluation%20Report.pdf. Accessed May 24, 2017.
- 18. Pearsall B. Replicating HOPE: can others do it as well as Hawaii? *Natl Inst Justice J.* 2014(273):36-41.
- National Institute of Justice. "Swift and certain" sanctions in probation are highly effective: evaluation of the HOPE program. https://www.nij.gov/topics/corrections/community/drugoffenders/pages/hawaii-hope.aspx. Updated February 3, 2012. Accessed April 21, 2017.
- 20. Vera Institute of Justice. More than the sum of its parts: why Hawaii's Opportunity Probation with Enforcement (HOPE) program works. http://www.scfcenter.org/resources/Background-and-Analysis/201002%20More%20than%20the%20Sum%20of%20lts%20Parts.pdf. Accessed August 2, 2017.

Amy B. Cadwallader, PhD, is a senior policy analyst in the Science, Medicine, and Public Health Unit at the American Medical Association in Chicago who has nearly ten years of experience working in the drug testing field. She received her doctoral degree in pharmacology and analytical toxicology and has a master's degree in biology/forensic science.

Related in the AMA Journal of Ethics

Addiction, 12-Step Programs, and Evidentiary Standards for Ethically and Clinically Sound Treatment Recommendations: What Should Clinicians Do?, June 2016 Teaching about Substance Abuse, January 2008 What Does Health Justice Look Like for People Returning from Incarceration?, September 2017

<u>Why It's Inappropriate Not to Treat Incarcerated Patients with Opioid Agonist Therapy,</u> September 2017

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 939-946

POLICY FORUM

Surgery in Shackles: What Are Surgeons' Obligations to Incarcerated Patients in the Operating Room?

Sara Scarlet, MD, and Elizabeth Dreesen, MD

Abstract

Incarcerated patients frequently require surgery outside of the correctional setting, where they can be shackled to the operating table in the presence of armed corrections officers who observe them throughout the procedure. In this circumstance, privacy protection—central to the patient-physician relationship—and the need to control the incarcerated patient for the safety of health care workers, corrections officers, and society must be balanced. Surgeons recognize the heightened need for gaining a patient's trust within the context of an operation. For an anesthetized patient, undergoing an operation while shackled and observed by persons in positions of power is a violation of patient privacy that can lead to increased feelings of vulnerability, mistrust of health care professionals, and reduced therapeutic potential of a procedure.

What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about. Hippocratic Oath [1]

We are men: We are not beasts and we do not intend to be beaten or driven as such. L.D. Barkley [2]

Introduction

Providing health care to patients within the criminal justice system presents unique challenges. This is especially true for incarcerated persons requiring surgery outside of the correctional setting. Under these circumstances, the privacy at the core of the physician-patient relationship must be balanced against the need to control the incarcerated patient for the safety of health care workers, corrections officers, and society at large. For incarcerated patients requiring surgery, this tension between privacy and control exists throughout all phases of surgical care—from the office, where corrections officers observe the history and physical; to the operating room, where

patients are, in our experience, sometimes shackled to the operating table and observed throughout the duration of a procedure.

Respect for <u>patient privacy</u> is critical to the development and maintenance of trust in one's physician. The belief that sensitive information will remain confidential can enable patients to reveal disturbing and painful information that might be essential to the physician and the patient during the decision-making process. The patient's willingness to reveal information and subsequently to believe that the physician is accurately representing medical problems, treatments, and alternatives are all based on trust. Conversely, patients who distrust their clinicians might be more reticent to discuss personal information. In turn, decision making based on inaccurate or incomplete information might contribute to inappropriate tests, ineffective treatment plans, and costlier care [3]. Patients who distrust their clinicians are less likely to adhere to treatment plans, seek medical care, or consent to undergo a surgical procedure [3]. Surgeons recognize the heightened need for gaining a patient's trust within the context of an operation, in which patients lack the ability to protect themselves and must completely depend on the "knowledge, skills, and professional integrity" of the surgical team [4]. Without trust, the potential benefits of surgical intervention can be outweighed by the fear and vulnerability that such interventions engender.

