UC Santa Cruz
UC Santa Cruz Previously Published Works

Title

"We're Not Patients. We're Inmates": Older Black Women's Experience of Aging, Health, and Illness During and After Incarceration

Permalink

https://escholarship.org/uc/item/67p5w8k9

Journal

The Gerontologist, 64(4)

ISSN

0016-9013

Author

James, Jennifer Elyse

Publication Date

2024-04-01

DOI

10.1093/geront/gnad114

Peer reviewed

eScholarship.org Powered by the California Digital Library
University of California

The Gerontologist, 2024, **64**, 1–9
https://doi.org/10.1093/geront/gnad114
Advance access publication 31 August 2023
Research Article

THE GERONTOLOGICAL SOCIETY OF AMERICA®
OXFORD

"We're Not Patients. We're Inmates": Older Black Women's Experience of Aging, Health, and Illness During and After Incarceration

Jennifer Elyse James, PhD, MSW, MSSP*,

Institute for Health and Aging, University of California, San Francisco, California, USA.
*Address correspondence to: Jennifer Elyse James, PhD, MSW, MSSP. E-mail: jennifer.james@ucsf.edu

Decision Editor: Andrea Gilmore-Bykovskyi, PhD, RN

Abstract

Background and Objectives: The incarcerated population is growing older and by the year 2030, more than one third of people incarcerated in the United States will be over the age of 55. This population shift will have a profound impact on correctional health care systems as older incarcerated people often have multiple chronic illnesses and correctional institutions were not designed with aging and disability in mind. Black women experience greater burdens of comorbid conditions and are disproportionately represented among incarcerated women.

Research Design and Methods: We utilized Black Feminist Epistemological Methodology to explore the intersection of aging, chronic illness, and mass incarceration via in-depth interviews with 13 formerly incarcerated older Black women.

Results: First, participants described needing to prove themselves to be trustworthy prior to becoming ill in order to be believed and granted access to care when they report symptoms. Next, participants report being treated, not as patients, but as "inmates." The punitive nature of prison health care disrupted the patient–provider relationship and complicated the ability of patients to maintain autonomy in health care interactions. Finally, I describe how carceral health extends beyond the walls of both the clinic and the institution.

Discussion and Implications: For older Black women, medical care and decision making inside prisons occur within a punitive context, which presents unique barriers when seeking care. Their experiences of health and illness while incarcerated may continue to influence if and how they seek care as they age in the community and thus must be interrogated when discussing aging in the Black community.

Keywords: African American older adults, Qualitative research, Prison, Race.

Fox is a 52-year-old Black woman, who was recently released from prison after being incarcerated for more than two decades. *Fox* experienced the onset of chronic and debilitating back pain while she was incarcerated. This is quite common; the mattresses in the prison are thin, the labor performed is often strenuous. *Fox* was working cleaning the prison visiting room one day and she leaned down to empty a trash can. She told me,

> I remember taking a bag out and getting another bag and putting it on and I couldn't stand up. I tried … and I hit the floor. I started crying and crawling. And my boss came by me she said, 'what are you doing? I've been calling.' And I was like 'I can't move. Call medical.' They took me to medical. And then it was like, 'nothing's wrong with you.' And I'm like, really? I peed on myself, I can't move. 'Nothing's wrong with you, nothing's wrong with you.'

For months after this she asked for help and complained of pain. She reported that finally a doctor said, "'I'm going to order you an MRI so you can stop coming here and complaining. I see you just keep coming here talking about your back. We're not going to give you narcotics.'" *Fox* told me that they assume that patients are drug-seeking and noted that some patients likely are, but this assumption disrupts pain management for many. The Magnetic resonance imaging scan (MRI) was finally scheduled and occurred on a portable machine, brought into the prison on a diesel truck. *Fox* remembered being slid into the machine and being able to hear the technicians talking to each other through the speaker. She said, "I heard one saying, 'it's a wonder she can walk.' Tears just started rolling down my eyes. I just wanted the validation. Okay, something *is* wrong." Finally, then, after a year of pain, being in and out of a wheelchair unable to walk for weeks at a time, she was able to begin a path toward recovery.

In this paper I will present the narratives of *Fox* and other formerly incarcerated Black women to describe if and how older Black women were able to access health care behind bars and the implications of the barriers to quality care on the health of aging Black women behind and beyond prison walls.

The incarceration rate increased dramatically over the last 50 years, rising fivefold since 1975 (Pettit & Western, 2004), with the number of incarcerated women growing eightfold since 1980. There are now nearly 200,000 women incarcerated in the United States, with Black women

Received: March 11 2023; Editorial Decision Date: July 31 2023.
© The Author(s) 2023. Published by Oxford University Press on behalf of The Gerontological Society of America. All rights reserved. For permissions, please e-mail: journals.permissions@oup.com.

imprisoned at over 1.7 times the rate of White women (Sentencing Project). Due to an increase in the lengths of sentences, the incarcerated population is growing older. By the year 2030, more than one-third of people incarcerated in the United States will be over the age of 55 (Chettiar and Gupta, 2012).

