Barriers and Facilitators to Quality Healthcare for African Americans with Incarceration Histories

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ABSTRACT

BACKGROUND: Prior research has shown that African American men and women are more likely to receive lower quality healthcare compared to their white counterparts, which is exacerbated in jail and prison healthcare systems.

OBJECTIVE: The purpose of this study is to explore barriers and facilitators to quality healthcare among African American men and women released from Illinois State Prisons or Cook County Jail by examining their opinions and experiences with overall healthcare and cancer screening during and after incarceration.

DESIGN: Four focus groups ($n=25$ "co-researchers") were conducted to understand how formerly incarcerated African American men and women perceive and describe their experience of accessing, understanding, and utilizing healthcare during and after incarceration. Co-researchers' reports on healthcare during incarceration are retrospective.

KEY RESULTS: Multiple facilitators and barriers to accessing healthcare were described. Unique themes from during incarceration included lack of access to adequate and appropriate healthcare, lack of trustworthiness of healthcare systems, excessive and punitive co-pays for questionable and inadequate healthcare, responses to inappropriate or inadequate healthcare motivated by negative attitudes, and actions by correctional staff or healthcare professionals which dis-incentivized medical help-seeking, and gaps in knowledge and understanding about cancer screening and chronic health conditions. Post-release themes included strong motivations to access and routinely utilize healthcare systems, the ability to prioritize health, increased access to healthcare and healthcare systems (though this required structural assistance), good or better-quality healthcare, and on-going support, knowledge, and positive interactions with healthcare professionals.

CONCLUSIONS: This study highlights the need to address barriers to accessing healthcare during and after incarceration, particularly given racial disparities in healthcare treatment and outcomes.

KEY WORDS: incarcerated African Americans; formerly incarcerated African Americans; reentry; healthcare disparities; cancer screening

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BACKGROUND

The USA houses over 1.9 million incarcerated individuals.[1] Many suffer disproportionately from chronic and acute health challenges particularly during and after incarceration.[2,3] Scholars consistently cite mass incarceration in America as a systemic form of structural racism that produces and reproduces healthcare inequality, with African Americans disproportionally represented.[4] Substance use disorders (SUD), HIV, other infectious diseases, mental illness, chronic diseases, and reproductive health problems are overrepresented in incarcerated populations. Cancer prevention in incarcerated populations is overlooked and understudied. African Americans are disproportionately impacted by cancer, including increased rates, mortality, morbidity, and lower quality of life.[5,6] Key healthcare barriers must be addressed to decrease these disparities.[7,8]

African Americans are more likely than whites to be arrested, be convicted, and face lengthy prison sentences, and are 5.9 times as likely to be incarcerated.[9] In 2022, nearly 49% of all persons under correctional supervision (probation and parole, or in jails or state or federal prisons) were African American,[10] yet African Americans comprise only 13.7% of the US population.[11] Compounding chronically worse health outcomes, African Americans are also less likely to receive treatment during and after incarceration. The "spillover affects"[12] of mass incarceration lead to

Prior Presentations

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vast social disadvantage, stigmatization, and marginalization in black communities.[12] Contributing social determinants of health include socioeconomic status, homelessness, less education, and lack of healthcare access.[13,14]The criminalization of persons without access to appropriate and adequate mental health resources, stable housing, and substance use treatment continues to propel disproportionate incarceration rates.[15]

Incarcerated women have even higher health burdens.[16,17] They experience more treatment interruption, health disempowerment, and mental and physical health problems compared to the general population.[18] Key healthcare barriers must be addressed to decrease these disparities.[7,8]

OBJECTIVES

While compromised health among recently released individuals is described, less is known about specific barriers for African Americans. The current study aims to (1) identify key barriers and facilitators to healthcare during and after incarceration, among formerly incarcerated African Americans, and (2) to describe specific healthcare, chronic health condition treatment, and preventive disparities in jails and prisons through the lived experiences of impacted persons.