In the United States, a patient's right to the privacy that enables trust is not solely upheld by ethical values—the Constitution also affords citizens a legal right to privacy. For example, the 1973 ruling in *Roe v Wade* upheld a person's right to privacy, justified by the First, Fourth, Ninth, and Fourteenth Amendments [5]. Additionally, the Health Insurance Portability and Accountability Act (HIPAA) of 1996 specifies requirements for maintaining patient confidentiality for health care professionals, insurance plans, and health care systems [6, 7]. The creation of HIPAA reflects recognition of the sensitive nature of patient health information and the need to protect this information in order to prevent harms. Of note, the HIPAA regulations specifically state that inmates' individually identifiable health information is not excluded from the definition of protected health information (PHI) [8]. It thus must be kept confidential, with the exception of situations in which covered entities, such as prison clinics, can disclose PHI to a correctional institution or to law enforcement officials for the provision of health care or if the safety of the patient, other inmates, corrections officers, or the correctional facility is jeopardized [8].

Issues of privacy and trust are particularly acute for incarcerated persons. Incarcerated persons are often from medically underserved populations and include ethnic minorities, who tend to have higher levels of <u>distrust</u> in the health care system [3, 9, 10]. Many incarcerated persons have experienced physical violence and sexual assault [11]. Mental illness is also common [9]. These types of experiences can heighten incarcerated persons' feelings of vulnerability and hinder the development of the mutual trust

between physicians and incarcerated patients that is required for treatments to be accepted and effective. Unfortunately, providing health care to incarcerated patients presents additional obstacles to building mutual trust. Unlike the general population, incarcerated patients are unable to choose their physicians and freely contact them with questions or concerns, and they are afforded few opportunities to interact with health care professionals in the clinical setting without observation by a corrections officer or without being in the presence of physical barriers. In this paper, we explore the tension that exists between trust and safety when incarcerated persons require surgical care.

The Need for Trust during Surgical Procedures

Undergoing an operation is one of the most vulnerable patient experiences in all of medicine. Patients agree to be naked and unconscious in front of strangers and to be cut open. During this period of unconsciousness, patients trust surgeons to honor their wishes and act in their best interest when presented with the unexpected. Afterwards, they accept reduced strength and functionality for the length of recovery or even permanently. For patients alert to the potential danger of postsurgical effects that might render them unable to protect themselves in their lives as incarcerated persons, these vulnerabilities are significant. In contrast, in noncorrectional settings, the therapeutic goals of surgery and the respect, care, and confidentiality provided by the surgical team can help mitigate this sense of vulnerability.

The authors have cared for incarcerated patients in the operating rooms of multiple hospitals and have frequently witnessed these patients, for the duration of their anesthetic and operation, either attended by armed guards or shackled to the OR table. In the authors' current home institution, the level of security for incarcerated patients within the hospital is ultimately the responsibility of the prison agency. In the operating room, security is maintained by accommodating hospital stipulations agreed upon by the custodial agency, hospital police, and clinical personnel. Frequently, two armed guards are present observing the entire surgical procedure. It is difficult to know the extensiveness of such practices; however, evidence suggests that they are not unique to the authors' institution [12, 13].

Undergoing surgery in the presence of persons in positions of power while physically restrained has the potential to limit trust between surgeons and patients. Corrections officers able to observe an operation might purposefully or inadvertently reveal private information gleaned during the procedure. If corrections officers who are insensitive to issues of privacy purposefully reveal these details to others in the correctional setting, stigmatization or even abuse of incarcerated patients might result. For those who learn of privacy violations, mistrust will replace any trust they might have established with their surgeon.

The Need for Safety during Surgery

Restraints and surveillance are sometimes appropriate in clinical settings, when patients pose a risk to the safety of others or might attempt to escape. Neither rationale seems particularly applicable to the intraoperative period. While it is possible that a patient could escape from the operating room before or after a general anesthetic, it is unlikely that this would occur once a procedure is underway. Anesthesiologists, with their armamentarium of paralytic and sedative medications, are well versed in treating a heightened level of consciousness during an operation. Nearly all perioperative staff members are accustomed to treating patients who develop "emergence delirium," a state "characterized by transient agitation, confusion, and violent physical and verbal behavior" [14]. It is likely that an incarcerated patient attempting to commit a violent act or escape during the intraoperative period while still under the influence of anesthesia would behave similarly and could be easily chemically restrained by anesthesiologists.