Correctional institutions were not designed with aging and disability in mind (Williams et al., 2012). There are unique "Prison Activities of Daily Living" that more than half of older adults report struggling to do such as dropping to the ground for alarms or climbing onto a top bunk (Williams et al., 2006). Many older women in prisons reporting having difficulty navigating stairs, standing in line, and walking long distances, all of which may be a necessity to access meals, health care appointments, and daily medications while incarcerated (Wahidin, 2004). For more than two decades, researchers have been studying the concept of *accelerated aging* in prisons (R. H. Aday, 2003). Typically, older adulthood in this population is designated for those over the age of 50 or 55 due to the earlier presence of chronic disease, reduced life expectancy, and differences between chronological and physiological age (Williams et al., 2012).

Older incarcerated women have significant burden of chronic illness, including heart conditions, diabetes, HIV, and cancer (Caldwell et al., 2001; Genders & Player, 2016; Leigey & Hodge, 2012; Nijhawan et al., 2010; Nowotny et al., 2017; Proca et al., 2006), with one study estimating that as high as 85% of incarcerated people may have multiple comorbidities (Loeb et al., 2007). Incarcerated Black women are considered to be particularly vulnerable, with a greater risk of poor health (Oser et al., 2016).

It has been argued that incarceration presents a unique opportunity to engage underserved women in preventative health care (Nijhawan et al., 2010). However, numerous barriers such as co-pays, poor perceptions of prison health care staff, and security protocols may dissuade women from seeking health care while incarcerated (Wahidin, 2006) and the overall quality of medical care for chronic health conditions is highly variable across correctional settings (Wildeman & Wang, 2017). Lack of access to adequate care, treatment delays, and staff shortages have been associated with worsening medical conditions for women in prisons (Aday & Farney, 2014).

While the process of aging involves biological components, it is, importantly, a social process; one that is dramatically disrupted by incarceration. Little research has studied what it is like for Black women to grow older while incarcerated. Therefore, this study aimed to elucidate how formerly incarcerated older Black women experienced and managed chronic disease while incarcerated, as well as the lived experience of aging behind bars.

Method

The findings described here come from a larger research project on experiences of health and illness for older, formerly incarcerated Black women, which included both in-depth interviews and ethnography of community-based organizations working with and on behalf of incarcerated women. Study participants were recruited first through e-mail, flyers, and word of mouth through several community-based organizations and subsequently through snowball sampling. For this paper, we will focus on interviews conducted with 13 older, formerly incarcerated Black women using Black Feminist Epistemological Methodology (BFEM; James, 2021).

Black Feminist Epistemological Methodology

BFEM adopts Black Feminist Epistemology (Collins, 2000) as a way to build and produce knowledge through theory and methodology. It involves centering Black women's lived experience, applying an ethic of caring and personal responsibility, and creating a collective dialogue between researcher and participant, by sharing back research findings and questions with participants as a part of the data collection and analysis process. Each participant was invited to participate in two interviews. In the first interview, participants were asked to narratively describe their experiences of health and illness before, during, and after incarceration. Interviews were intentionally open-ended, allowing the participant to direct the pace and scope of the interviewing and ensuring the research was centered on her lived experience. Interviews were conducted by a Black feminist researcher with a background in social work.

After each interview, I reviewed the transcript and field notes and wrote a brief description of the participant, themes that emerged in the interview, points of confusion or clarification, and additional question. This summary was then shared back with the participant in the second interview, allowing the participant to expand, correct, contradict, or reframe. This process creates a collective dialogue between the researcher and the participant and allows the participant to play a more active role in the analytic process. Additionally, participants were asked to choose their own pseudonym. This is to both offer the participant more agency and to allow her to recognize herself in the research, obliging more personal responsibility from the researcher in how each participant is depicted. Some participants chose names, while others chose nouns or adjectives that describe their current approach to or vision of life and health. This method of naming is both common in BFEM as well as reflective of the nickname culture in many women's prisons. This study was approved by the University of California, San Francisco Institutional Review Board (UCSF IRB).

Data Analysis

Interviews were audiorecorded and transcribed verbatim, then analyzed using techniques based in grounded theory (Corbin & Strauss, 2008). Data analysis occurred concurrently with data collection. Three researchers collaborated on data analysis for this project. To start, each read two to three transcripts independently and engaged in a process of open coding (Bryant & Charmaz, 2007) to create an initial set of inductive codes (Vanover et al., 2021). We discussed our individual lists of codes and worked collaboratively to develop an initial code list, which we continued to iterate over the course of our analysis. Two members of our team then independently coded each transcript utilizing the qualitative analysis software Atlas.ti for data storage and management. Reports were generated for each code, and the quotations associated with each code were then further refined into categories and then into themes in an iterative process based in grounded theory. These themes were discussed in-depth in research meetings. They were also shared back with community members who have lived experience of incarceration to deepen analysis (Cutcliffe & McKenna, 2002).

Findings

Thirteen formerly incarcerated Black women participated in interviews for this study. Eligibility criteria included being formerly incarcerated, identifying as Black or African American, being over the age of 50, and having at least one chronic health condition. Black cisgender women, transgender women, transgender men, and nonbinary individuals were invited to participate in the study, but only cisgender women participated. All participants in this study had been incarcerated in jails and/or state prisons, and 12 had been incarcerated in California. Participants were incarcerated for 6 months to 34 years, with most participants spending more than 20 years in prison. They had been home for prison for a range of 3 months to 30 years, with an average time of 3 years since release. All participants were released from prison when they were aged 50 or older (see Table 1).