DESIGN

This study uses an abductive approach framed by phenomenology.[19] The approach is non-hierarchical as is illustrated by our reference to research participants as "co-researchers." Abductive approaches afford researchers a blended inductive-deductive style that moves between emergent data (inductive) and theoretical underpinnings (deductive).[20] In qualitative methods, phenomenology is a way of conducting both data collection and analysis that captures lived experience from co-researchers (study participants) via narratives and open perceptual disclosure.[21]

RECRUITMENT

Co-researchers were recruited via snowball sampling and referral by key community informants. Five community-based, Chicago programs serving persons returning from Illinois prisons and jails participated as recruitment sites. Investigators conducted brief, individual, face-to-face eligibility pre-screening interviews to verify that they met inclusion criteria: (1) formerly incarcerated, African American adult men and women aged 40 and above (to better describe potential chronic health conditions); (2) current residents of Chicago or Cook County; (3) released from Cook County Jail and/or Illinois prisonsduring or after 2015; and (4) having direct or indirect knowledge of cancer screenings (in order to understand preventive healthcare) or treatment during or post-incarceration. Co-researchers were given a $40 gift card and a bus pass.

DATA COLLECTION

Data were collected in four focus groups with women ($n=12$) and men ($n=13$). The average age of co-researchers was 55 and most (68%) were released between 2018 and 2019. Confidential focus groups were conducted at a community health center and a transitional residential reentry program in June and July 2019 by four experienced investigators trained in qualitative research methods.[22] Interviews lasted 60–90 min and were audio recorded. The study was approved by the Governors State University Institutional Review Board and required informed consent. Three members of the research team with advanced degrees and training in criminology, social work, public health, and/or nursing developed the semi-structured interview guide. Questions explored included co-researcher's beliefs and experiences during or after incarceration in four categories: (1) access to healthcare; (2) knowledge and utilization of healthcare resources and systems; (3) knowledge about chronic disease treatment, and prevention; and (4) barriers to cancer screening for themselves and others. Because the interviews took place after release from incarceration, the data are based upon their memories of their during and after incarceration health experiences.

A pilot interview conducted with a formerly incarcerated, key community informant was not included in the study outcomes but led to interview guide revisions. Member checking was conducted with expert community members, including persons with histories of incarceration who were not participants in the study, correctional healthcare providers, and reentry direct services professionals. All interviews were transcribed and de-identified to protect confidentiality.

DATA ANALYSIS

The analytic team included researchers in anthropology, medicine, social work, public health, and criminal legal systems. Upon completion of interview/focus group transcription, the research team began coding. To do this, the team created a list of preliminary codes based on prior theoretical and empirical work (deductive). During coding within Dedoose (a qualitative coding/analysis program),[23] the researchers also relied on a grounded-theory (inductive) approach to coding that allows new codes to emerge from the data.[24] While two researchers coded the data, the team met regularly to discuss the five primary and 28 secondary codes to ensure intercoder reliability and prevent coding drift.[25] The coding process included both primary (first-round, largely descriptive) and secondary coding (deeper, theoretical) cycles.[26] Upon coding completion,

the research team considered the frequencies of codes and code occurrences and co-occurrences to consider analysis by focus group and participant sex/gender. The analysis process included the research team discussing coded data as answers to the four areas of inquiry: healthcare access, knowledge/use of healthcare resources, chronic disease knowledge, screening, and treatment barriers. The team developed analytic memos[26] to delve more deeply into each focal area by examining the co-researchers' perceptions based on their sex/gender and other characteristics such as formerly in prison or jail, geographic living location (Chicago or other Cook County locales), and age. The COVID pandemic interrupted our plans to present preliminary findings to our study co-researchers. However, we shared preliminary findings with key community experts including correctional healthcare professionals, persons with lived experience, and persons employed by transitional reentry agencies who verified the authenticity of our findings.

RESULTS

Five primary themes emerged as *barriers* to accessing healthcare: (1) lack of appropriate and adequate access to healthcare, (2) lack of trustworthiness of healthcare systems; (3) the role of medical co-pays for incarcerated persons; (4) responses to inappropriate or inadequate healthcare; and (5) gaps in knowledge and understanding about cancer and chronic health conditions. Four themes emerged as *facilitators* to accessing healthcare and cancer screening: (1) ability to prioritize health; (2) access to healthcare; (3) good or better-quality healthcare; and (4) support and knowledge provided by healthcare professionals. Co-researcher perceptions of each of these areas are provided below using representative quotes to detail their understandings and experiences.

Barriers

1. Lack of access to adequate and appropriate care

Many co-researchers recalled multiple adverse experiences during incarceration as evidence of the lack of access to appropriate or adequate care during and after incarceration. They described their incarceration experiences and observations of others who received inadequate care for serious health conditions, incidents of ignored requests, medical neglect, misdiagnosis or misinformation about their illnesses, receipt of minimal care, and treatment with ineffective or wrong medications.