It is feasible that an accomplice could assist an incarcerated patient in escaping from the operating room; however, correctional facilities avoid informing incarcerated persons of the location or timing of health care encounters in an effort to reduce the likelihood of this occurrence. Additionally, allowing corrections officers to guard any entry points to operating rooms would protect against this threat without privacy violations.

Precedents and Paradigms

The Prison Rape Elimination Act (PREA) is a federal law passed in 2003 with the intention of preventing sexual abuse within correctional settings [15]. Recognizing that vulnerabilities of incarcerated persons can result in an increased risk of victimization and abuse, PREA national standards prohibit certain procedures that might lead to abuse [16], including cross-gender pat downs of females in facilities with a maximum of 50 inmates "absent exigent circumstances" and cross-gender strip searches and cross-gender body cavity searches "except in exigent circumstances or when performed by medical practitioners" [17]. Additionally, inmates are allowed "to shower, perform bodily functions, and change clothing without nonmedical staff of the opposite gender viewing their breasts, buttocks, or genitalia, except in exigent circumstances or when such viewing is incidental to routine cell checks" [17].

Should the principles and language of the PREA national standards—created to reduce victimization and sexual abuse of incarcerated persons by corrections staff—be extended to and used in the OR? In the OR, the majority of patients undergoing surgery will have their clothes removed, as they would in a prison shower or changing room. Patients might undergo procedures on the breast, buttocks, or genitalia, during which these areas are exposed for the entirety of the procedure. It is possible that patients would regard other operations not involving these areas to be considerably revealing as well. The PREA exception to the cross-gender viewing prohibition raised privacy concerns [16]; similar violations of privacy within the health care system can reveal

patient vulnerabilities and might translate into abuse and victimization of incarcerated persons within the correction setting. Thus, preventing corrections officers from viewing a patient's surgery, irrespective of which body part it is performed on, would be an appropriate extension of the PREA. Extending the PREA protections to incarcerated patients undergoing surgery would help preserve the trust between these patients and their physician that is part of a true therapeutic relationship.

Crafting Policy to Balance Trust and Safety

According to feminist ethics theory, a "rich empiricism" should inform decisions and policy [18]. In our opinion, policies directing care of incarcerated patients in the surgical setting should reflect the prevalence of events that breach safety. While it is essential that appropriate safety precautions be taken when caring for incarcerated patients outside of the correctional setting, little data exists regarding actual safety breaches during these episodes of care. It is unclear, for instance, how often incarcerated patients attempt to escape from the surgical setting. Going forward, observational data regarding safety breaches should be collected and used to develop policy related to guards and the shackling of incarcerated patients in the OR. At present, it is unclear whether current policies are justified in protecting safety given their questionable effectiveness and propensity to erode trust between surgeons and their patients.

Recommendations for Surgeons

In light of our conclusions, we set forth several recommendations.

- Surgeons should discuss institutional practices regarding corrections officers and shackles during <u>informed consent</u> discussions with incarcerated persons, thereby allowing incarcerated persons to factor the potential implications of these practices into their decision-making process.
- 2. Surgeons should work with correctional staff to remove shackles while a person is fully anesthetized.
- 3. If correction officer presence during an operation is required, corrections officers should be positioned in operating rooms in locations where they are unable to observe elements of the procedure.
- 4. Operating room staff should not discuss patient health information in the presence of corrections officers or, at minimum, avoid discussing information irrelevant to the operation being performed.
- 5. Surgeons, health care systems, and correctional institutions should rely on data to guide policy creation. Minimally, efforts should be made to compile epidemiologic data regarding safety breaches during the perioperative period.