Structure of Care Delivery

Participants described annual appointments with a primary care provider, though it did not always meet needs or expectations. As Fox described, "Primary care provider, you see them once a year and they just pull you in and they will say, 'have you been coughing? Do you have fever or chills? Okay, that's your TB test.' And that's it once a year. And you wait literally like four hours just for those three questions. And you can't do nothing else." This setting makes it difficult to form relationships with providers and even more difficult to discuss issues of aging and chronic illness.

As medical problems arise throughout the year, prison residents put in a form to request a "ducat" to be able to go to the medical center. As they complete this form, residents are restricted to only list two problems at a time. All participants interviewed in this study reported having multiple chronic health conditions in middle age and older adulthood while incarcerated. Limitations on number of conditions that could be discussed in an appointment were noted as a barrier to managing aging-related symptoms. As one participant described, "if I have migraines and a big lump on my breast and discharge and an open boil back here, I need to pick what I think is priority." Forty state prisons systems across the country charge co-pays for incarcerated patients (Prison Policy Initiative, 2022). California ended this practice in 2019 and most participants were incarcerated during the time when co-pays were still charged and reported paying $5 for each visit to the medical, which can be a full week's worth of wages (which start at $0.08 per hour in California). If one's care is denied or they feel they have received inadequate care, you can file a grievance, known as a 602. Your case then receives further review.

Table 1. Participant Demographic Information

Characteristic	*N*
Age	
50–59	6
60–70	6
80+	1
Race	
Black	12
Mixed	1
Gender	
Woman	13
Household income	
Less than $35,000	6
$35,000–50,000	5
More than $50,000	2
Primary site of incarceration discussed	
Jail	2
State prison	8
Jail and state prison	3
Length of time since release	
Range	4 months to 30 years
Median	3 years

Accessing Care by Proving Character and Illness

In the community setting, patients can be prevented from accessing care by things like insurance status, which are not a concern in carceral settings. In carceral settings, patients can instead be prevented from accessing care by a process of having to prove both their character and their illness. As described above, patients indicate that they want to see a health care provider by filling out forms, which are held by corrections officers and, according to participants, could be refused. Participants described a system wherein people who are incarcerated had to prove their character prior to becoming ill, so that they would be believed to be in need when they requested access to care. *Second Chance* spoke of the importance of demonstrating one's character while in prison and that she felt she was lucky in that she was first incarcerated in her late 30s and knew to be "respectful." The guards came to know her as "one of the good ones" but she cautioned, "if you don't have that type of character … they're not going to show you any type of caring, any type of sympathy." According to participants, this assessment of character is highly racialized, gendered, and classed. Personal characteristics like being "well spoken" or "educated" influence how individuals are perceived, while being perceived as highly sexualized, nongender conforming, or gang affiliated could negatively influence how a participant was perceived or approached in health interactions. Participants described two advantages for older women: first, being more respected within the prison by both staff and residents. Second, most older adults have been incarcerated for many years. *Fox*, *Second Chance*, and *Annie* all described becoming leaders inside the prison who had established relationships with the staff; they were known as residents who could be counted upon to encourage positive behavior in others. However, not all older incarcerated Black women experienced this. Some described continuing to be perceived as "hot-headed" or "aggressive" based on assessments of their character made earlier in their incarceration.

If the guards didn't see you a certain way, you wouldn't be believed when you got sick. In this sense, correctional officers act as gatekeepers to health care. Many formerly incarcerated women understand this, noting that there are "fakers" who as one participant described it, "do pull shenanigans" and fake illness at times. This leads to scenarios wherein those presenting with emergent cases may be assumed to be seeking care for ulterior or less severe motives, which can have dire consequences. *Fox* shared one story saying, "a girl, her stomach, she is tiny, her stomach blew up like a balloon. And they were

kicking her saying, get up, get up, nothing's wrong. She died two hours later. Her appendix ruptured. She died two hours later." *Second Chance* described how this occurs with progressive disease as well noting, "a lot of ladies have died in there because of the lack of care, because they didn't believe them. I've had quite a few friends that died in there from cancer and stuff like that because when they got sick, they just didn't believe that they were sick like that. And they waited until the cancer got to phase 3, phase 4 and then they died." While both accounts are secondhand stories, they demonstrate the perception of people who are and have been incarcerated that illness may not be believed and that deferred care can lead to untimely death.

The overarching feeling of participants was that they did not receive quality health care while incarcerated. Some pointed to exceptions, such as a provider who took particular care. However, and especially for routine medical care of issues of chronic health and aging, the care was often not sufficient. As *Kat* said, "While you're in they care for you, but you don't get the care that you would if you were out." *Second Chance*, described the care saying, "You do not get care in prison, okay? You do not get care. There is no one that really cared. You have to care about yourself." *Warrior* agreed with this noting, "we did a lot of doctoring ourselves."