One co-researcher described how her repeated requests for medical attention were ignored and resulted in losing her vocal cords during her incarceration:

> …before I became incarcerated, I had private insurance, whenever there was an issue, I'd go to my doctor…When I entered prison …I made sure I got copies of all my records… show[ing] that I previously had vocal cord cancer. [While] incarcerated, after three months I started experiencing some serious issues and I was ignored... …I told them I think my cancer has returned. It was documented…they ignored that. They said I had COPD, I had bronchitis, I had everything but cancer…. they made me go back to my unit. They said if I did not go back to my unit, I was going to go to [solitary]. …That night I went into respiratory arrest. At 4:00 a.m. I was discovered unresponsive. They told the nurse. [the guards] was gonna send me to the healthcare unit –[the nurse] told them to call 911...it was discovered that I had a tumor blocking my vocal cords … if I had been seen sooner, I might have retained my voice. (Female)

Another co-researcher detailed the lack of medical care for someone incarcerated with him, dying from pancreatic cancer:

> I met a man that was in there with pancreatic cancer. The [correctional facility] …don't even have a hospice program. I initiated that… I was able to assist him… We come through the institutions…we are given physicals…your blood is taken and a host of …different things are done to you, but [cancer] is not addressed …I wrote grievances for him. I was …his advocate. I saw where [medical furlough] was denied on multiple occasions, until it got…to a point where it was dire straits, and even then…. he was prescribed morphine, and I didn't see nurses, medical doctor…, healthcare administrator. I never saw the actual care that was needed…. I was able to come over to the healthcare unit [and]… I was able to spend some time with him over the last days. Unfortunately, I left. One week after I left, he passed away….it was a mess. And I know that he's not the only one. (Male)

Another co-researcher recalled his experience of receiving a bare minimum of care because he had public insurance and was a Black man.

> I experienced severe sinus infection that caused me to have to have brain surgery [severe swelling] …I realized in that…process there are a lot of medical cares and procedures that if you are not insured privately, it's just not afforded to you…[T]here's different practices and different chances that they'll take before they actually…do what's absolutely necessary for you…when it come to your health, we shouldn't be gambled on. We should be afforded the same care as everybody else… But just as I look back on that experience of how they played around with my health and I wasn't really con-

sidered, as a Black man…afforded the care around the procedures that I know now that other people are afforded…[My] perspective is they don't care about us…like… people that have private care. (Male)

2. Lack of trustworthiness of healthcare system

Some co-researchers recalled feeling hopelessness and expressed personal beliefs that they were incarcerated in a system where they did not have control over their personal health and complaints about inadequate care would put them at risk of mistreatment and retribution:

I didn't wanna put up no fight toward the people, because I already knew I was gonna lose…I just prayed and prayed and prayed that one doctor would come here [and] really understand that I have blood pressure…It was still…me praying to the day that I [got] released, if I can get out there. That's the way it made me feel. It made me stay focused about…not losing it with these people [prison staff] about my health. (Male)

Some co-researchers described avoiding healthcare and instead adopting personal health strategies due to the lack of trustworthiness in prison or jail healthcare systems:

During my…incarceration…I [never requested] a call pass [a pass to walk from the cellblock to the medical unit], 'cause… I seen how they treated people, and I didn't want to go through that. Plus, I was doing the right things to keep my health up. (Male)

3. Role of medical co-pays for incarcerated persons

The research analytic team was unaware of the important role of co-pays to see physicians or nurses in jails and prisons prior to these focus groups. Yet, a majority of co-researchers cited medical co-pays as the main barrier to seeking and receiving medical attention during incarceration.

I spent nearly 30 years inside, and access to medical care tended to slide really out of control when they brought in privatization of healthcare. It was all about co-pay. It was very difficult to see a doctor. You could talk to a nurse about your medical situation. She would make a determination of whether or not it warrants a doctor, she may just provide you …Tylenols or Motrins, depending on [how] many times you be willing to sign a $5 co-pay [to see the nurse], or file grievances about denial to see a medical professional other than just a nurse. [After] five, six times maybe complaining…they would get you in front of a nurse practitioner [or] get on a doctor call line….it had to be extreme emergency situation…you had to be suffering from a heart attack or stroke or at least something that severe in nature…[or] it was just virtually impossible to see a doctor. (Male)

