A Systematic Review on the Barriers to Healthcare Among those with Chronic Diseases in United States Prisons

By

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B.A., Brown University, 2023

Thesis

Submitted in partial fulfillment of the requirements for the degree of

Master of Public Health at Brown University

PROVIDENCE, RHODE ISLAND

2024

This thesis by ***Alison Kim*** is accepted in its present form
by the Brown University School of Public Health as satisfying the
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Preface and acknowledgements

First and foremost, I want to thank God and give all the glory to Him. He is my rock and solid foundation and has faithfully led me to where I am now. My time during Brown is a demonstration of God's miracle, and I dedicate all my accomplishments to Him. For everything is meaningless without God at the center of it all. "Jesus replied, 'You must love the Lord your God with all your heart, all your soul, and all your mind.' This is the first and greatest commandment" (Matthew 22:37-38).

Next, I want to thank Dr. Lauren C. Bohlen for her invaluable mentorship for the last four years. With no prior public health research experience, she welcomed me with open arms and patiently taught me the necessary skills to excel in her lab. I am eternally grateful to be able to call her my mentor and witness how a true leader upholds themself. I would also like to thank Professor Bradley Brockmann for his support and uncovering my passion for the incarcerated population.

Last, I want to thank my parents, Isaac Yi Kim, Sr. and Linda Hyunjoo Kim, for endlessly supporting all my academic endeavors. They are my biggest cheerleaders and encourage me during my hardest times. I am also grateful for my older siblings, Isaac Kim, Jr. and Juliana Kim, for their advice and mentorship and my younger sibling, Micah Kim, for his support. And again, all glory to God!

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Abstract of A Systematic Review on the Barriers to Healthcare Among those with Chronic Diseases in United States Prisons by Alison Kim, MPH, Brown University, May 2024

Background & Aims. Chronic diseases in prisons are a significant problem, with at least 50% of those incarcerated in state and federal prisons estimated to have a chronic medical condition. Moreover, the percentage of the incarcerated population who are over 55 years old is rising, and chronic diseases are also significantly more prevalent in older individuals. Prisons were never designed to accommodate the needs of an aging population; thus, the older prison population is especially vulnerable to excess morbidity and premature mortality. This review seeks to understand the perceived barriers to medical care among those in United States prisons who have been diagnosed with any chronic disease. **Methods.** A systematic review was conducted using PubMed, Ovid Medline, Web of Science, CINAHL, and Embase. Covidence was used to manage the data, and common themes were extracted through NVivo. Studies were eligible to be included if they were conducted in the United States, presented a population of inmates that were explicitly classified to have a chronic disease, and measured perspectives of healthcare inside of prisons. Retrospective accounts of care in prison from released individuals were included as well. **Results.** Searches yielded 234 unique studies. After abstract and full text screening, 5 studies were included in the analysis. The most reported barriers include inability to afford co-pays (5 out of 5 studies), provider actions and attitudes (5 out of 5 studies), distrust towards providers (5 out of 5 studies), issues with medications (5 out of 5 studies), fear of punishment (3 out of 5 studies), and administrative obstacles (5 out of 5 studies). Fear of punishment includes fear of being written-up for no longer presenting symptoms at the time of the medical appointment or for asking too many questions during a medical visit. **Conclusions.** Those with chronic diseases in United States prisons face significant hurdles to

seeking and receiving appropriate medical care. Barriers to receiving care range from structural barriers (costs), interpersonal (i.e., distrust), and interact with the nature of carceral settings (i.e., fear of punishment). A future analysis can investigate provider and prison staff perspectives on the barriers presented in this review.