Perceptions of Providers

Descriptions of relationships with and perceptions of individual providers were quite mixed. There was a common refrain that the providers in carceral settings are different from those you could see in the community. This ranged from more commonplace complaints, like *Kat* who noted her frustration with only being able to see mental health providers who were in training (and as a woman in her 60s was reluctant to speak openly with those she perceived to be students in their early 20s) to more extreme perceptions and accusations. *Second Chance* described the prison doctors as "not the normal doctors." She asserted, "prison doctors are doctors that can no longer work in society." This was a sentiment shared by *Annie* who asked, "Why was it most of the doctors had had multiple malpractice suits and all kinds of stuff? I am so serious. And I'm like, why are they here working on me?" The California Department of Corrections and Rehabilitation has faced many lawsuits over the quality of its medical care, including the *Plata* class action suit, which led to medical care being placed under federal receivership (Bradley, 2006). While many changes have been made to increase the quality of medical care over the last 15 years, these perceptions and assumptions about health care providers have meaning and significance for care. For example, *Annie* went on to question the care and intention of these providers saying, "And then things happened like, okay, this six months everybody is getting treated for cancer. Everybody in the institution has high blood pressure. And everybody is taking this one drug. And so I was like, they must be getting kickbacks or something for these medicines or something because everybody is doing this." *Annie's* perception that the health care providers may have ulterior motives deterred her from seeking care, which, regardless of the validity, had implications for her health.

Most of the critiques expressed by participants were not of individual health care providers, but of the system under which they provided care. Continuity of care is a critical problem of disease management in chronic illness and aging, and disruptions can be magnified in the prison setting. One participant, *Content*, who was in her 50s and had a long history of high blood pressure, described starting her care with a new provider after being transferred from a different prison. She recalled,

> [The doctor] assumed that my blood pressure was in control because when they set up my first appointment, my blood pressure was normal. And she said, 'Oh, [Content], your blood pressure is normal. We're going to take you off this.' I said, 'but you can't take me off the blood pressure meds, it's only normal because of the meds.'

Yet, she did not feel like she could challenge her doctor in this setting. The doctor took her off her blood pressure medications and *Content*'s blood pressure went back up. She made appointments to go back in and each time had to pay the $5 co-pay, which was a challenge for her. She remembered this time being incredibly stressful noting,

> I started having this fear of a heart attack. Because my mom was 54 years old when she passed away from a heart attack. And my grandma was 60 years old when she passed away from a heart attack. So here I am in my early 50s and she's telling me she's going to take me off these meds. And I started stressing about it. Of course the stress would make my blood pressure go higher.

Content eventually went back on her blood pressure medications, which she has remained on since. Still, *Content* reflects quite positively on her relationships with her health care providers, whom she felt were "pretty good about following up" when she expressed health concerns. She felt that the system was not designed to manage aging and chronic illness, even with caring providers.

Fox noted how difficult it is for health care providers working in this environment and how valued the "nice" providers are because incarcerated patients are "so hungry for compassionate and acknowledgement." In describing positive health care interactions she said, "They are gentle, they are kind, they are professional. … You walk in there and it is sterile, it's beautiful, it's clean." Another participant, *Freedom*, described a positive relationship with a doctor saying, "she was very good. If something was wrong, she made sure she'd take care to find out what was going on." These providers and clinics do exist inside, yet for many participants they still spoke negatively about their overall experience of health care. Most pointed to the punitive nature of the prison itself as being the driver of poor health care.

Lack of Choice and Refusal of Care

A key example often pointed to of the punitive nature of health care is that patients are often not given a choice in their treatment plan. A recurring theme heard throughout the interviews was that there was often only one intervention offered to a health concern. For example, *Warrior* shared, "All my teeth that's missing is because they don't give you a choice … If you go in with a toothache, they pull it. You don't get to [decide]. That's just it. You get your tooth pulled." *Annie*, who had a history of high blood pressure, shared a similar story. She had a poor reaction to a medication; she described it as making her "feel high." Yet, she

didn't have the option to try another medication. She could take a lower dose, but even that made her feel poorly. So, she went without medication noting, "it's either that or nothing. So I think you do have a choice and the option is just no help at all." This refusal of a specific medication can then be interpreted as refusing all medical care. *Ms. Legacy*, who is in substance use recovery, reported that when she refused narcotics for pain to protect her sobriety that the response was "when you refuse that, then they say you are refusing medical attention."

And, indeed, this is an option available to patients. Legally, patients in carceral setting have the right to refuse care. Despite this right, patients reported facing forms of retaliation or punishment for refusing care. One woman, *Isis*, shared a story of facing such retaliation. Isis was quite ill during her time in prison. She was diagnosed with Lupus and went through periods of severe neutropenia. She spent time in the skilled nursing facility as she convalesced and she reported that she was sexually assaulted by a nurse during this time. For a period after this, she refused to go to medical. She described this time saying,

> I was threatened if I didn't go to my medical appointments—because I became very fearful of going to medical, I didn't trust them no more and I didn't want to be there—I was threatened to get written up. I would get in trouble. I've gotten written up a few times for refusing to go so, yeah, that was definitely a form of retaliation.

While this is the story of only one person, these types of stories circulate the prison and perpetuate the idea that "medical" is not a place for healing or a source of care. Another participant told me,

> You see people so sick. I've seen people die in their rooms because they won't go to medical. [Friend] died in her own room because she wouldn't take medical, she's like, 'why, they're not going to do nothing. They're not going to do nothing.' She died in the room three nights later. Because you don't want to go. You don't want to deal with it. You just want to be like, okay, I can handle this.

This is only magnified by the punitive nature of the prison; for example, if someone has an abscess from drug use they are doubly disincentivized from seeking care. As was described, "Now two things is preventing her from going. One is because she's not supposed to be using drugs in prison. But two, she knows they're not going to do anything to help her. They are not going to lance it."