When I got to [the first prison] you pay...that $5, co-pay…But when I got to [the second prison] you have to pay $15 before you see this doctor… They give you some medicine to hold you over, and then that's gone, you still didn't pay, and then you drop another [request for medical care]; they give you a little bit more medicine. And then you wait almost a month before you see the doctor. But now since I'm not incarcerated, I go to the doctor when I get ready. (Female)

4. Responses to inappropriate or inadequate healthcare

Co-researchers' belief systems also de-motivated them to seek medical help when needed. Co-researchers' observations about inadequate healthcare delivery included suspicions of experimentation and being given test medications or treatments without their knowledge; expectations of unfair, subpar, and disrespectful treatment; beliefs that requests for help would only be ignored or disbelieved; and perceptions that some doctors lacked expertise and did not care about them. One co-researcher describes his suspicions of medical experimentation in-prison:

…the doctors, the nurses were looking…for people with hernias. They'd hurry up and take care of hernias, because I guess they was going through some type of experimental stuff to really find out how to deal with the hernias. So, you start looking at things and realize that this was all about money…You know, mesh they put in your hernia. everybody was getting surgery…I had a hernia for 20 years. They would not fix it. (Male)

5. Gaps in knowledge and understanding about cancer screening and chronic health conditions

Some co-researchers acknowledged a general lack of understanding and resource knowledge about chronic health conditions and cancer screening, during and after incarceration, as well as a lack of trust toward doctors who did not look like them:

…it has a lot to do with the messaging, too. I've sat in groups were someone's presenting and facilitating health awareness, but the only thing is we [are] not connected. … and that's what I mean by when I look for a doctor that look like me, who can relate with my struggles, whether it be the experience of a trauma, the dysfunction and [or] being in the community of failed Chicago public school system...who can identify with some of my other struggles. (Male)

> Cancer, I would like to know what cancer screening consists of… how do you know if you got cancer or don't have cancer…I'm feeling good. I'm feeling great…I sat in the Department of Corrections for a while. And I asked them…Ain't nothing but…a mole…But I get so many of them, got me wondering… But they just won't diagnose you. (Male)

Facilitators

1. Ability to prioritize health

Co-researchers shared why they prioritized their health: aging, stopping drug use, getting answers regarding health concerns, screening for cancer, referrals from trusted healthcare providers, getting help they wanted when needed, having the freedom to make decisions about and to control what happens to their bodies, and encouragement from family members and friends:

> I have more knowledge about the effects of cancer in the different areas of the body. [When] I was much younger, I wouldn't have wanted to know. I would be afraid to know …so I wouldn't even go to the doctor, because I'm afraid they gonna tell me something is wrong. But as I've gotten older, I understand the importance of getting myself checked out. I was having a conversation with my son. He's like 'I ain't going to no doctor. [My sister] went to the doctor, and she only 20, and they told her she had cancer. So, I'm not going.'…that just made me think about the age difference [and] how we perceive things as we age. (Female)

In addition, co-researchers described post-release motivation and practices they adopted after incarceration for maintaining and improving their health including stopping drug use, self-care routines (inside prison), following doctor's orders, and scheduling regular doctor's visits.

> In my addiction. I didn't go to the clinic. I didn't get checked up... Now I been clean for a minute, I take my medicine regularly. I'm getting checked up twice a month. I know my body and know if there's something wrong. (Female)

2. Access to healthcare

Findings revealed co-researchers overwhelmingly recalled trauma caused by not getting appropriate or adequate healthcare during incarceration. However, a few individuals identified experiences during incarceration that were helpful, in some cases with a Black physician.

> ...In [the] Department of Corrections [if] it wasn't for…a new doctor coming in and me going to him, (he was Black) they wasn't giving colonoscopies. They wasn't sending you to…the hospitals to get it checked. You['re] a guy 40 years old, 50 years old, you s'posed to get those things. But they wasn't giving us that stuff. But him being there, he would adjust the rules, and he wasn't there too [long]. (Male)

In addition to prioritizing health after release, many co-researchers identified system issues in healthcare access to facilitate their healthcare access. They spoke of being taught about insurance, receiving insurer rewards and incentives for maintaining health routines, easy appointment access, and nearby or on-site health facilities at transitional or residential programs:

> I chose the doctor I have because [of] convenience to get there. I live right … around the corner from them. And they provide a gym. And my way of picking my insurance provider was …they …want[ed] to make sure that you are aware that there's cancer, there's hepatitis B, … we should want to take a look at and…have knowledge [about] what's going on. And I see a loving kindness when I always go into that facility… They do follow-up calls. They provide you with the doctor that you choose...I got a membership to the gym...I'm overweight…and I want to maintain the level of discipline in that area, because I don't want to end up with diabetes or stuff that I don't already have. (Female)

