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Cases from the Cleveland Clinic

Incarcerated Patients and Equitability: The Ethical Obligation to Treat Them Differently

Lisa Fuller and Margot M. Eves

ABSTRACT

Prisoners are legally categorized as a vulnerable group for the purposes of medical research, but their vulnerability is not limited to the research context. Prisoner-patients may experience lower standards of care, fewer options for treatment, violations of privacy, and the use of inappropriate surrogates as a result of their status. This case study highlights some of the ways in which a prisoner-patient's vulnerable status impacted the care he received. The article argues the following: (1) Prisoner-patients are entitled to the same quality of care as all other patients, and healthcare providers should be vigilant to ensure that the stigma of incarceration does not influence care decisions. (2) Options for treatment should reflect what is most medically appropriate in the hospital or other healthcare setting, even when not all treatments would be available in the correctional setting. (3) The presence of guards at the bedside requires that additional measures be taken to protect the privacy and confidentiality of prisoner-patients. (4) When end-of-life decisions must be made for an incapacitated patient, prison physicians are not well placed to act as surrogate decision makers, which heightens the obligations of the healthcare professionals in the hospital to ensure an ethically supportable process and outcome. Therefore, healthcare professionals should provide extra protection for those prisoner-patients who do not have decision-making capacity, by utilizing a robust process for decision making such as those used for incapacitated patients without surrogates, rather than relying solely on prison physicians as surrogates.

Lisa Fuller, PhD, is an Assistant Professor of Philosophy at Merrimack College in North Andover, Massachusetts, and was a 2017 Participant in the Cleveland Clinic Clinical Ethics Immersion Program (CLEIP).

Margot M. Eves, JD, MA, is the Director of the Clinical Ethics Immersion Program and Staff in the Department of Bioethics at the Cleveland Clinic in Cleveland, Ohio. *evesm@ccf.org*

INTRODUCTION

Prisoners are legally categorized as a vulnerable group for the purposes of medical research. However, their vulnerability is not limited to the research context. The current literature reflects a recognition that prisoners are also more vulnerable than non-incarcerated patients when they are undergoing treatment.[1] This article will begin with a preliminary discussion of vulnerability before proceeding with an analysis of a recent case involving a prisoner-patient. The case study highlights some of the ways in which a prisoner's vulnerability may manifest in the hospital setting.

A person is vulnerable when she or he has "a greater likelihood of . . . being denied adequate satisfaction of certain legitimate [moral or legal] claims."[2] While in one sense all human beings are fragile and therefore "vulnerable," certain circumstances or situations expose people to an increased chance that their rights may be violated or their interests disregarded. This notion is specifically po-

litical, in that someone's circumstances are the source of her or his vulnerable state, and those circumstances are created by socially constructed norms, policies, and institutional constraints. Being located within these social circumstances is, then, what puts a person at greater risk of being wronged and/or harmed as compared with others not similarly placed.[3] Generally speaking, individuals who are vulnerable in this way are more exposed to harm and threats of harm and have fewer resources with which to protect themselves from such threats. This greater exposure generates a moral claim on others to provide members of vulnerable groups with special protection.[4] The concept of vulnerability is useful in connection with the current case because although hospitalized patients are vulnerable for many reasons, they are not ordinarily under the power of a "totalizing" institutional authority. Despite being guaranteed access to healthcare by law,[5] prisoners nevertheless may have their interests undermined in various ways while receiving treatment, since they remain under the power of the prison authorities and may be subject to stigma, disrespect, and unfairness as a result of their status.

CASE DESCRIPTION

Mr. Maken was a 66-year-old male inmate at a federal prison. He was admitted to a nearby community hospital after experiencing chest pain and severe shortness of breath. Mr. Maken had a history of chronic obstructive pulmonary disease, hypertension, chronic kidney disease, diabetes, and coronary artery disease. He had undergone quadruple coronary artery bypass graft surgery 20 years prior. A few days after admission, he had a heart attack and his condition deteriorated. As a result, he was transferred to the cardiac intensive care unit (CICU) at a large tertiary care teaching hospital for continued treatment. Mr. Maken was successfully treated for cardiogenic shock and significant retroperitoneal bleeding. His heart failure was treated with dobutamine, an infusion drug intended only for short-term support. Unfortunately, Mr. Maken was not a candidate for cardiac surgery or heart transplantation.

During his CICU stay, he rarely responded to commands and was typically either confused or nonresponsive. Therefore, he was unable to demonstrate the capacity to make his own medical decisions. Prison personnel informed the CICU team that the prison physician would be responsible for providing consent, or acting as a surrogate decision maker, until or unless the patient regained decision-making capacity. Even though Mr. Maken was not able to get out of bed on his own, he was supervised by two guards at all times. They sat in his room at bedside. They did not know him before they were assigned to guard him at the hospital.