Navigating Autonomy in a Punitive Setting

Within a punitive system, even mundane interactions can quickly move from caring to carceral. As described, when seeing a provider inside the prison, patients have a limited appointment time and are limited in the number of topics that can be discussed. Patients can be punished for attempting to ask questions or report a problem outside of what has been preapproved. As was described above, notions of someone's character or intentions highly predicate how they are perceived as they seek care. *Fox* told a story of receiving the results of her mammogram back, with a medical code and a notation of benign. She described asking a follow up question saying,

> 'I want to ask you ma'am, please, as a woman, can you please tell me what is this code and what is benign?' She said, 'it's of no consequence to you. It doesn't matter. And you need to leave before I push the alarm.' I'm like, wow. That's how things go.

This interaction demonstrates the perception many of the participants held that their concerns and understanding were not central to patient–provider interactions, which lessened trust in the providers themselves. In this context, having the alarm pushed and being chastised for being disrupted can mean the individual received a write-up that goes on their record. As *Fox* described, "once they press the button you automatically get a disciplinary: Disruptive inmate, disrespecting staff, or refusing a direct order … So now I can potentially stay in prison 10 more years."

Overcoming these concerns to seek care requires tremendous work on the part of the incarcerated patient. First, the work of navigating the process and waiting to be triaged and then seen. Many participants described waiting weeks for an appointment and then spending all day in the clinic and perhaps still not being seen. Second, perhaps more labor-intensive, is the work of navigating the boundaries of autonomy and self-advocacy in this space. *Fox* described that for nearly a decade when she was middle-aged, she didn't go to medical. She put off care because she was so distrustful of the care and providers. When she finally went back, because she could no longer wait, she described having to figure out how to get her needs met saying " It took me years to even speak up for myself, and then I had to get really overly … I can't even say over assertive. I had to find a balance between assertive and aggressive to get the help I need." Many Black women are familiar with this negotiation in many arenas of our life. Black women take strides to avoid being labeled as angry or aggressive in the workplace, in relationships, and, yes, in health care. There are particular consequences if one trips when walking the fine line between assertive and aggressive in the prison health context. *Sputnik* articulates this tension as someone who often approached her care from a place of aggression because she felt it was the only way to get care "because in there you don't have a voice unless you act like a complete ass. And then you end up getting writeups. And if you a lifer, those writeups are no good for you." Black women weigh the risks of not getting the care they need with the risk of potentially being punished and spending more time behind bars.

Health Outside of Health Care

Just as it does in the free world, health inside prisons and jails, extends far beyond the boundaries of the clinic. Things like diet, exercise, sleep, and stress all play critical components of our overall health and are often involved in care provider recommendations. Yet, the tools individuals use to optimize their own health may be inaccessible for people who are incarcerated. For example, as *Kat* described, "the food they serve you is crap." Many individuals described refusing to eat the food served at mealtime because of its quality and instead relying on what could be purchased in commissary. *Kat* went on to say,

> You know if you want to eat, they have chips and the food is high in carbs … There is no fruit. There was apples and oranges and sometimes [they] may be bad. … Not a lot

> of green leafy vegetables. You know so I battled with my weight in there cause sometimes it's like, forget it, you've got to eat, so then I ended up eating the cookies and the noodles … all this unhealthy stuff. And it made me feel sluggish and slow.

Another participant, *Sputnik*, described a similar trajectory when she was incarcerated in county jail for 3 years awaiting trial and the toll that lack of movement took on her body:

> I went in the county jail weighing 220. When I got to prison I was weighing 489 pounds … The first year that I was in the county jail they never let me out of my cell except to take a shower and make a five-minute phone call. My lawyer had to go to court against the county jail to get me one hour exercise. And that was before they enacted the 23-one activity for maximum-security inmates in a county facility. So he had to fight the issue … and I finally got to get out of my cell for one hour a day.

Sputnik felt this toll on her body for years to come. She struggled with not having control over critical decisions related to how she cared for her body.

Isis, the patient who was diagnosed with Lupus while incarcerated, described being told by her health care providers to avoid the sun. In community settings, this becomes a burden of the individual. One can decide whether or not they will wear sunscreen, hats, long sleeves, and stay inside during peak hours. Much of this autonomy is stripped away while incarcerated. While the medical directives were relayed to the corrections staff, *Isis* felt they were not honored and she was not allowed to be in the shade while outside. She described this saying,

> I mean they put these procedures and things in place, don't get me wrong … But do they actually honor those regulations and procedures? No. They do what they want to do. And nine times out of 10 they're going to do things to make the inmate feel like they are imprisoned.

Many of the strategies patients are told to use to stay healthy as they age are unavailable to people during incarceration. This can be particularly worrisome in middle and older ages when many people develop chronic health conditions. One participant, *Content*, was incarcerated in her mid-40s and, prior to her incarceration, she had always been a physically active person. She noticed that after being in prison, she wasn't able to do the same things physically that she used to do. She could no longer run and noticed this had a "profound effect on [her] body." She started having sciatic nerve problems, which she'd never had before. She described this time saying,

> I don't know if that's because of the sleeping on metal or that I wasn't exercising and working out as much as I was accustomed to prior to incarceration. So obviously there was weight gain. So that obviously started to affect my health even more, gaining weight, given the fact that I have high blood pressure. So I had to try to figure out other … ways to stay in shape. But it was a challenge for me because of its just a circle you get to walk around on the rec [yard].