Many co-researchers noted access to on-site care and resources provided by visiting medical professionals as an essential component of transitional residential programs:

> I'm going to the doctor every chance I get. I'm not using anymore…I guess it's different for different folks, because I was in a recovery setting… that is one of the better hous[ing] facilities…where you have access to just about everything. And we need more facilities like that one. So, we had [nurses] that would come to us to provide the healthcare services, be it mental health, physical. I had access to a therapist…Doing the work that I do now and going into various halfway houses, other folks don't have that access. (Female)

3. Good or better-quality healthcare

A majority of co-researchers detailed their experiences with receiving good quality healthcare which they described as effective treatment, respect, and positive interactions with providers, sometimes with more trust in African American doctors:

> I have veterans' health insurance, also county, and plus … Obamacare… So, far they've been doing pretty well, [running] blood tests, urine tests…they

scheduled me for a colonoscopy in September…. I had one before, but that's over ten, eleven years ago… (Male)

I have a primary doctor. I pay for healthcare through my job…it wasn't until I stopped drinking [and] drugs and started living a better quality of life…Paying for that healthcare start me going and I chose my doctor… and I'm looking for doctors that look like me. I'm looking at their experience. I'm looking at what they specialize in. …I have a phobia of doctors…as far as trust...When I would go see a doctor, I wouldn't tell him much. I wouldn't be totally honest…So I look[ed] for someone [who] looked like me that I [felt] comfortable talking to… An African American doctor, which turned out to be a good experience for me, because I could share whatever. I feel comfortable talking and allow[ing] him to do what he need[s] to do. Just like for the prostate, I avoided that so long. I was like nope. but…I understand this has to be done in order for me to survive…I'm 50...A lot of my peers are dead from illness. (Male)

4. Support and knowledge provided by healthcare professionals

Co-researchers described how being listened to, being believed, and having their chronic health concerns addressed motivated them to take better care of themselves. They also described their physicians giving them tools and information to better understand their health and be vigilant against risk factors:

When I came home …I told them …I feel something in my stomach, they listened to me thoroughly, they wrote everything down. Sent me to a specialist and I had fibroids as big as grapefruit, and they were growing… Two years ago I had a full hysterectomy. So they really listened and they did follow ups, making sure I didn't miss appointments, guiding me along in the process. They send me reminders for everything…time for your mammogram… … (Female)

DISCUSSION

This study describes barriers and facilitators to accessing healthcare during and after incarceration. During incarceration, co-researchers described major barriers to care including mistrust, refusal of access, and the need for them to pay to see a jail or prison nurse or healthcare provider. However, after incarceration, their readiness to address their health indicates a missed opportunity to address key health disparities which were in some cases only facilitated at system levels. Yet, prisons are required to engage in health screenings on admission consistent with the National Commission on Correctional Healthcare (NCCHC) standards.[27] There is not a clear oversight process for this, and practice varies widely.[27] The quotes regarding barriers during incarceration in particular describe a lack of routine monitoring, assessment, and treatment for chronic health conditions, including cancer screenings. However, the standard of medical care includes initial health assessments, comprehensive physical and mental health exams and screenings, and subsequent treatments. Co-researchers described a lack of clear communication to inform incarcerated individuals of the outcomes of their exams, and subsequent engagement in their plan of care. Prison and jail climates are a crucial factor in healthcare provision and access, and a positive climate for both incarcerated individuals and custody and health staff has been shown to promote access to quality healthcare services.[27]

