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Who Should Make Decisions for Unrepresented Patients Who Are Incarcerated?

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Abstract

The United States has a high incarceration rate. Incarceration is associated with increased risk for cancer, chronic illness, serious mental illness, and substance use disorder. People who are incarcerated are less likely to be offered or participate in advance care planning, less likely to document their treatment preferences, and might not have a surrogate if one is needed. This article explores medical decision making for patients who are incarcerated and unrepresented and considers advantages and disadvantages of different classes of decision makers for them.

Incarceration and Aging

Criminal justice reform has increasingly become a consensus issue over the past decade, with many jurisdictions working to overturn aggressive policing and hyperpunitive prosecutorial and sentencing policies.[1] Incarceration history is associated with poorer health and social outcomes,[2,3] so carceral policies regarding the care individuals receive deserve clinical and ethical attention.

The United States has the highest rate of incarceration in the world,[2] with the rate of incarceration of African Americans in state prisons being 5 times higher than that for whites.[4] At any given time, roughly 2 million Americans are incarcerated and 4.7 million others are under judicial control through probation and parole systems.[5] These 6.7 million individuals—2% of the nation's population[6]—are more likely than the average American to be members of racial or ethnic minority groups, be poor, have experienced homelessness, or have a serious mental illness, substance use disorder, or chronic medical illness.[4] Incarcerated people are also the only group in the United States with a constitutionally guaranteed right to health care.[7] When patients are incarcerated, physically isolated from family and community, and lack decision-making capacity and a surrogate, they are extremely vulnerable.

In addition, people who are incarcerated age at a faster rate than their peers (acquiring multiple comorbid conditions and dying earlier),[8,9] and the average age of people who are incarcerated is increasing[8] as a result of tough-on-crime legislation in the 1990s, which eliminated parole possibilities for those convicted of low-risk offenses. As these individuals become older and more frail, more attention should be paid to their treatment

preferences, values, and relationships with prospective surrogates before they lose decision-making capacity. For patients who are incarcerated and who don't have decision-making capacity or surrogates, we suggest strategies for identifying decision makers and responding to these patients' needs.

Restricted Liberty

Health care decision making is one of the few means by which people who are incarcerated can exert autonomy and independence.[10] Yet health care decision-making can be limited during incarceration, especially for decisions that could cause financial burden from a corrections management standpoint or cause harm to others in a correctional population.[11] Medical decisions can also become a form of protest or self-advocacy when people who are incarcerated refuse medication or treatment as part of a dialogue regarding other unmet needs or malinger to receive secondary benefits from engagement with clinicians.[10,12]

Health decision making can present unique difficulties for people who are or who have been incarcerated, including a lack of confidence about their health choices. For those who are still incarcerated, one reason for this lack of confidence could be a sense of futility about their ability to self-advocate in other domains of their lives.[13] Patients affected by incarceration might not feel comfortable speaking up about their symptoms or sharing important information when they visit emergency departments or are hospitalized, for example.[14] Concerns about discrimination can also contribute to the reticence of patients who were recently incarcerated,[15] as can limited understanding of their disease processes[14] or past experiences. On the other hand, correctional health care facilities have been observed to diminish patients' care choices by limiting available treatments and access to care.[16] Similarly, not all correctional settings allow individuals to complete advance directives,[14] and there is evidence that correctional clinicians have limited knowledge of the role of advance care planning.[17]

Identifying Possible Decision Makers

Because patients who are incarcerated face structural barriers to exercising their autonomy and developing trusting relationships, clinicians should approach with care situations in which such patients lack decision-making capacity, advance directives, or surrogates. Specifically, patients who experience incarceration and are nearing the end of life carry risk factors associated with not having an assigned decision maker.[18] Assigning a decision maker to represent the preferences of people who are incarcerated and incapacitated—or defining a statutory hierarchy of potential decision makers—presents a challenge. The Table describes the advantages and disadvantages of potential decision makers for unrepresented patients who are incarcerated in states or jurisdictions in which no explicit hierarchy of surrogates is specified by law.