Conclusion

The experience of incarceration is one of social isolation and loss of control. Incarcerated patients, however, still have autonomy in medical decision making, as demonstrated by their ability to consent to medical and surgical treatments. Incarceration therefore

should not include unnecessary violation of a patient's privacy or dignity since it can contribute to distrust in the clinician-patient relationship and interfere with autonomy in medical decision making. All patients with decisional capacity, regardless of whether they are incarcerated, have the right to make medical decisions free from coercion and have adequate information to make choices. Within the context of surgical care, autonomy depends on trust in one's surgeon to honor one's preferences in the operating room.

Although legislation such as the PREA is demonstrative of incremental attempts to recognize and protect the privacy of incarcerated people, there is much progress to be made. We contend that shackling a person to the operating table in the presence of armed corrections officers is an inappropriate means of exerting control. There is no evidence that we know of indicating that incarcerated patients have threatened the safety of corrections officers, operating room staff, or society at large during the intraoperative period. In contrast, the potential harms of this practice—violations of privacy, victimization of incarcerated persons, and undermining of the clinician-patient relationship—are considerable. Providing high-quality surgical care to incarcerated patients necessitates the development of trust between physicians and patients. We must unlock the shackles as we unfurl the drapes.

References

- Johns Hopkins Sheridan Libraries. Hippocratic Oath. Edelstein L, trans. http://guides.library.jhu.edu/c.php?g=202502&p=1335752. Updated July 27, 2017. Accessed June 5, 2017.
- 2. Thompson HA. *Blood in the Water: The Attica Prison Uprising of 1971 and Its Legacy.* New York, NY: Pantheon Books; 2016:78.
- 3. Thom DH, Hall MA, Pawlson LG. Measuring patients' trust in physicians when assessing quality of care. *Health Affairs (Millwood)*. 2004;23(4):124-132.
- 4. Sade RM. Introduction. In Sade RM, ed. *The Ethics of Surgery: Conflicts and Controversies*. Oxford, UK: Oxford University Press; 2015:5.
- 5. Roe v Wade, 410 US 113 (1973).
- Health Insurance Portability and Accountability Act of 1996, Pub L No. 104-191, 110 Stat 1936. https://www.gpo.gov/fdsys/pkg/PLAW-104publ191/html/PLAW-104publ191.htm. Accessed July 31, 2017.
- 7. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. 7th ed. New York, NY: McGraw-Hill Medical; 2010.
- Standards for privacy of individually identifiable health information; final rule. *Fed Regist*. 2000;65(250):82462-82827. To be codified at 45 CFR sec 160, 164. https://www.gpo.gov/fdsys/pkg/FR-2000-12-28/pdf/00-32678.pdf. Accessed July 14, 2017.
- 9. Prins SJ. The prevalence of mental illnesses in US state prisons: a systematic review. *Psychiatr Serv.* 2014;65(7):862-872.

- Glaze LE. Correctional populations in the United States, 2010. US Department of Justice Office of Justice Programs Bureau of Justice Statistics; December 2011. https://www.bjs.gov/content/pub/pdf/cpus10.pdf. Accessed June 5, 2017.
- 11. Wolff N, Shi J, Siegel JA. Patterns of victimization among male and female inmates: evidence of an enduring legacy. *Violence Vict*. 2009;24(4):469-484.
- 12. Smith FD. Perioperative care of prisoners: providing safe care. *AORN J.* 2016;103(3):282-288.
- 13. Munns J, Samora JB, Granger JF, Ng VY. Caring for the incarcerated: an orthopedic perspective. *Orthopedics*. 2013;36(12):904-906.
- 14. McGuire JM, Burkard JF. Risk factors for emergence delirium in US military members. *J Perianesth Nurs*. 2010;25(6):392.
- 15. Prison Rape Elimination Act of 2003, Pub L No. 108-79, 117 Stat 972. https://www.gpo.gov/fdsys/pkg/PLAW-108publ79/pdf/PLAW-108publ79.pdf. Accessed July 31, 2017.
- National standards to prevent, detect, and respond to prison rape; final rule. *Fed Regist.* 2012;77(119):37106-37232. To be codified at 28 CFR sec 115. https://www.prearesourcecenter.org/sites/default/files/library/2012-12427.pdf. Accessed July 17, 2017.
- 17. National standards, 37201.
- Wolf SM. Introduction: gender and feminism in bioethics. In Wolf SM, ed. *Feminism and Bioethics: Beyond Reproduction*. New York, NY: Oxford University Press; 1996:23.