The co-researchers suggested ways to motivate the utilization of prison healthcare services, including eliminating co-pays, increasing funding and resources for prison medical services and staff, removing delays to be seen by prison medical staff, and institutionalizing effective and expedient follow-up or appointment protocols. In 2019, the John Howard Association[28] successfully campaigned to eliminate co-pays for medical care in Illinois prisons; however, co-pays continue elsewhere. In 2015, at least 35 states charged incarcerated persons medical fees in state and county jails[29] for both nurse and provider visits. Yet, incarcerated individuals work for what could be considered slave wages at 14–36 cents hourly. The comparison to slavery is notable in our co-researcher comments regarding medical experimentation.[30] There have been arguments that people who commit crimes should contribute to the costs of incarceration. However, 70% of those in jails are awaiting a trial (presumed innocent);[1] African American men are 22% more likely to be arrested, be convicted, and have higher sentences than their white counterparts.[1] Incarcerated individuals purchase necessities that prisons or jails do not provide, such as personal care products, over-the-counter medicine, additional food, clothes, and shoes, phone cards, stamps, and paper.[31] Often, they depend on family members to pay bills or are forced to prioritize their criminal legal system debt over other pressing needs upon release, such as food, clothing, and housing, which can create a barrier to successful reentry.[32] Illnesses are more likely to worsen when avoiding healthcare, which can lead to more aggressive and expensive treatments later.[32] These statistics support our co-researchers' gaps in care indicating that correctional leaders should work collaboratively with key healthcare administration to ensure during incarceration access to care is not limited due to the unavailability of staff, equipment, medications, or other healthcare resources. Similarly, post-incarceration system-level facilitation to healthcare is a priority.

Increasing access to and providing effective prescribed medications can alleviate symptoms and improve quality

of life for many incarcerated individuals with health conditions and have the potential to impact public health both in the facilities and when they are released. Early identification and prevention of chronic health conditions such as cancer[33] and diabetes are lacking and are both better for health and prevent future system burdens. Yet many for-profit contract agencies that serve these facilities do not meet standards of patient care and are not subject to independent review. Generally, jail administrators and healthcare staff are not adequately aware of healthcare standards and NCCHC requirements.[25,33] The implementation of quality healthcare also decreases the overall demand for services, which would alleviate burdens on jail and prison staff.[1]

Our co-researchers described filling out a healthcare request slip as the usual but inadequate way to receive care due to requests being ignored or delayed. An alternative would be to describe their symptoms and health needs and conduct clinical assessments and then prioritize needed care accordingly. Healthcare workers in jails and prisons are often warned about the tendency for incarcerated individuals to get out of work by complaining of symptoms and advised to provide over-the-counter analgesics and dismiss the concerns.[34] This would be considered unethical medical practice in any other setting. Instead of making judgments about the legitimacy of health concerns as displayed in some of the co-researcher's experiences, their role is to listen and gather preliminary information to make an informed clinical decision on the priority of patients' healthcare needs and then discuss next steps. It is worth noting that the hopelessness, mistrust, stigma, and lack of health literacy generated by these incarceration experiences can have long-term impacts on health and healthcare-seeking behavior that increase racial health disparities.

Concerns raised by our co-researchers regarding incarcerated dying individuals have been previously described. Institutionalizing prison hospice programs would facilitate incarcerated individuals receiving the care they need. Hospice programs are a standard of care and can help planning, including do-not-resuscitate orders, medical directives, and medical parole.[27,35]

There is evidence that the Transitions Clinic Network (TCN) model improves post-release care linkage and health outcomes and decreases costs.[36] The TCN includes providers and staff trained in caring for the population, as well as community health workers with lived experience of incarceration. There is evidence that the perceived stigma which worsens health outcomes can be addressed using this model.[36] System-level strategies linking incarcerated persons pre-release to a continuum of healthcare services and insurances post-release include Medicaid, transitional health clinics, and reentry programs.[37–39]

STRENGTHS AND LIMITATIONS

A strength of this study is its focus on the understudied population of African Americans, which are overly represented in incarceration facilities and suffer health and healthcare inequities. The qualitative data provide a deeper understanding of barriers and facilitators to improved health. The data are based solely on participants' recall and self-report, although 68% of our co-researchers were released within 1 year of the study. Additionally, the average co-researcher age was 55 and 52% were residents of the same Chicago-based, transitional reentry housing program. Therefore, our results may not be generalizable to younger populations, to persons not in transitional housing, or to other communities. Despite these limitations, we captured thick descriptions of the lived experiences of our co-researchers, and this adds trustworthiness, authenticity, and credibility to our findings.[40]

IMPLICATIONS

Our results demonstrate the need for expanded investigation. Future research on the links between post-incarceration pathways and assimilation into health services in the community for persons returning home from incarceration is crucial. There is also a compelling need for future exploration on disadvantages caused by and the impact of incarceration on health equity. In particular, further study is imperative to better understand the human costs to health resulting from incarceration healthcare co-pays and medical staff trained to minimize health problems. Finally, research identifying innovations and best practices on educating community health providers and incarceration personnel on health promotion and prevention among incarcerated and formerly incarcerated persons is essential.

