

## 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 [mental illness](#) 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 patient-physician 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 in 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, [social stigma](#) 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 [advocate](#) 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.

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