Table. Advantages and Disadvantages of Potential Surrogate Decision Makers for People Who Are Incarcerated

Decision Maker	Advantages	Disadvantages
Family member	• Most common surrogate for nonincarcerated people, including analogous vulnerable groups (ie, homeless patients) • Common default surrogate in state statutes	• Increased rates of estrangement in incarcerated populations • Might not know patient's most recent desires or preferences
Correctional custodian	• Presumed proximity to patient and knowledge of patient preferences	• Potential conflicts of interest; financial and security concerns could supersede patient's best interests
Correctional clinician	• Sophisticated medical knowledge • Code of ethics to guide decision making and support beneficence towards patient	• Lack of knowledge of patient preferences • Potential conflicts of interest; medical resource considerations could supersede patient preferences
Friends both from "outside" and from the prison "family"	• Might have intimate relationships with patient • Prison "family" validates relationships cultivated in stigmatized and dehumanizing setting	• No system to ensure closeness of relationships

Family member. Because family separation comes with incarceration, a family member might not seem to be an appropriate surrogate. Circumstances surrounding an arrest and court processes can damage the close relationships of those in prison.[19] Substance use disorders and serious mental illness—both dramatically overrepresented in correctional populations[4]—can also exacerbate social isolation associated with fractured relationships. Moreover, if friends and family members share behavioral or social risk factors with a person who is incarcerated and incapacitated, they, too, might experience

incarceration, premature mortality, or—if suffering from a disorder—be deemed not to have capacity for making health decisions.

Despite these risks for those experiencing fractured relationships, family members remain likely surrogates for patients who are incarcerated and incapacitated. Homeless people estranged from friends and family members are a similarly vulnerable comparison group associated with fractured relationships,[20] and one study found that a family member was named as the surrogate decision maker in 87% of cases.[21] Another reason why a family member might make a suitable surrogate is that, despite the punitive nature of carceral policies and the risk of relationship fracturing, family integrity can persevere through an episode of incarceration. Men in prison, for example, experience similar rates of childrearing to the general population, even though by age 26, the marriage rate of men who have been incarcerated is over 50% lower than that of men who have never been incarcerated.[22] Although 22% of fathers and 15% of mothers in state prisons reported having no contact with their minor children,[23] the extent to which family ruptures render family member surrogates innappropriate is worthy of investigation and consideration. It should also be noted that regulations that limit visitation and privacy in the interest of security—both in correctional facilities and during hospitalization—pose additional barriers to an inmate discussing his or her preferences with potential surrogates.[24] Ultimately, selecting friends and family members as surrogates might be more complex for patients who are incarcerated than for members of the general population. Similar logic would also suggest a lower frequency with which the best decision maker would be a friend "on the outside" (ie, who is not incarcerated).

Correctional staff. Staff within a correctional or health care system are often named as alternate surrogates for patients who are incarcerated and incapacitated. Potential conflicts of interest can exist for employees, however, and can cause substantial ethical problems.[11] A correctional custodian, such as a prison superintendent, who serves as a surrogate might be biased by a desire to boost morale of other incarcerated persons or by incentives to limit (or increase) the duration or complexity of care.[14] Specifically, correctional health care professionals could be motivated to provide more care for financial benefit or to provide less care due to conscious or unconscious biases or beliefs. Potential for harm to patients who are incarcerated, incapacitated, and unrepresented suggests why many states have implemented statutes to avoid these kinds of conflicts of interest.[25] Many states, for example, accept (as a last resort) a signed statement from 2 attending clinicians who agree to make an important decision for an unrepresented patient.[26] Of additional concern is that both correctional custodians and correctional health care professionals could lack adequate knowledge of a patient's preferences, the most important duty of a surrogate.

Friends. A potentially appealing option for unrepresented patients who are incarcerated is for a member of the prison "family"—that is, a close friend who is also incarcerated—to

serve as surrogate. Social networks and relationships formed during incarceration can serve as sources of well-being and meaning.[27,28] People who are incarcerated serve health-related roles in some facilities—as prison hospice volunteers, for example—and can develop an intimate relationship with others who are incarcerated and nearing the end of life.[29] Many states' surrogate decision-making statues allow, in specified circumstances, a friend to serve as a decision maker,[26] which can be helpful and humane.

