A Right to Privacy and Confidentiality: Ethical Medical Care for Patients in United States Immigration Detention

Amanda M. Gutierrez, Jacob D. Hofstetter, Emma L. Dishner, Elizabeth Chiao, Dilreet Rai, and Amy L. McGuire

Recently, John Doe, an undocumented immigrant who was detained by United States Immigration and Customs Enforcement (ICE) was transferred from an ICE detention facility and urgently admitted as a patient to a large academic teaching hospital because of complications related to his HIV disease. The patient was accompanied by custodial officers who were employed by a privately-owned firm contracted by ICE to provide security services and run the detention facility where Mr. Doe was held. The officers accompanied the patient into the exam room and refused to leave as Mr. Doe was examined by physicians, even though the medical team asked the officers to leave the exam room on multiple occasions. The officers took notes during the examination and documented the names of everyone who entered the exam room, including the physicians, which made the patient concerned that the information could be used in immigration court proceedings against him. Mr. Doe's situation is one of many cases reported recently[1] that have raised questions about the right to privacy and confidentiality of patients in immigration detention. In this paper, we analyze what US immigration detention standards and US law allow regarding immigration enforcement or custodial officers' presence in medical exam rooms in the context of detainees, and the documentation of detainees' health information. We also describe the ethical implications and effects of the presence of immigration enforcement or custodial officers in medical exam rooms.

The US Immigration Detention System

Under the Department of Homeland Security (DHS), the United States has two immigration law enforcement agencies, both of which may detain immigrants. US Customs and Border Protection (CBP) is responsible for usually shorter term immigration detention within 100 miles of the border and at ports of entry, while ICE operates in the interior of the country and manages longer term detention facilities.[2] Undocumented immigrants in the US can be detained by ICE or CBP for a variety of reasons, the most common of which are: (1) they have asked for asylum at a border crossing and an immigration court is deciding whether to deport them or grant them asylum; (2) they have been arrested or convicted of a crime and are transferred to ICE custody for deportation proceedings; or (3) they had contact with immigration officials who detained them for not having documentation.[3] Once arrested for an immigration offense, immigrants without legal status begin the process of deportation and during this process can be held in ICE detention facilities until removal from the US. Unless they have been convicted of a crime, undocumented immigrants

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in ICE custody (like Mr. Doe in this case) are in civil detention, and thus they are not considered prisoners.[4]

Undocumented immigrants can be held in either federal or private immigration detention facilities. Despite immigrant detainees being distinct from prisoners, ICE regularly turns to federal and private prisons to house immigrant detainees when immigration detention facilities lack holding space.[5] Privately-owned detention centers are facilities run by for-profit companies contracted by ICE to detain immigrants, and therefore are accountable to the US federal government through ICE's Performance-Based National Detention Standards governing immigration detention conditions and treatment of detainees, including respecting privacy and confidentiality of detainee health information.[6] Thus, any facility detaining immigrants, whether federal or private, must abide by ICE's detention standards.[7] Employees of private security firms contracted by ICE, such as the custodial officers in Mr. Doe's case, must also honor ICE's standards. However, it is difficult to assess if the officers in this case abided by those rules because the standards are unclear about the permissibility of officers' presence during detainees' medical exams. Custodial officers are employees of private firms and should not be confused with immigration enforcement officers from agencies such as ICE and CBP.

Presence of Officers during Medical Examination of ICE Detainees

In the case of John Doe, the custodial officers accompanied the patient into the exam room and refused to leave despite being asked multiple times to do so by the medical team. The physician and patient were uncertain about their rights in this situation or if the officers were allowed to be in the room in the first place. This practice does not comply with the National Commission on Correctional Health Care (NCCHC) standards that state that medical visits should be private and confidential sessions, especially in cases of non-violent detainees.[8] ICE detention centers are expected to maintain NCCHC accreditation and remain in compliance with NCCHC's standards with regard to medical facilities.[9] However, ICE's own guidelines around officers' observation of medical exams are not straightforward. In their detention standards, ICE states that the detention facility and off-site medical provider caring for the detainee "negotiates and maintains arrangements" about the patient's care, which include "identifying custodial officers to transport and remain with detainees for the duration of any off-site treatment or hospital admission."[10] While this standard suggests that officers must accompany detainees to the medical facility, it does not explicitly state that officers should or can be in any exam room with the patient. Additionally, in Mr. Doe's case there was no arrangement made between the provider and detention facility about how and where the custodial officers would accompany Mr. Doe during his off-site hospital admission.