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REFERENCES

1. BJS Releases Preliminary Statistics on Incarcerated Populations in 2022. U.S. Department of Justice Office of Justice Programs. 2023. Available at: https://www.ojp.gov/files/archives/pressreleases/2023/bjs-releases-preliminary-statistics-incarcerated-populations-2022#:~:text=About%2030%25%20(197%2C000)%20of,convicted%20and%2071%25%20were%20unconvicted. Accessed March 17, 2024.
2. **Binswanger IA, Kreuger PM, Steiner JF.** Prevalence of chronic medical conditions among jail and prison inmates in the USA compared with the general population. J Epidemiol Community Health. 2009; 63(11): 912-919.
3. **Spaulding AC, Seals RM, McCallum VA, Perez SD, Brzozowski AK, Steenland NK.** Prisoner survival inside and outside of the institution: implications for health-care planning. Am J Epidemiol. 2011; 173(5): 479-87.
4. **Bailey, Z.D., Feldman, J.M., & Bassett, M.T.** (2021). How Structural Racism Works-Racist Policies as a Root Cause of U.S. Racial Health Inequities. N Engl J Med. 384(8), 768-773. https://doi.org/10.1056/NEJMms2025396.
5. **Duggan MA, Anderson WF, Altekruse S, Penberthy L, Sherman ME.** The Surveillance, Epidemiology, and End Results (SEER) Program and Pathology: Towards Strengthening the Critical Relationship. Am J Surg Pathol. 2016 Dec; 40(12): e94-e102. https://doi.org/10.1097/PAS.0000000000000749.
6. American Psychological Association. Improving mental health for inmates. Available at: https://www.apa.org/monitor/2019/03/mental-heath-inmates. Accessed January 19, 2023.
7. **MacDonald M, Williams J, Kane D.** Barriers to implementing throughcare for problematic drug users in European prisons. International J Prisoner Health. 2012; 8(2): 68-84.
8. **Barry LC, Ford JD, Trestman RL.** Comorbid mental illness and poor physical function among newly admitted inmates in Connecticut's jails. J Correct Health Care. 2014 Apr; 20(2):135-44. https://doi.org/10.1177/1078345813518634.
9. The Sentencing Project. Report to the United Nations on racial disparities in the US criminal justice system. Available at: https://www.sentencingproject.org/reports/report-to-the-united-nations-on-racial-disparities-in-the-u-s-criminal-justice-system/. Accessed January 19, 2023.
10. **Buehler ED, Kluckow R.** Correctional populations in the United States, 2022 –statistical tables. U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics;2024. https://bjs.ojp.gov/document/cpus22st_sum.pdf. Accessed November 5, 2024.
11. U.S. Census Bureau. Quick Facts. Population estimates July 1, 2023. https://www.census.gov/quickfacts/fact/table/US. Published July 1, 2023. Accessed November 5, 2024.
12. **Wildeman C, Wang EA.** Mass incarceration, public health, and widening inequality in the USA. *Lancet.* 2017;389(10077):1464-1474. https://doi.org/10.1016/S0140-6736(17)30259-3.
13. Pew Research Center. Black Americans' views of and engagement with science: Black Americans' views about health disparities, experiences with healthcare. Available at: https://www.pewresearch.org/science/2022/04/07/black-americans-views-about-health-disparities-experiences-with-health-care/. Accessed January 19, 2023.
14. **Galea S, Vlahov D.** Social determinants and the health of drug users: socioeconomic status, homelessness, and incarceration. Public Health Rep. 2002; 117 Suppl 1(Suppl 1): S135-S145. PMID: 12435837; PMCID: PMC1913691.
15. Vera Institute of Justice. 2023 Annual Report. Vera Institute of Justice; 2023. https://www.vera.org/annual-report-2023.
16. **Binswanger IA, Merrill JO, Kreuger PM, White MC, Booth RE, Elmore J.** Gender differences in chronic medical, psychiatric, and substance-dependence disorders among jail inmates. Am J Public Health. 2010; 100(3): 476-82.
17. **Besney JD, Angel C, Pyne D, Martell R, Keenan L, Ahmed R.** Addressing Women's Unmet Health Care Needs in a Canadian Remand Center: Catalyst for Improved Health? J Correct Health Care. 2018 Jul; 24(3): 276-294. https://doi.org/10.1177/1078345818780731.