At this point she started having a cascade of problems. Her blood pressure increased, she found out that her L3 and L4 had started to deteriorate, she was unable to lift heavy objects, and eventually her hands would go numb. She was told just prior to leaving prison was the beginning stages of rheumatoid arthritis. The health effects of prison have continued to follow her as she navigates reentry.

Implications Beyond the Prison Walls

Following incarceration, some participants continued to find it difficult to access health care; not only due to structural barriers, but in large part due to their own reluctance to seek out care. As *Clarence* described, "I don't like going to the doctor … it basically takes an act of congress." This is not an abnormal sentiment, but is shaped by experiences of incarceration. *Annie* spoke candidly about the profound effect of witnessing what she saw as the failures of the prison health care system. She spoke of an epidemic of suicides and inadequate mental health care and, as described above, her concerns about provider kickbacks for widely prescribed medications. All of this taken together meant that she did not trust medical care. When asked about her care inside she said, "I went to the doctor as little as possible."

Now, as she is home and growing older, she thinks about what her time inside meant for her health. She told me,

> I'll be 65 in a couple of months and it's been hard. I think that I probably could be in better medical health if I had trusted them. But, I may be in better medical health because I *didn't* trust them.

She wonders if there is more preventative care she could have been doing along the way, but the trust wasn't there. *Annie* told me that out of the 27 years she was in prison, she had two doctors who she felt invested in her as a person. She has struggled to change her approach to health care describing,

> So now I'm here and I still have those habits. I still don't go [to the doctor]. Because for 27 years I created this habit. And I don't have to because the place I work now pays 100% medical. They pay 100% dental and vision. But it's become a habit after 27 years of trying to save my life. And I'm still, right now, after two years of being here, trying to create better habits and to get out of my mind that I can't trust doctors.

Discussion and Implications

Mass incarceration is "a system of racialized and gendered social control [that] has disproportionately impacted Black women" (Mitchell & Davis, 2019). It has been well established that incarceration can have serious negative health consequences. High levels of communicable disease, exposure to violence, and decline in socioeconomic status beyond incarceration can all lead to lifelong poor health (Hogg et al., 2008). Mass incarceration thus serves as a "key component of structural racism that creates and exacerbates health inequities" (LeMasters et al., 2022).

Women transitioning back into society after incarceration are predisposed to poorer health outcomes (Oser et al., 2016) and face a high burden of disease (Kulkarni et al., 2010; Oser et al., 2016). Black women may experience a particular

precarity and be especially vulnerable due to both higher rates of incarceration and "significant barriers to maintaining their health and well-being, exacerbated by their multiple marginalized status" (Oser et al., 2016). Recent quantitative research has shown that formerly incarcerated older women of color have the greatest burden of both depressive symptoms and physical limitations among all older adults (Latham-Mintus et al., 2022). After release, women face competing demands including securing documentation, housing, and employment, and reestablishing relationships with family, which, in addition to factors like the cost of medical care, may disrupt their ability to seek health care (Oser et al., 2016). Formerly incarcerated patients are less likely to have a primary care provider or receive routine medical care (Kulkarni et al., 2010), which has significant implications for older adults. Thus, understanding the health care of those who are or have been incarcerated is essential for understanding health across the life course, especially in the Black community, which has been disproportionately targeted by the social policies that have created a system of mass incarceration.

This study used BFEM to center the lived experience of older Black women navigating health, illness, and health care during incarceration. The structure of care delivery in prison, which includes limitations on the number of medical problems that can be presented and correctional officers acting as gatekeepers to care, can create a punitive care environment. The perceived punitive nature of care is magnified by those who, often due to perceptions of their race, gender, and class, are perceived to be aggressive, assertive, or unworthy of care. These women described racialized and gendered experiences of care, where their character and illnesses were questioned and where their ability to manage chronic illness and aging was limited due to the punitive nature of the prison environment. Importantly, as described elsewhere (James, 2021), within this system Black women also took on caregiving and healing roles as a form of resistance within an oppressive environment.

The findings in this study suggested that perceptions of care during incarceration may influence if and how older Black women seek care during and after incarceration. Patients who are incarcerated often do not feel they are seen as patients, but as inmates. They way that care is delivered in prisons is not meeting the needs or expectations of incarcerated older Black women and there may be specific implications of this that extend far beyond incarceration. Black women may continue to avoid medical care past incarceration, even if they have the available means. Research has demonstrated the health manifestations of the community-level trauma of incarceration (Hatzenbuehler et al., 2014). What has yet to be explored in depth are the ways that a personal or familial history of incarceration may influence if and how individuals in overly policed communities may approach health care and form relationships with their providers. Further research is needed to understand this phenomenon.

This study had both strengths and limitations. This research focused on the experiences of older Black women, the vast majority of whom were incarcerated within one state prison system. Each state's prison system operates independently and often with quite different processes for the payment and delivery of health care. Descriptions in this paper may not apply in all contexts. Many of the women interviewed are actively involved in advocacy work on the topic of incarceration. They may be more likely to have had negative experiences during incarceration, which led them to pursue this work and to agree to participate in an interview. All participants were reflecting on events that took place months, years, or even decades in the past. Further research conducted with currently incarcerated women and utilizing ethnographic observations of clinical encounters would offer more insight into health care interactions in the carceral setting.