The only personnel explicitly stated in ICE standards as being allowed in the room during a patient's physical examination are "chaperones," who must be medical personnel.[11] To accompany them to on- and off-site medical visits, detainees are allowed to request a healthcare provider of the same gender, and if one is not available, they can request a same-gendered chaperone.[12] ICE automatically provides a chaperone to accompany patients regardless of request if a patient's sensitive body parts are to be examined by a physician of the opposite gender.[13] Even with a chaperone present, ICE clearly states that detainees should have their medical exams conducted in a setting that respects their privacy.[14] In the case of Mr. Doe, where the custodial officers were not medical personnel, these officers may have violated ICE's standards by being in the medical exam room with the patient.

These questions about the right to privacy and confidentiality of patients in immigration detention also

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apply to detainees in CBP custody. Even though in this case the patient was detained by ICE, it should be noted that CBP has even more ambiguous standards regarding the presence of immigration enforcement or custodial officers in medical exam rooms. Regarding hospitalization and health information privacy, CBP standards state only that "officers/agents will follow their operational office's policies and procedures."[15] It is crucial that any policy changes regarding how to provide ethical medical care for patients in US immigration detention apply to detainees in either ICE or CBP custody.

Privacy and Confidentiality of ICE Detainee Health Information

In this patient case, the custodial officers took notes during Mr. Doe's medical examination, though it is unclear what information was recorded. The patient and physician were unsure at the time if the officers had any authorization to take down the patient's protected health information (PHI), including the names of the physicians, which is generally protected by the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule.[16] ICE states that medical record information should be kept secure and separate from detention records and that all detention facility staff, including officers, should respect detainee privacy.[17] There is nothing in ICE's detention standards stating that either chaperones or accompanying officers who are not medical personnel are allowed to record detainee patient health information during medical visits. However, there are situations in which patient information can legally be collected and shared with certain parties. Like other state law enforcement agencies, ICE may not be required to comply with HIPAA under some circumstances.[18] The Department of Health and Human Services outlines in which situations HIPAA-covered entities may disclose PHI to law enforcement without a person's signed HIPAA authorization, including for reasons of health and safety, as criminal evidence, and for law enforcement purposes if the detainee is deemed a threat to the community.[19] In these instances, it may be legally permissible for custodial officers to collect detainees' PHI from the medical record, however the question remains if they are justified in documenting such information themselves to create a separate record, which may be subject to their own interpretations. ICE's standards suggest that officers should have to show legal justification, such as a court order or warrant, for collecting patient PHI during the visit[20], and the officers did not do that in this case. However, when the medical team attending Mr. Doe confronted the officers about what information they were taking down and why, the officers did stop taking notes.

ICE standards also highlight certain instances when a detention center health administrator can give medical information to the facility administrator and certain staff for health, security, and administrative purposes.[21] However, when the desired medical information is covered by HIPAA, then HIPAA restrictions are applied to the release of that information. ICE standards require confidentiality of detainees' health status according to law with an exception for certain cases of communicable disease.[22] ICE can report information, such as name, date of birth, diagnosis, and treatment information of detainees who have been diagnosed with "a communicable disease of public health significance," including active tuberculosis, syphilis, and gonorrhea.[23] Record of these communicable diseases can be reported to government bodies such as health departments,[24] and accompanying officers may be legally allowed to document this information for reporting purposes and may also be required to report this information to ICE. It is important to note that prior to 2010, HIV was also considered a communicable disease of public health significance and HIV-infected persons could be banned from entering the country.[25] After a federal ruling that removed HIV from this list came into effect on January 4, 2010, ICE updated its detention standards to reflect this change. Similarly, US Citizenship and Immigration Services, the DHS agency that adjudicates immigration applications, also states that officers "should disregard a diagnosis of HIV infection when determining whether an applicant is inadmissible on health-related grounds."[26] In Mr. Doe's case, the detention facility was aware of his HIV-positive status, as this was part of the patient's reason for hospital admission, and there had been communication between his outpatient physician and facility practitioners who administered medications. Given that HIV is no longer an inadmissible infection, the fact that Mr. Doe was HIV-positive is not grounds for deportation and should not affect the outcome of his immigration case.