After Mr. Maken had been in the CICU for 12 days, Dr. Holt requested an ethics consultation due to concerns arising from a suggestion made by the prison physician about treatment options. Dr. Holt explained that attempts to wean Mr. Maken from dobutamine were unsuccessful, effectively making it a life-sustaining intervention. Dr. Holt reported that during his conversation to update the prison physician about Mr. Maken's condition and discuss implementation of a do-not-resuscitate (DNR) order, the prison physician said the hospital could stop the dobutamine, that is, withdraw life-sustaining treatment. Dr. Holt expressed concern that this decision might be premature, and sought guidance regarding the ethical permissibility of proceeding.

The ethics consultants conducted some independent research. The bioethics literature regarding prisoners primarily focuses on human subject research in prison populations; there is a dearth of literature pertaining to clinical decision making for prisoners. The United States Department of Justice Federal Bureau of Prisons (DOJ/FBP) published a Program Statement on Patient Care, which was informative.[6] The prison cited this document as the source of its authority to make medical decisions if there were no family members available. It also provided documentation in which Mr. Maken declined, on two separate occasions, to have family notified in the event of emergency or death. However, a careful reading of the DOJ/FBP Program Statement raised questions as to whether the prison's interpretation was accurate, or if the statement authorized nonprison hospitals to use their usual institutional protocols for decision making when an incarcerated patient is hospitalized. Additionally, a colleague with more experience in caring for incarcerated patients reminded the ethics consultants that Mr. Maken retained his privacy rights as a patient under applicable state and federal law.[7]

DISCUSSION

Over the course of the consultation, it became clear that Mr. Maken was vulnerable in three ways: (1) to unjustified limitations on treatment resulting from his status as a prisoner, (2) to inappropriate deference to the prison authorities as decision makers, and (3) to unjustified invasions of his privacy. It was also clear that most clinical caregivers had not interacted with someone in Mr. Maken's particular

situation before, and did not realize that his status as a prisoner had the potential to ethically complicate his care in distinct ways. Principles of fairness, respect, and protection of the vulnerable require healthcare professionals to *actively* ensure that prisoner-patients receive the same care—in both the processes and outcomes of medical treatment—that non-incarcerated patients would typically receive.

Fairness and Nondiscrimination

Basic fairness requires healthcare professionals to treat incarcerated patients as they would any other patient. Incarcerated patients risk facing suboptimal medical care as a result of the (often unconscious) bias associated with their status as prisoners. For example, they may be seen as lacking social worth, or as less valuable members of society because of their transgressions. A significant social stigma attaches to involvement with the correctional system, and this may negatively impact healthcare professionals' interactions with incarcerated patients. Lack of equal treatment on the basis of such stigma is, nevertheless, a form of invidious discrimination, and, as such, requires that healthcare professionals make a conscious effort to avoid it.

One way that such unequal treatment can occur is when healthcare professionals unconsciously "import" constraints and permissions from the correctional setting into the hospital. For instance, in this case, prison guards were often present for Mr. Maken's physical examinations and likely overheard information regarding his condition and treatment plan. Although prisoners' rights to and expectations of privacy are reduced (or non-existent) in correctional facilities, and even though some prison officials are entitled to access to prisoners' healthcare information, the manner in which prisoners are treated in the correctional setting is inappropriate in the hospital setting. One reason is that the fundamental goals of the institutions differ. The purpose of correctional facilities is to punish inmates by depriving them of their liberty, which is a goal that inmates presumably do not share, and so its pursuit requires constant surveillance and coercion.[8] By contrast, the purpose of hospitals is to promote the health of patients, which requires treating each patient as a unique individual with whom healthcare professionals must develop a relationship of trust, and whose interests are at least equal to, and often supersede, other stakeholders' interests. Additionally, patients typically want to feel better. Unlike prisoners, patients share this broad purpose with those responsible for providing medical care, or those in the position of power or authority.