It is well documented that aging in the United States is fundamentally unequal and that examining aging allows us to better see and understand social stratification and inequality (Abramson & Portacolone, 2017). Mass incarceration is both the embodiment of this inequity and a key (but understudied) driver of inequity across the life course. Incarceration fundamentally disrupts the aging process. Incarcerated individuals are separated from their families and communities, deprived of autonomy, and denied access to tools to focus on health and well-being. Further, as the findings in this study demonstrate, incarcerating through middle age challenges women's abilities to establish trusting health care relationships and find strategies to manage chronic illness.

Calls to gerontological research and expertise on Black older adults date back to the 1960s (Jackson, 1967), and research on racism has grown rapidly since 2020. Yet, to consider anti-Black racism without considering incarceration is a glaring omission. Centering Black women in research and considering the intersection of racism, sexism, and classism are key features of Black Feminist Theory (Collins, 2000). This study provides an important intervention to extend this theoretical commitment to the study of aging and incarceration. The reach of incarceration is clear: 3.8 million Black Americans were arrested in 2018 (Prison Policy Initiative, 2022) and half of Black women have a loved one who is incarcerated (Clayton et al., 2018). When we consider "noncompliance," "mistrust," and "hesitancy" in the Black community, we must consider the role of incarceration, lack of autonomy, and intergenerational trauma and we must develop multilevel interventions to address this harm. As we work to transform the care of an aging population, we must consider the implications of incarceration on the health of those aging behind and beyond the bars.

Funding

This work was supported by the UCSF Center for Aging in Diverse Communities (P30AG015272) and UCSF Pepper Center (P30AG044281). The author is supported by the Aging Research in Criminal Justice Health Network (R24AG065175).

Conflict of Interest

None.

Data Availability

Participants in this study did not give consent for their data to be shared. Due to the sensitive nature of the subject material and potentially identifiable nature of the data, data are not available to be shared. This is a qualitative study and thus analysis was not preregistered.

Acknowledgments

The author gratefully acknowledges Leslie Riddle, Giselle Perez-Aguilar, and Belinda Thomas for their assistance with this project and their role in shaping the themes presented here. The author is incredible grateful for the UCSF Center for Aging in Diverse Communities for their support of this ongoing work. The author thanks of the Black Feminist Health Science Studies Collaboratory for reading an early draft of this paper and their thoughtful feedback on how to share this work with multiple audiences. The research described in this project would not have been possible without the support and partnership of the California Coalition for Women Prisoners and all the amazing women who shared their stories.

References

Abramson, C. M., & Portacolone, E. (2017). What is new with old? What old age teaches us about inequality and stratification. *Sociology Compass*, 11(3), e12450. https://doi.org/10.1111/soc4.12450

Aday, R., & Farney, L. (2014). Malign neglect: Assessing older women's health care experiences in prison. *Journal of Bioethical Inquiry*, 11(3), 359–372. https://doi.org/10.1007/s11673-014-9561-0

Aday, R. H. (2003). *Aging prisoners: Crisis in American corrections*. Praeger. https://doi.org/10.1086/422540

Bradley, C. M. (2006). Old remedies are new again: Deliberate indifference and the receivership in Plata v. Schwarzenegger. *New York University Annual Survey of American Law*, 62, 703. https://www.law.nyu.edu/journals/annualsurveyofamericanlaw/issues/archive/vol62/issue4

Bryant, A., & Charmaz, K. (2007). *The SAGE handbook of grounded theory*. Sage.

Caldwell, C., Jarvis, M., & Rosefield, H. (2001). Issues impacting today's geriatric female offenders. *Corrections Today*, 63(5), 110–114.

Chettiar, I., & Gupta, V. (2012, June 13). *Why are we spending so much to lock up elderly prisoners who pose little threat?* American Civil Liberties Union. https://www.aclu.org/blog/smart-justice/parole-and-release/why-are-we-spending-so-much-lock-elderly-prisoners-who-pose

Collins, P. H. (2000). *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*. Psychology Press.

Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Sage Publications.

Clayton, G., Richardson, E., Mandlin, L., & Farr, B. (2018). *Because she's powerful: The political isolation and resistance of women with incarcerated loved ones*. Essie Justice Group.

Cutcliffe, J. R., & McKenna, H. P. (2002). When do we know that we know? Considering the truth of research findings and the craft of qualitative research. *International Journal of Nursing Studies*, 39(6), 611–618. https://doi.org/10.1016/s0020-7489(01)00063-3

Genders, E., & Player, E. (2016). Women lifers: Assessing the experience. *The Prison Journal*, 70, 46–57. https://doi.org/10.1177/003288559007000106

Hatzenbuehler, M. L., Keyes, K., Hamilton, A., Uddin, M., & Galea, S. (2014). The collateral damage of mass incarceration: Risk of psychiatric morbidity among nonincarcerated residents of high-incarceration neighborhoods. *American Journal of Public Health*, 105(1), 138–143. https://doi.org/10.2105/ajph.2014.302184

Hogg, R. S., Druyts, E. F., Burris, S., Drucker, E., & Strathdee, S. A. (2008). Years of life lost to prison: Racial and gender gradients in the United States of America. *Harm Reduction Journal*, 5, 4. https://doi.org/10.1186/1477-7517-5-4

Jackson, J. J. (1967). Social gerontology and the Negro: A review. *Gerontologist*, 7, 168–178. https://doi.org/10.1093/geront/7.3_part_1.168

James, J. E. (2021). Black feminist epistemological methodology: Bridging theory and methods to research health and illness. In Z. Luna & W. Pirtle (Eds.), *Black feminist sociology: Perspectives and praxis*. Routledge.