Still, it is not clear if the officers were ordered by a court to collect medical information during Mr. Doe's medical visit for any reason, including around his HIV status. ICE policies do specify that "information about a detainee's health status and a detainee's health record is confidential, and the active medical record shall be maintained separately from other detention records."[27] Even if the officers were ordered to document Mr. Doe's PHI, the officers still violated the patient's right to privacy by not presenting legal justification to collect the detainee's HIPAA-protected information.[28] Since, the patient's HIV-positive status was already known to

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ICE, it is unclear what information the officers were documenting and if it was about Mr. Doe's disease, other related conditions (e.g., mental health status), or other details about the detainee's well-being.

Legal Uses of ICE Detainee Health Information

In this case, Mr. Doe was HIV-positive and was urgently hospitalized for care regarding complications from his HIV disease. As the patient's immigration case had not been heard by a judge, he was particularly concerned that the information the custodial officers collected during the medical exam would be used against him in immigration court. Mr. Doe reported that he heard the custodial officers discussing deporting him because of the high cost of his hospitalization, and the primary care team stated that a social worker had approached them about transferring his care to Mexico, his country of origin. Anecdotal evidence does show that medical repatriation, or transferring a patient to medical care in their country of origin, can be triggered by high hospitalization costs for undocumented immigrants without health insurance.[29] Mr. Doe's medical team stated they received a directive from ICE for potential transfer but told ICE they did not support his repatriation from a medical perspective.

Aside from medical deportation, there are different grounds for removal that would explain why the federal government would consider deporting Mr. Doe. Within these grounds for removal, there may be particular cases in which a detainee's health status could be presented to the court as a significant public health risk, including if the detainee has a communicable disease of concern to the general public,[30] although as noted, HIV is no longer categorized as one of those diseases. DHS states that medical information can be used in legal proceedings if there is concern about the mental health of the person.[31] In addition, DHS allows for medical information related to the reason for removal or regarding potential immigration benefits to be presented in court.[32] The Department of Justice may also have detainees' information shared with them in cases where the patient's medical condition is being questioned, or to order required medical treatments that the detainee is refusing.[33] In these situations, courts may use detainees' medical information, though it should not affect the overall outcome of their immigration case, including asylum cases.[34] Although there are these various grounds for DHS collecting health information for use in a removal proceedings, none of these circumstances applied to Mr. Doe.

Ethical Implications

Patient and healthcare worker reports suggest that immigration enforcement or custodial officers' presence during medical exams is common practice. From a legal perspective, officers should not be allowed in non-criminal detainee patient exam rooms or to document information without a specific, legally justified reason. If there are concerns about security, then hospital security can be utilized, or ICE officers can be present, but they must maintain patient confidentiality. Firsthand accounts of patients and providers in situations like those in Mr. Doe's case have brought to light the larger ethical implications of this practice, including negative effects on the patient-provider relationship, patient privacy and confidentiality, and providers' ability to provide ethical care.

Effects on the Patient-Provider Relationship

Anecdotal accounts from physicians suggests that the presence of immigration enforcement or custodial officers in exam rooms may negatively affect the quality of the patient-provider relationship by interfering with the patient's ability to openly communicate with the physician.[35] In addition, reports from patients depict how officers abase immigrant detainees' dignity by denying them access to basic medical attention and care for health concerns.[36] These abuses have both acute and long-term effects, as they can lead detainees to avoid necessary medical treatment.[37] There are also reports of female detainees forgoing preventative medical care, such as pap smears and breast exams, citing discomfort in knowing an officer would be present during those procedures.[38] These accounts demonstrate the chilling effect that officers' presence has on detainees' desire to seek medical treatment. As the US moves toward harsher immigration policies that will allow detainees to be held for longer periods of time[39], this fear and reluctance to seek care coupled with already low-quality medical care[40] will further endanger the health of those in immigrant detention. In Mr. Doe's case, his concerns regarding the use of his medical information for his immigration case caused a delay in his receiving life-saving therapy. Since he was afraid to communicate with the healthcare providers in the presence of the custodial officers, the physicians were unable to determine if the patient could give consent to the treatment.