Sara Scarlet, MD, is a fifth-year general surgery resident and member of the hospital ethics committee at the University of North Carolina at Chapel Hill in Chapel Hill, North Carolina. She is currently pursuing advanced training in surgical ethics at the MacLean Center for Clinical Medical Ethics at the University of Chicago. Her interests include moral distress among health care professionals, the ethics of correctional health care, and ethics education for surgeon trainees.

Elizabeth Dreesen, MD, is a trauma surgeon and the chief of the General and Acute Care Surgery Division of the Department of Surgery at the University of North Carolina at Chapel Hill in Chapel Hill, North Carolina. She completed her surgical residency at the New England Deaconess Hospital and a fellowship in trauma and critical care at the University of Maryland.

Acknowledgements

We would like to thank Gary Gala, MD, Eric Juengst, PhD, and Anthony Meyer, MD, for their insight and support.

Related in the AMA Journal of Ethics

The AMA Code of Medical Ethics' Opinions Related to Health Care for Incarcerated People, September 2017 Breaking Down Walls, February 2008 Delivering Care in a Non-Health-Care Space, February 2008 Federal Privacy Protections: Ethical Foundations, Sources of Confusion in Clinical Medicine, and Controversies in Biomedical Research, March 2016 How to Talk with Patients about Incarceration and Health, September 2017 How Should a Health Care Professional Respond to an Incarcerated Patient's Request for a Particular Treatment?, September 2017 Shackling and Separation: Motherhood in Prison, September 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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 947-948

IMAGES OF HEALING AND LEARNING

Hydrochlorothiazide

Artwork and caption by Satyajeet Roy, MD



Figure 1. Hydrochlorothiazide, by Satyajeet Roy

Media

Pencil on paper.

Caption

I prescribed hydrochlorothiazide to treat my patient's hypertension. He was in solitary confinement. I still remember the stench of urine in his prison cell.

Satyajeet Roy, MD, is an associate professor of medicine at the Cooper Medical School of Rowan University in Camden, New Jersey. He is also an internal medicine-primary care physician at Cooper University Health Care and the director of resident research for the Cooper University Hospital Internal Medicine Residency Program. He enjoys taking care of his patients, teaching medical students and residents, conducting research, performing music, and sketching and painting various aspects of human emotions he has observed in his interactions with others.

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 2017 American Medical Association. All rights reserved. ISSN 2376-6980

AMA Journal of Ethics®

September 2017, Volume 19, Number 9: 949-953

ABOUT THE CONTRIBUTORS

Theme Issue Editor

Lisa Simon, DMD, is a second-year medical student at Harvard Medical School in Boston and a fellow in oral health and medicine integration at the Harvard School of Dental Medicine. She works as a dentist at Boston's Suffolk County Jail and is the faculty dentist for the jail's student clinic.

Contributors

Cyrus Ahalt, MPP, is a researcher and policy analyst in the Department of Medicine at the University of California, San Francisco, where he co-directs the program on criminal justice and health and the US-European Criminal Justice Innovation Program. Mr. Ahalt conducts policy-oriented research on the individual and public health consequences of the US criminal justice system.

David Beckmann, MD, MPH, is a fellow in child and adolescent psychiatry at Massachusetts General Hospital and McLean Hospital and a clinical fellow at Harvard Medical School in Boston. He is interested in correctional psychiatry and helped to create a new residency rotation at a Boston jail, where he works as the mental health faculty advisor and preceptor for a student-faculty collaborative clinic.

Marielle Bolano is a fourth-year medical student at the University of California, Davis School of Medicine. She has worked at the University of California, San Francisco Division of Geriatrics as a research assistant to study health needs of older adults in the criminal justice system and as a National Institute on Aging Medical Student Training in Aging Research Fellow. She has a strong interest in geriatrics and is particularly interested in improving access to care for vulnerable older adults, including those in the criminal justice system.