18. **Ahmed R, Angel C, Martel R, Pyne D, Keenan L.** Access to healthcare services during incarceration among female inmates. Int J Prison Health. 2016 Dec;12(4):204-215. https://doi.org/10.1108/IJPH-04-2016-0009.
19. **Wojnar DM, Swanson KM.** Phenomenology: an exploration. J Holist Nurs. 2007; 25(3): 172-80.
20. **Deterding NM, Waters MC.** Flexible coding of in-depth interviews: A twenty-first-century approach. *Sociol Methods Res.* 2021;50(2):708-739.
21. **Freistadt J.** Understanding others' experience: Phenomenology and/beyond violence. *J Theor Philos Criminol.* 2011;3(2).
22. **Greenbaum TL.** The handbook for focus group research. Sage; 1998.
23. Dedoose Version 9.0.17, cloud application for managing, analyzing, and presenting qualitative and mixed method research data (2021). Los Angeles, CA: SocioCultural Research Consultants, LLC. https://www.dedoose.com/.
24. **Charmaz K.** *Constructing grounded theory: A practical guide through qualitative analysis.* Sage; 2006.
25. **Cascio MA, Lee E, Vaudrin N, Freedman DA.** A team-based approach to open coding: Considerations for creating intercoder consensus. Field Methods. 2019; 31(2), 116–130. https://doi.org/10.1177/1525822X19838237.
26. **Tracy SJ.** *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact.* John Wiley & Sons; 2024.
27. National Commission on Correctional Health Care. Receiving Screening. *CorrectCare.* 2019. Available at: https://www.ncchc.org/spotlight-on-the-standards/receiving-screening/. Accessed March 17, 2024.
28. John Howard Association. Eliminating medical co-pays for prisoners. 2019. Available at: https://www.thejha.org/success-stories/eliminating-medical-co-pays-for-prisoners. Accessed August 19, 2023.
29. Brennan Center for Justice Research and Reports. Charging inmates perpetuates mass incarceration. Available at: https://www.brennancenter.org/our-work/research-reports/charging-inmates-perpetuates-mass-incarceration. Accessed January 19, 2023.
30. **Washington HA.** *Medical Apartheid: The dark history of medical experimentation on Black Americans from colonial times to present.* Penguin Random House; 2008.
31. Criminal Justice Fact Sheet. National Association for the Advancement of Colored People. 2020. Available at: https://naacp.org/resources/criminal-justice-fact-sheet. Accessed March 17, 2024.
32. Prison Policy Initiative. The steep cost of medial co-pays in prison puts health at risk. Available at: https://www.prisonpolicy.org/blog/2017/04/19/copays/. Accessed January 19, 2023.
33. **Maner M, Omori M, Brinkley-Rubinstein L, Beckwith CG, Nowotny K.** Infectious disease surveillance in U.S. jails: Findings from a national survey. PloS one. 2022; 17(8). https://doi.org/10.1371/journal.pone.0272374.
34. **Brooks KC, Makman, AN, Haber LA.** Caring for Hospitalized Incarcerated Patients: Physicians and Nurse Experience. Journal of general internal medicine. 2022; 37(2): 485-487. https://doi.org/10.1007/s11606-020-06510-w.
35. **Linder JF, Meyers FJ.** Palliative care for 'prison inmates: "Don't let me die in prison." *JAMA.* 2007;298(8):894-901.
36. Transitions Clinic Network: Evidence and Evaluation. 2019. Available at: https://transitionsclinic.org/evaluation-quality-improvement/. Accessed March 17, 2024.

37. **Ross, MW, Liebling A, Tait S.** The relationships of prison climate to health service in correctional environments: Inmate healthcare measurement, satisfaction and access in prisons. The Howard Journal of Criminal Justice. 2011; 50(3): 262-274. https://doi.org/10.1111/j.1468-2311.2011.00658.x
38. **Marks JS, Turner N.** The critical link between healthcare and jails. *Health Aff.* 2014;33(3):466-473.
39. **Bellass S, Canvin K, McLinktock K, Wright N, Farragher T, Foy R, Sheard L.** Quality indicators and performance measures for prison healthcare: a scoping review. Health & justice. 2022; 10(1): 13. https://doi.org/10.1186/s40352-022-00175-9.
40. **Creswell JW.** Qualitative inquiry and research design: Choosing among five approaches. 2012. Sage Thousand Oaks, CA.
41. Statista. Prisoners in the United States-statistics and facts. Available at: https://www.statista.com/topics/1717/prisoners-in-the-united-states/#topicOverview. Accessed January 19, 2023.