Another ethically challenging issue to consider is the allocation of resources. Prisoners have a constitutional right to healthcare, based in the Eighth Amendment to the U.S. Constitution, which prohibits cruel and unusual punishment.[9] Correctional facilities are responsible to provide medical care or to transfer prisoners to a hospital with the capacity to provide it, as well as to provide payment for the care. Prison resources might constrain what can be offered upon a patient's discharge due to capacity issues or possible budget considerations; however, this is true of most patients, as insurance coverage often determines what type and level of continuing care patients are eligible to receive. Nevertheless, while being treated in the hospital, choice regarding interventions should reflect the usual standard of care for patients with the same medical profile as the prisoner-patient. An issue may arise when a prison physician acts as the patient's surrogate and recommends a course of treatment that would be normal in the correctional setting, when that setting does not offer the same level of care as the hospital. In Mr. Maken's case, Dr. Holt was not comfortable discontinuing the dobutamine without further exploring whether it would be available after discharge. There was also the question of whether Mr. Maken might be eligible for hospice, which needed to be explored, given his status. The ethics consultants recommended that all options be explored for Mr. Maken that would be appropriate to his medical condition, even if ultimately those options after discharge were determined by what the prison system could provide.

Decision Making for Prisoners without Capacity

At first it was unclear whether the hospital should make efforts to locate Mr. Maken's family, or if this had already been done by the prison health officials. Once the prison health administration forwarded documentation of the patient's wish that no family be contacted, the ethics consultants began exploring the prison's assertion that their physicians were the authorized surrogate decision makers. The prison referenced the DOJ/FBP Program Statement on Patient Care to substantiate its position. The document specified that "the authority, parameters and procedures for creating such proxies are governed by the laws of the state in which the institution operates," but also that "all DNR orders . . . must be approved by the Clinical Director."[10] In a separate passage concerning DNR orders, which specified that such an order may be written when it is "the attending physician's decision that the inmate is in a terminal condition," no clear distinction was

made between patients located in community hospitals and those in correctional medical facilities.

In this case, the attending physician was not the prison doctor, and because state law did not identify correctional staff as potential surrogates for incapacitated patients, the ethics consultants were not convinced that the prison doctor was authorized to serve as a surrogate decision maker. Although the corrections system has custody of inmates and is responsible for their welfare, there did not seem to be adequate legal or ethical grounds to support giving the prison doctor sole responsibility for decision making regarding the end of an inmate's life.

Ideally, end-of-life decisions are made by patients themselves, in person or through an advance directive, or more often, by an appropriately identified surrogate decision maker using a substituted judgment standard. By contrast, if a surrogate decision maker does not know the patient very well, or does not know what the patient would have wanted in an end-of-life situation, then the surrogate must fall back on the "best interest standard" in order to make decisions. Since Mr. Maken did not have capacity for decision making throughout his hospitalization and did not wish for family members to be contacted, no one who knew him personally was available to apply substituted judgment. Therefore, the best interest standard was the applicable framework for making decisions about his care. This meant that the prison doctors were no better positioned to make decisions regarding Mr. Maken's care than his healthcare team at the hospital.

Utilizing a prison physician as a surrogate decision maker raised several ethical challenges beyond those that faced hospital personnel. One challenge was that the correctional facility (and its employees) had a financial conflict of interest: prison healthcare is administered through the correctional budget, not through a separate payer source (for example, Medicare or other third-party insurance). As such, there was an intrinsic conflict among three competing interests: the government's interest in preserving life, its interest in meting out punishment for criminal activity, and the potentially high cost of complex healthcare. Nancy Dubler highlighted another challenge: "the options offered [in the correctional setting] are generally not all those that medicine could and should provide given the condition of the inmate," and the recommendations of a correctional setting are likely to be formed by its everyday practice.[11] Further, it has been argued that prison physicians may become acculturated to their institutions, which may cause them to see patients as lacking agency and individual worth.[12] Prison physicians may begin to adopt "custodial values and norms in place of health care values and norms," which prioritize cost reduction, security, and order.[13] As such, the ethics consultants recommended that Mr. Maken's care team take a *hybrid* approach to surrogate decision making.

The essence of this approach is as follows: the care team could utilize a prison physician as a surrogate decision maker on the condition that the team's own professional medical judgments acted as a safeguard to ensure that Mr. Maken's care reflected the same high standard of care that other patients received. In furtherance of this responsibility, less deference would be afforded to the prison physician as a surrogate than would normally be afforded to a surrogate decision maker, since the prison physician had no additional knowledge of the patient's wishes. Since respect for autonomy was not grounding the decisions, and the prison physician might have been influenced by institutional (prison) culture and constraints, professional integrity required that Mr. Maken's care team should oversee his care as they would if he were an incapacitated patient without a surrogate. This hybrid approach operationalized moral concern for Mr. Maken's vulnerability, since it offered him an extra layer of protection against the incentives and culture of the penal system.