Amy B. Cadwallader, PhD, is a senior policy analyst in the Science, Medicine, and Public Health Unit at the American Medical Association in Chicago who has nearly ten years of experience working in the drug testing field. She received her doctoral degree in pharmacology and analytical toxicology and has a master's degree in biology/forensic science.

Joseph P. Calderon, CHW, is a community health worker with the Transitions Clinic Network in San Francisco, where he also teaches and trains community health workers. He has a passion for working with diverse and disenfranchised populations, leveraging his personal experience with incarceration to advocate the ideals of social justice and community investment.

Anna M. Darby, MD, MPH, is a second-year emergency medicine resident at Los Angeles County + USC Medical Center, where she works in the dedicated Jail Emergency Department that serves Los Angeles County. She has worked as a litigation assistant at the Prison Law Office advocating for prisoners' health care needs and as a National Institute on Aging Medical Student Training in Aging Research Fellow at the University of California, San Francisco, doing research on older adults in jail.

Elizabeth Dreesen, MD, is a trauma surgeon and the chief of the General and Acute Care Surgery Division of the Department of Surgery at the University of North Carolina at Chapel Hill in Chapel Hill, North Carolina. She completed her surgical residency at the New England Deaconess Hospital and a fellowship in trauma and critical care at the University of Maryland.

Monica L. Gerrek, PhD, is an assistant professor in the Department of Bioethics at Case Western Reserve University in Cleveland, Ohio, where she is co-director of the Center for Biomedical Ethics. She is also the co-director of the MetroHealth Institute of Burn Ethics. Her interests include food ethics, the ethics of addiction, and international perspectives on health care.

Jonathan Giftos, MD, is the director of clinical education for the NYC Health + Hospitals Division of Correctional Health Services in New York City, where he teaches and provides clinical care to incarcerated patients in the New York City jail system. He is also a clinical instructor of medicine at the Albert Einstein College of Medicine and a voluntary attending physician in the Bronx Transitions Clinic at Montefiore's Comprehensive Health Care Center.

Leah Jeunnette, PhD, is a senior research associate in the Department of Bioethics at Case Western Reserve University and a clinical ethicist at the MetroHealth System in Cleveland, Ohio. She has interests in clinical ethics consultation, ethics education, and the ethics of fertility preservation.

Ross MacDonald, MD, is the chief medical officer for the NYC Health + Hospitals Division of Correctional Health Services in New York City. He is also an assistant professor of medicine at New York University School of Medicine and the author of numerous articles on correctional health and human rights.

Despina Mavrakis, MBA, is the ambulatory director of the MetroHealth Correctional Health Program at the Cuyahoga County Corrections Center in Cleveland, Ohio. She is certified in executive coaching, serves on MetroHealth's ethics committee, and has an interest in ethics education.

Lia Metzger is an assistant clinical research coordinator for the Division of Geriatrics at the University of California, San Francisco, where she conducts research to identify and assess the health needs of older adults in the criminal justice system. She has a strong interest in geriatrics and palliative medicine and is especially interested in improving health outcomes for vulnerable older adults.

Andreas Mitchell is a fourth-year medical student at Harvard Medical School and is also pursuing a master's degree in public policy at the Harvard Kennedy School of Government in Boston. He has served as co-chair of the student leadership committee of the Harvard Medical School Center for Primary Care and is a student member of the board of the Academic Consortium on Criminal Justice Health, an organization with which he has partnered to create a digital curriculum on criminal justice and health.

Annalise Norling is a fourth-year undergraduate at Loyola University Chicago, where she studies philosophy and biology with a concentration in bioethics. During the summer of 2017, she was an intern for the American Medical Association's Ethics Group.

Tom Peteet, MD, is an internal medicine physician and rural health fellow at Massachusetts General Hospital in Boston. His interests include bioethics, addiction medicine, public health, and correctional medicine.

Lisa Puglisi, MD, is an assistant professor of general internal medicine at the Yale School of Medicine in New Haven, Connecticut. She is also co-director of Transitions Clinic Network-New Haven, a clinical program focused on providing postincarceration primary care in partnership with community health workers.