Selecting friends as surrogates for unrepresented patients who are incarcerated has 3 merits. First, it treats friendships formed in correctional facilities on par with those formed elsewhere, modeling respect for relationships forged among marginalized citizens. Second, it suggests the importance of expressing regard for the dignity of a vulnerable patient as a person connected socially to others who care about him or her. Third, it prioritizes the value of an incapacitated person's preferences over those of potentially uninformed clinicians, correctional personnel, or estranged family members.

Inclusive Responsiveness

The above Table is a guide only and not intended to suggest that default standards should be implemented without careful attention to the needs and treatment preferences of particular unrepresented patients who are incarcerated. States and other jurisdictions should not, for example, standardize or assign default decision-making hierarchies for persons who are incarcerated and lack decision-making capacity. Instead, the legal and medical communities should sponsor research to better understand these patients' needs and preferences. Current research on surrogate selection for people experiencing incarceration is sparse.[17,30,31] Without more robust input from key stakeholders, especially those who are incarcerated, health care professionals' ability to take good care of unrepresented patients who are incarcerated will be limited. Although the prospect of engaging an individual's prison family is promising, views of people actually experiencing incarceration should be gathered first.

We encourage clinicians and ethics committees faced with the not-uncommon dilemma of decision making for persons in custody to carefully consider pros and cons of possible surrogate decision-making candidates in states where a surrogate is not specified by law. When evidence of a patient's preferences is not available, a surrogate could be a close family member or a close friend—including from the prison family—or a carefully documented opinion from multiple health professionals could guide decision making. Regardless, the circumstances of a particular patient's case should be carefully documented and considered.

Due to aging among those incarcerated, the numbers of incarcerated persons unable to make health decisions in the United States will probably increase. Correctional systems should anticipate this trend and develop strategies for better advance care planning by soliciting patient input prior to loss of decisional capacity and formally assigning

surrogates. Clinicians, ethics committee members, and correctional personnel will continue to care for patients who experience incarceration, lack decision-making capacity, and for whom there is no evidence of their preferences. Future research on ascertaining these patients' treatment preferences can inform best practice development. Until then, considering potential surrogates—including family, friends inside and outside of correctional facilities, and health care staff—will require a patient-centered approach.

References

1. US Senate Committee on the Judiciary. Poll shows Americans overwhelmingly support prison, sentencing reforms. https://www.judiciary.senate.gov/press/rep/releases/poll-shows-americans-overwhelmingly-support-prison-sentencing-reforms. Published August 23, 2018. Accessed December 16, 2018.
2. 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.
3. Alex B, Weiss DB, Kaba F, et al. Death after jail release. *J Correct Health Care*. 2017;23(1):83-87.
4. Nellis A; the Sentencing Project. The color of justice: racial and ethnic disparity in state prisons. https://www.sentencingproject.org/wp-content/uploads/2016/06/The-Color-of-Justice-Racial-and-Ethnic-Disparity-in-State-Prisons.pdf. Published June 2016. Accessed January 4, 2019.
5. Kaeble D, Glaze L; US Department of Justice. Correctional populations in the United States, 2015. https://www.bjs.gov/content/pub/pdf/cpus15.pdf. Published December 2016. Accessed January 4, 2019.
6. US Census Bureau. US and world population clock. https://www.census.gov/popclock/. Accessed April 6, 2019.
7. *Estelle v Gamble*, 429 US 97 (1976).
8. Williams BA, Goodwin JS, Baillargeon J, Ahalt C, Walter LC. Addressing the aging crisis in US criminal justice health care. *J Am Geriatr Soc*. 2012;60(6):1150-1156.
9. Kouyoumdjian FG, Andreev EM, Borschmann R, Kinner SA, McConnon A. Do people who experience incarceration age more quickly? Exploratory analyses using retrospective cohort data on mortality from Ontario, Canada. *PLoS One*. 2017;12(4):e0175837.
10. Peteet T, Tobey M. How should a health care professional respond to an incarcerated patient's request for a particular treatment? *AMA J Ethics*. 2017;19(9):894-902.
11. Scott Smith M, Taylor LA, Wake A. Healthcare decision-making for mentally incapacitated incarcerated individuals. *Elder Law J*. 2014;22(1):175-208.
12. McDermott BE, Dualan IV, Scott CL. Malingering in the correctional system: does incentive affect prevalence? *Int J Law Psychiatry*. 2013;36(3-4):287-292.