Kulkarni, S. P., Baldwin, S., Lightstone, A. S., Gelberg, L., & Diamant, A. L. (2010). Is incarceration a contributor to health disparities? Access to care of formerly incarcerated adults. *Journal of Community Health*, 35(3), 268–274. https://doi.org/10.1007/s10900-010-9234-9

Latham-Mintus, K., Deck, M. M., & Nelson, E. (2022). Aging with incarceration histories: An intersectional examination of incarceration and health outcomes among older adults. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 78, 853–865. https://doi.org/10.1093/geronb/gbac088

Leigey, M. E., & Hodge, J. P. (2012). Gray matters: Gender differences in the physical and mental health of older inmates. *Women & Criminal Justice*, 22(4), 289–308. https://doi.org/10.1080/08974454.2012.716358

LeMasters, K., Brinkley-Rubinstein, L., Maner, M., Peterson, M., Nowotny, K., & Bailey, Z. (2022). Carceral epidemiology: Mass incarceration and structural racism during the COVID-19 pandemic. *The Lancet Public Health*, 7(3), e287–e290. https://doi.org/10.1016/S2468-2667(22)00005-6

Loeb, S. J., Steffensmeier, D., & Myco, P. M. (2007). In their own words: Older male prisoners' health beliefs and concerns for the future. *Geriatric Nursing*, 28(5), 319–329. https://doi.org/10.1016/j.gerinurse.2007.02.001

Mitchell, M. B., & Davis, J. B. (2019). Formerly incarcerated black mothers matter too: Resisting social constructions of motherhood. *The Prison Journal*, 99(4), 420–436. https://doi.org/10.1177/0032885519852079

Nijhawan, A. E., Salloway, R., Nunn, A. S., Poshkus, M., & Clarke, J. G. (2010). Preventive healthcare for underserved women: Results of a prison survey. *Journal of Women's Health (2002)*, 19(1), 17–22. https://doi.org/10.1089/jwh.2009.1469

Nowotny, K. M., Rogers, R. G., & Boardman, J. D. (2017). Racial disparities in health conditions among prisoners compared with the general population. *SSM—Population Health*, 3, 487–496. https://doi.org/10.1016/j.ssmph.2017.05.011

Oser, C. B., Bunting, A. M., Pullen, E., & Stevens-Watkins, D. (2016). African American female offender's use of alternative and traditional health services after re-entry: Examining the behavioral model for vulnerable populations. *Journal of Health Care for the Poor and Underserved*, 27(2A), 120–148. https://doi.org/10.1353/hpu.2016.0052

Pettit, B., & Western, B. (2004). Mass imprisonment and the life course: Race and class inequality in U.S. incarceration. *American Sociological Review*, 69(2), 151–169. https://doi.org/10.1177/000312240406900201

Prison Policy Initiative. (2022). *Chronic Punishment: The unmet health needs of people in state prisons*. Retrieved August 14, 2022, from https://www.prisonpolicy.org/reports/chronicpunishment.html

Proca, D. M., Rofagha, S., & Keyhani-Rofagha, S. (2006). High grade squamous intraepithelial lesion in inmates from Ohio: Cervical screening and biopsy follow-up. *CytoJournal*, 3, 15. https://doi.org/10.1186/1742-6413-3-15

The Sentencing Project. (n.d.). *Incarcerated Women and Girls*. https://www.sentencingproject.org/publications/incarcerated-women-and-girls/

Vanover, C., Mihas, P., & Saldana, J. (2021). *Analyzing and interpreting qualitative research: After the interview*. Sage Publications.

Wahidin, A. (2004). *Older women in the criminal justice system: Running out of time*. Jessica Kingsley Publishers.

Wahidin, A. (2006). Time and the prison experience. *Sociological Research Online*, 11(1), 104–113. https://doi.org/10.5153/sro.1245

Wildeman, C., & Wang, E. A. (2017). Mass incarceration, public health, and widening inequality in the USA. *Lancet (London, England)*, 389(10077), 1464–1474. https://doi.org/10.1016/S0140-6736(17)30259-3

Williams, B. A., Lindquist, K., Sudore, R. L., Strupp, H. M., Willmott, D. J., & Walter, L. C. (2006). Being old and doing time: Functional impairment and adverse experiences of geriatric female prisoners. *Journal of the American Geriatrics Society*, 54(4), 702–707. https://doi.org/10.1111/j.1532-5415.2006.00662.x

Williams, B. A., Stern, M. F., Mellow, J., Safer, M., & Greifinger, R. B. (2012). Aging in correctional custody: Setting a policy agenda for older prisoner health care. *American Journal of Public Health*, 102(8), 1475–1481. https://doi.org/10.2105/AJPH.2012.300704