Effects on Privacy & Confidentiality of Detainee Health Information

This review has shown how immigration enforcement or custodial officers' presence encroaches on detainees' right to privacy during medical exams afforded to them through HIPAA. There are also implications

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for the confidentiality of detainee health information. Interviews with detainees have shown that officers are often cognizant of detainees' medical conditions and do not keep that information private.[41] In some instances, officers have even served as language interpreters for patients, making them privy to detainee PHI and in control of the communication of the patient's information.[42] There is an inherent conflict of interest for officers and, because they lack HIPAA training, it cannot be certain that officers will keep patients' PHI confidential even if they agree to do so. For these reasons, it is important for ICE to clarify and enforce restrictions for when officers are legally allowed to be stationed in medical exam rooms for detainee patients who are not an obvious threat to the public.

Challenges for Healthcare Providers of Detainees
Immigration enforcement or custodial officers' presence in exam rooms also poses ethical challenges for physician's ability to treat detainees and fulfill their Hippocratic duty to protect their patients' privacy and confidentiality. Physicians are instructed by the American Medical Association to prevent instances where an outside observer might compromise patient care or breach patient privacy.[43] The ethical principle of "respect for persons" transcends immigration status,[44] and the Principles of Medical Ethics Relevant to the Protection of Prisoners Against Torture outline physicians' duty to protect detained patients' health and treat them with the same quality care as a patient who is not detained.[45] ICE standards state that "all medical providers, as well as detention officers and staff shall protect the privacy of detainees' medical information in accordance with established guidelines and applicable laws" and that access to medical records is limited "to only authorized individuals and only when necessary."[46] Yet, there are no regulations directly addressing detainee patients' or physicians' rights to ask an officer to leave or to stop documenting health information if they believe these rights are being violated. ICE standards should be clearer about what physicians and patients can do to maintain privacy in cases like Mr. Doe's, where a patient or physician feels uncomfortable with an officer's presence or their documentation of health information.

Per ICE and CBP standards, hospitals and providers can make "arrangements" regarding the care of detainee patients.[47] However, hospitals may not be aware that they can have their own institutional policies regarding detainee care and provider interaction with immigration law enforcement agencies. In hospitals where these policies are in place, providers may not be aware that such policies exist or, as in Mr. Doe's case, how to best abide to them because the policy is vague regarding both detainees' privacy and confidentiality and officers' presence in exam rooms. In Mr. Doe's case, the hospital had a general policy for patients in federal custody and thus dId not have specific guidelines for caring for non-violent civil detainees. This lack of clarity around patients' and providers' rights and the boundaries of immigration law enforcement has led to a lack of accountability from immigration authorities, leading to instances such as that of Mr. Doe where detainees are denied the care and protection they are afforded by US law and guiding ethical principles.

Rules are Not Enough
It should be noted that even if ICE clarifies their standards regarding the permissibility of officers' presence in medical exam rooms, this may not be enough to protect detainees' rights. Even though all contractors are required to abide by ICE's standards, the conditions and treatment of detainees at privatized immigration detention facilities have been criticized for not meeting those standards.[48] Many human rights violations, including withholding of medical treatment, have been reported in private criminal facilities, which do not specialize in immigration detention.[49] As a result of these inadequacies in care, the American Correctional Association provided ICE and DHS with the Civil Immigration Detention Standards to compel the civil detention system to be less reliant on prisons to hold undocumented immigrants.[50] Outside of clarifying standards related to this particular case, ICE should tighten enforcement of these standards to ensure that practice reflects the policies in place.