Privacy and Confidentiality

A prisoner-patient has the same legal rights to privacy and confidentiality in the treatment setting as other patients, provided this can be accomplished without putting anyone at risk of harm or creating a risk of the prisoner's escape.[14] Although the terms *privacy* and *confidentiality* are frequently used interchangeably in healthcare (both in common use and in the literature), it is helpful to conceptualize them as separate but interrelated ideas. *Privacy* is primarily considered in terms of visual and physical space, while *confidentiality* refers to the disclosure, or lack thereof, of information.

The limited literature available concerning treating a prisoner outside prison indicated that the situation we found was very common. Findings of a study by Helen Tuite and colleagues indicate that "Breaches of confidentiality were considered to occur commonly in the management of prisoners who were patients," and "hospital doctors have a low awareness of guidelines for due preservation of confidentiality and also report patterns of professional conduct that militate against confidentiality."[15] The study reports that only 3 percent of doctors "always" asked guards to leave the room during examinations

or physical care, and 31 percent "never" did this. Other studies report that guards "listen attentively to conversations," watch women in labor, and gossip with colleagues about events that should have been kept confidential.[16]

While this should prompt healthcare professionals to take special care to ensure that these rights are respected, one might question the ethical significance of doing so in a case such as Mr. Maken's. After all, given his unresponsive or inconsistently responsive condition, it was unclear whether Mr. Maken was able to appreciate that his privacy had been invaded and confidentiality might have been breached. Additionally, while the guards who attended him were not entitled to information about his medical condition, the federal prison system *was* entitled to it. Ultimately, although Mr. Maken did not enjoy the same degree of protection of his confidentiality, this diminished protection did not waive the healthcare professionals' obligation to protect it to the fullest possible degree. The ethical importance of confidentiality has been defended on a variety of grounds. That Mr. Maken's personal autonomy and his overall well-being might not be compromised if his privacy rights were breached does not mean that there was no ethical obligation to honor them. In cases such as this, the values of respect and dignity required that Mr. Maken be treated as any other patient would.

Anita Allen has argued that "standard accounts of the value of health privacy . . . rely upon privacy to help control or limit health disclosures that could result in tangible, material losses" such as the loss of insurance or employment.[17] Typically, medical confidentiality is understood to be valuable because it fosters a relationship of trust between the patient and the medical team. But privacy does not merely involve the disclosure of information. Privacy in the healthcare setting also applies to when bodies and behavior may be observed, and by whom. Nudity, the administration of personal care services, and invasive physical procedures are private. Even when patients are unconscious or severely mentally incapacitated, and so will not be embarrassed should strangers witness the patients undergoing this type of care, moral respect demands that we prevent patients' intimate moments and experiences of suffering from becoming objects of curiosity or spectacles to be viewed by strangers.

Especially relevant to this case was the particular respect for privacy owed to those who are approaching the end of their lives. Allen observes that "there are occasions when nothing less than respect for human dignity and welfare demand that the unwanted stranger, and even the unwanted friend, stay away. Illnesses, including hopeless ones that spell the end of life, are such occasions."[18] Certainly if anyone is an "unwanted stranger" at the bedside of someone close to death, the agent of the state responsible for the punishment of the dying patient is one. During his last days, Mr. Maken was entitled to be treated as a distinctive, irreplaceable individual, rather than as a fungible, dehumanized "prisoner." Maintaining his privacy was one way his care team could demonstrate respect for his human dignity and affirm his value as an equal member of the moral community.

Given this analysis of the patient's rights to privacy and confidentiality, the ethics consultants reminded his clinical caregivers that his guards were not his family nor his designated powers of attorney, and so they were not entitled to his private medical information. The ethics consultants strongly recommended that Mr. Maken's healthcare professionals consistently pull the curtain around his bed or ask his guards to step out during physical care, and to hold discussions about Mr. Maken's condition and treatment plan in a more private location. One team member articulated her appreciation for this specific guidance and noted, "I don't think we have been doing that so far." As reflected in the literature discussed above, the need to heighten caregivers' awareness regarding the need for additional vigilance is not unusual and supports the argument that positive steps need to be taken to protect prisoner-patients from violations of their privacy rights.

CONCLUSION

Several days following the original consultation request, a DNR order was put in place, on the basis that it was reasonable for any patient in Mr. Maken's condition. The care plan was to discharge him to the hospital where he was originally admitted, while maintained on dobutamine, but he died before the transfer was accomplished.

It is easy for the vulnerabilities of prisoner-patients such as Mr. Maken to remain invisible. The authority of prison physicians and officials can be difficult to question, and the stigma attached to being incarcerated may cause prisoner-patients to be treated differently than other patients. Nevertheless, healthcare professionals are ethically obligated to provide prisoner-patients with the same quality of care provided to all patients. To do this, healthcare professionals need to be aware of the greater likelihood of violations of privacy and unjustified limitations on care for this patient population. This

awareness should be coupled with the acknowledgment that increased vigilance is necessary to prevent accidental violations. Healthcare professionals should provide extra protection for patients who do not have decision-making capacity by adopting a hybrid approach to decision making—particularly with respect to end-of-life decisions—rather than relying solely on prison physicians as surrogates. These special protections will ensure that healthcare professions will provide prisoner-patients with the care they deserve.