Satyajeet Roy, MD, is an associate professor of medicine at the Cooper Medical School of Rowan University in Camden, New Jersey. He is also an internal medicine-primary care physician at Cooper University Health Care and the director of resident research for the Cooper University Hospital Internal Medicine Residency Program. He enjoys taking care of his patients, teaching medical students and residents, conducting research, performing music, and sketching and painting various aspects of human emotions he has observed in his interactions with others.

Sara Scarlet, MD, is a fifth-year general surgery resident and member of the hospital ethics committee at the University of North Carolina at Chapel Hill in Chapel Hill, North Carolina. She is currently pursuing advanced training in surgical ethics at the MacLean Center for Clinical Medical Ethics at the University of Chicago. Her interests include moral distress among health care professionals, the ethics of correctional health care, and ethics education for surgeon trainees.

Oliver Schirokauer, PhD, MD, is a senior research associate in the Department of Bioethics at Case Western Reserve University (CWRU) in Cleveland, Ohio, where his responsibilities include oversight of the ethics curriculum for CWRU's medical students. He is also a clinical ethicist at the MetroHealth System. He recently launched a clinical program to support patients adjusting to major illness by helping them with communication, information processing, and decision making.

Rebecca Sudore, MD, is a professor of medicine at the University of California, San Francisco, where she serves as a geriatrician, palliative medicine physician, and clinician investigator and directs the Innovation Center for Action-oriented REsearch in Aging & Palliative Care. Dr. Sudore conducts research to improve advance care planning and medical decision making for diverse, vulnerable older adults.

Kimberly Sue, MD, PhD, is a resident physician in internal medicine primary care at Massachusetts General Hospital in Boston. Her clinical interests include addiction in primary care as well as optimizing care for people with histories of incarceration. Her ethnographic research examines the intersection of US prison systems, addiction policy, mental health, and drug treatment in Massachusetts at the state women's prison, a Boston jail, and a community-based buprenorphine and naloxone treatment program.

Thomas A. Tallman, DO, MMM, is medical director of the MetroHealth Correctional Health Program at the Cuyahoga County Corrections Center and a faculty member at the Cleveland Clinic Lerner College of Medicine in Cleveland, Ohio. A Navy veteran, he is board certified in emergency medicine and is a certified correctional health professional through the National Commission on Correctional Health Care. His interests include emergency preparedness, disaster medicine, education, and hands-on teaching.

Matt Tobey, MD, MPH, is an internal medicine physician at Massachusetts General Hospital in Boston. He supervises an interdisciplinary student clinic in a jail, coordinates an academic-rural partnership, and practices primary care. His interests include rural and correctional health.

Sarah E. Wakeman, MD, is the medical director for the Massachusetts General Hospital Substance Use Disorder Initiative in Boston, where she is also program director of the Addiction Medicine Fellowship, medical director of the Addiction Consult Team, and cochair of the Opioid Task Force. She is also an assistant professor of medicine at Harvard Medical School and a clinical lead of the Partners Healthcare Substance Use Disorder Initiative. Her research interests include evaluating models for integrated substance use disorder treatment in general medical settings, recovery coaching, physician attitudes and preparedness related to substance use disorder, and screening for substance use in primary care

Emily A. Wang, MD, MAS, is an associate professor at the Yale School of Medicine in New Haven, Connecticut, and co-founder of the Transitions Clinic Network. She has developed expertise in training formerly incarcerated people to become community health workers and researchers through community-based participatory research methods. Dr. Wang's research focuses on promoting health equity for vulnerable populations, especially people with a history of incarceration.

Brie Williams, MD, MS, is a professor of medicine in the Division of Geriatrics at the University of California, San Francisco, where she directs the Criminal Justice & Health Program and the Criminal Justice Aging Project. In her work on bringing the science of geriatrics and palliative care to criminal justice reform, she collaborates with colleagues from diverse disciplines, including criminal justice, public safety, and the law, to conduct impact-oriented research and education.

Copyright 2017 American Medical Association. All rights reserved. ISSN 2376-6980