13. de Viggiani N. Unhealthy prisons: exploring structural determinants of prison health. *Sociol Health Illn*. 2007;29(1):115-135.
14. Linder JF, Meyers FJ. Palliative care for prison inmates: "don't let me die in prison." *JAMA*. 2007;298(8):894-901.
15. Frank JW, Wang EA, Nunez-Smith M, Lee H, Comfort M. Discrimination based on criminal record and healthcare utilization among men recently released from prison: a descriptive study. *Health Justice*. 2014;2(1):6.
16. 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.
17. Ekaireb R, Ahalt C, Sudore R, Metzger L, Williams B. "We take care of patients, but we don't advocate for them": advance care planning in prison or jail. *J Am Geriatr Soc*. 2018;66(12):2382-2388.
18. Rothman A, McConville S, Hsia R, Metzger L, Ahalt C, Williams BA. Differences between incarcerated and non-incarcerated patients who die in community hospitals highlight the need for palliative care services for seriously ill prisoners in correctional facilities and in community hospitals: a cross-sectional study. *Palliat Med*. 2018;32(1):17-22.
19. Lafferty L, Chambers GM, Guthrie J, Butler T, Treloar C. Measuring social capital in the prison setting: lessons learned from the inmate social capital questionnaire. *J Correct Health Care*. 2018;24(4):407-417.
20. Song J, Ratner ER, Wall MM, et al. Effect of an end-of-life planning intervention on the completion of advance directives in homeless persons: a randomized trial. *Ann Intern Med*. 2010;153(2):76-84.
21. Klop HT, de Veer AJE, van Dongen SI, Francke AL, Rietjens JAC, Onwuteaka-Philipsen BD. Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. *BMC Palliat Care*. 2018;17(1):67.
22. Western B. Incarceration, marriage, and family life. Russell Sage Foundation. https://www.russellsage.org/sites/all/files/u4/Western_Incarceration,%20Marriage,%20%26%20Family%20Life_0.pdf. Published September 2004. Accessed May 9, 2017.
23. Glaze LE, Maruschak LM; US Department of Justice. Parents in prison and their minor children. https://www.bjs.gov/content/pub/pdf/pptmc.pdf. Published August 2008. Revised March 30, 2010. Accessed January 4, 2019.
24. Federal Bureau of Prisons. Institution supplement: visiting regulations. https://www.bop.gov/locations/institutions/sst/sst_visiting102617.pdf. Accessed March 5, 2019.
25. Natterman J, Rayne P. The prisoner in a private hospital setting: what providers should know. *J Health Care Law Policy*. 2016;19(1):119-147.
26. American Bar Association. Default surrogate consent statutes. https://www.americanbar.org/content/dam/aba/administrative/law_aging/201

4_default_surrogate_consent_statutes.authcheckdam.pdf. Published 2018. Accessed December 14, 2018.
27. Nargiso JE, Kuo CC, Zlotnick C, Johnson JE. Social support network characteristics of incarcerated women with co-occurring major depressive and substance use disorders. *J Psychoactive Drugs*. 2014;46(2):93-105.
28. Haynie DL, Whichard C, Kreager DA, Schaefer DR, Wakefield S. Social networks and health in a prison unit. *J Health Soc Behav*. 2018;59(3):318-334.
29. Cloyes KG, Rosenkranz SJ, Wold D, Berry PH, Supiano KP. To be truly alive: motivation among prison inmate hospice volunteers and the transformative process of end-of-life peer care service. *Am J Hosp Palliat Care*. 2014;31(7):735-748.
30. Sanders S, Stensland M. Preparing to die behind bars: the journey of male inmates with terminal health conditions. *J Correct Health Care*. 2018;24(3):232-242.
31. Sanders S, Stensland M, Juraco K. Agency behind bars: advance care planning with aging and dying offenders. *Death Stud*. 2018;42(1):45-51.

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