Although there has been much discussion in the literature of prisoners' participation in research involving human subjects, there has been little attention given to their clinical care needs. Importantly, further inquiry and consideration of relevant issues in clinical medicine, such as organ transplantation (both as recipients and donors), treatment of death row inmates, and other treatment limitations or access issues for this population is warranted.

PRIVACY

All names in the case have been changed to protect the stakeholders' confidentiality. Other personal characteristics about the patient have also been changed for the same purpose. Participants in the Cleveland Clinic Clinical Ethics Immersion Program (CLEIP) are integrated into the Ethics Consultation Service team and are held the same high expectations of confidentiality.

NOTES

1. H. ten Have, "Respect for Human Vulnerability: The Emergence of a New Principle in Bioethics," *Bioethical Inquiry* 12 (2015): 395-408.

2. N. Tavaglione et al., "Fleshing Out Vulnerability," *Bioethics* 29, no. 2 (2015): 98-107.

3. There are other ways to elaborate the concept of vulnerability that do not (only) emphasize external circumstances. However, this more limited notion is all that is needed for the purposes of the current analysis.

4. For a thorough review of the literature on the concept of vulnerability, see ten Have, "Respect for Human Vulnerability," see note 1 above.

5. In 1976, the U.S. Supreme Court recognized a right to healthcare for prisoners on the basis of Eighth Amendment protections against cruel and unusual punishment. Given that prisoners must rely on prison authorities to meet their medical needs, prison authorities who display a "deliberate indifference" to these needs are regarded as responsible for the unnecessary pain and suffering that results. Deliberate indifference can take several forms, for instance, "a refusal to investigate further when there is evidence that prisoner may need medical care or the choice to treat in a manner which is 'easier and less efficacious.'" See M.S. Smith, L.A. Taylor, and A. Wake, "Healthcare Decision-Making for Mentally Incapacitated Incarcerated Individuals," *Elder Law Journal* 22, no. 1 (2014): 175-208; *Estelle v. Gamble*, 429 U.S. 97; 75-947 (1976).

6. U.S. Dept. of Justice Federal Bureau of Prisons, "Patient Care Program Statement, Number 6031.04," June 2014, *https://www.bop.gov/policy/progstat/6031_004.pdf*

7. Monica Gerrek, PhD, verbal communication, June 2017; Health Insurance Portability and Accountability Act of 1996 (HIPAA; Pub.L. 104-191, 110 Stat. 1936, enacted 21 August 1996).

8. K. Kipnis, "Ethical Conflict in Correctional Health Services," in M. Davis and A. Stark, ed., *Conflict of Interest in the Professions* (New York: Oxford University Press, 2001), 302-13.

9. *Estelle v. Gamble*, 429 U.S. 97; 75-947 (1976).

10. DOJ/FBP, "Patient Care," see note 6 above.

11. N. Dubler, "Ethical Dilemmas in Prison and Jail Health Care," 2014, *http://healthaffairs.org/blog/2014/03/10/ethical-dilemmas-in-prison-and-jail-health-care/*.

12. Ibid.

13. K.L.A. White, C.F.C. Jordens, and I. Kerridge, "Contextualising Professional Ethics: The Impact of the Prison Context on the Practices and Norms of Health Care," *Bioethical Inquiry* 11 (2014): 333-45.

14. A. Junewicsz, "Shackled: Providing Care for Prisoners Outside of Prison," *American Journal of Bioethics* 14, no. 7 (2014): 13-4.

15. H. Tuite, K. Browne ,and D. O'Neill, "Prisoners in general hospitals: Doctors' attitudes and practice," *British Medical Journal* 332, no. 7540 (2006): 549.

16. B.A.L. Beech, "How Could I Breastfeed with a Man in the Room?" *British Medical Journal* 312, no. 7025 (1996): 256; B.L. Zust, L. Busaihn, and K. Janisch, "Nurses' experiences caring for incarcerated patients in the perinatal unit," *Issues in Mental Health Nursing* 34, no. 1 (2013): 25-9.

17. A. Allen, "Face to Face with 'It': And Other Neglected Contexts of Health Privacy," *Proceedings of the American Philosophical Society* 151, no. 3 (September 2007): 300-8.

18. Ibid., 305.