Conclusions
This case raises legal and ethical questions about the rights of patients in US immigration detention. John Doe, an undocumented immigrant detained by ICE was being examined by a physician at a large academic teaching hospital for complications related to his HIV disease. Custodial officers accompanied the patient into the exam room and documented information as Mr. Doe was being examined by the physician. It is unclear exactly what information the officers documented during the visit and for what purpose. The patient's concerns about the officers recording his health information were well-founded. From Mr. Doe's case and this review, we have learned that the practice of officers accompanying detainee patients into exam rooms is legally questionable yet appears to be common practice. However, there is nothing in ICE's detention standards that requires or obligates

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immigration enforcement or custodial officers to be present in medical exam rooms.

ICE detention standards also do not explicitly address whether officers can document information during a medical examination in which they are present or if the detainee can protest officers' presence. However, ICE standards do suggest officers should show justification for collecting PHI during the visit. Detainees' PHI can only be collected by law enforcement if the patient explicitly gave the officer permission or for reasons outlined by law, including recording PHI of public health importance, which notably no longer includes HIV status as of 2010. Given that HIV is no longer an inadmissible infection, the fact that Mr. Doe was HIV-positive should not affect the outcome of his immigration case. Additionally, ICE was already aware of Mr. Doe's HIV-positive status, as complications from the disease were the reason he was visiting the hospital, so it is unclear what information the officers were documenting or if they were ordered by a court to collect medical information during Mr. Doe's medical visit for any reason. Even if the officers were ordered to document Mr. Doe's PHI, they still violated the patient's right to privacy by not presenting legal justification to collect the detainee's HIPAA-protected information.

This case brings to light the negative medical consequences and ethical implications of a practice in detainee medical care that is not always in accordance with the law. In addition to potentially violating detainee privacy, a growing body of anecdotal evidence points toward the chilling effect that the presence of officers during medical exams can have on immigrants' desire to seek medical care in the US for fear of coming into contact with immigration authorities. Detainees' reluctance to seek care for fear of lack of privacy and confidentiality would further endanger the health of detainees who may increasingly be held for longer periods of time due to harsher US immigration policies.[51] As such, it is imperative to address these harmful practices that represent systemic violations of both privacy and human rights and also may degrade detained immigrants' willingness to access healthcare in the US. This analysis suggests that presence of immigration enforcement or custodial officers during medical examination of detainee patients, unless explicitly required by law, is a harmful, unethical, and unnecessary practice that should not be allowed.

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Recommendations

This case highlights the potential gaps in ICE's standards and also enforcement of their policies. In order to avoid unethical treatment of detainees, ICE should clarify, to the contractors with whom they work, their standards on detainee privacy and confidentiality and when officers are legally allowed to be stationed in medical exam rooms with patients who are not an obvious threat to the public. Since undocumented immigrants are not prisoners, the ICE standards of care for them should reflect that distinction. There are currently no regulations that directly address detainee patients' rights to ask an officer to leave or to stop recording health information, despite their having similar rights under the law as any other non-detained patient.[52] ICE should clarify standards regarding the presence of custodial officers in medical exam rooms and explicitly condemn officers' documentation of detainee PHI, except for limited reasons allowed by US law. Patients and their physicians should have clear recourse if an officer is not acting in accordance with these standards. The goal of these policy clarifications is to help ICE ensure that officers are only documenting information and interfering with medical care if absolutely necessary.

Hospitals and medical systems should develop and implement clear policies around the boundaries of immigration law enforcement in their institutions and how physicians of patients in immigration detention should interact with immigration authorities. Hospitals and medical professionals should be made aware of their and their patients' rights in cases such as Mr. Doe's. Hospitals and medical systems should create and release guidelines to inform physicians about their legal rights and the rights of patient detainees, ultimately empowering them to protect

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patient privacy in situations where a custodial officer is not required by law to be in the exam room or record information. Clinical ethicists can be used as resources and patient advocates in situations where medical staff are unclear around the ethical situation of their detainee patients.[53] Clinical ethicists can also aid in drafting hospital policies to ensure that undocumented immigrants can receive the ethical, respectful healthcare they deserve. Together, these efforts are a crucial step toward improving medical care for patients in US immigration detention.

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