INTRODUCTION

Prisons are an institution in which individuals are guaranteed the right to healthcare. The U.S. Supreme Court's decision in *Estelle v. Gamble* ensured that custody of an individual's body meant a requirement to provide healthcare (Aday and Farney, 2014). Neglect of such care means cruel and unusual punishment, directly contradicting the U.S. Constitution Eighth Amendment (Aday and Farney, 2014). Prisons thus have the responsibility to render proper health care services. However, U.S. prisons do not recognize this in terms of equivalent care and fall short of the human rights framework established by the World Health Organization; such that the provision of and access to appropriate services or treatment among the incarcerated population should be at least consistent in range and quality with that available to the wider community (Stover et al., 2007). This is partly due to the autonomy and responsibility of individual states to provide healthcare in their prisons, leading to vastly different care across the country. Moreover, consequences from a lack of proper healthcare in prisons is exacerbated after individuals are released from prison. The Medicaid inmate exclusion policy (MIEP) established when Medicaid was authorized in 1965, declared that federal funding for Medicaid would not extend to incarcerated or detained individuals, meaning that Medicaid would be suspended upon admission to a correctional facility (Binswanger et al., 2007; Barnert et al., 2022). As a result, there exists a healthcare coverage gap where individuals lose health coverage once incarcerated and that lack of coverage continues after release if proper pre-release planning is not administered. The affordable care act did not alter the MIEP. The MIEP leaves many incarcerated individuals vulnerable to poor health outcomes shortly after release, with the risk of death more than 12 times higher for people leaving custody than individuals in the general U.S. population (Binswanger et al., 2007). Evidently, compounding effects of poor health due to inadequate healthcare in prisons, a lack of health insurance after release, and other social factors can lead to

disproportionate morbidity and mortality among formerly incarcerated individuals. To improve upon this, it is imperative that barriers to healthcare in prisons are identified and addressed.

Prevalence of chronic diseases

Chronic diseases in prisons are a significant problem, as the most recent survey of prison inmates in 2016 demonstrated that 40% of state and 33% of federal prisoners had a chronic medical condition at that time (Maruschak et al., 2021). In this survey, the most commonly reported chronic condition was heart disease at a prevalence of 29% and 26% in state and federal prisons respectively (Maruschak et al., 2021).

An aging population

Chronic conditions are significantly more prevalent in older individuals, and overall, the prison population is aging. In 2004, the average age of state inmates was 35, but this rose to 39 in 2016 (Beatty et al., 2021). The average age of federal inmates was 40 in 2016 (Beatty et al., 2021). Furthermore, the proportion of state and federal prisoners aged 55 and older rose from 3% to 15% from 1991 to 2021 (Widra, 2023). Among those serving life sentences, 30% were at least 55 years old in 2020 (Widra, 2023). Prisons also accelerate aging and decrease life expectancy. Patterson (2012) investigated the relationship between length of stay in prisons and mortality after release among New York State parolees. The author found that there was a 15.6% increase in the odds of death for every extra year spent in prison (Patterson, 2012). In terms of chronic disease and fall prevention, prisons lack handrails in bathrooms, have hard and steel bunks in cells, require inmates to trek long distances for medical visits, and have poor food quality (Aday and Farney, 2014; Alves et al., 2016; Novisky, 2018). The infrastructure to accommodate the healthcare needs of the prison population is poorly supported, and this is compounded by the more complex needs of an aging and

older prison population; thus, older incarcerated individuals are especially vulnerable (Novisky, 2018).

Purpose and aims

Researchers have thoroughly explored and established the high prevalence of chronic diseases among incarcerated individuals. However, there is more to addressing the chronic healthcare needs of the incarcerated population beyond understanding the prevalence and beyond detailing the policies and practices set forth in prisons to provide health care. There is little understanding of how healthcare is perceived and used from the perspective of the prison population. Understanding these perspectives are important for tailored interventions to address chronic disease healthcare needs of incarcerated individuals that may have been overlooked. Thus, this review seeks to address the question of what the most perceived significant barriers to health care are among those in United States prisons who have been diagnosed with any chronic disease.

METHODS

A systematic review was conducted using PubMed, Ovid Medline, Web of Science, CINAHL, and Embase. To identify potentially relevant studies the search string that was developed was: ("correctional facilit*" OR "prison*" OR "incarceration*" OR "inmate*" OR "correctional setting*" OR "correctional system" OR "imprison*" OR "convict" OR "justice involved" OR "criminal offender" OR "criminal justice system" OR "penal" OR "penitentiar*" OR "detain*") AND ("chronic disease*" OR "chronic illness*" OR "chronic condition*" OR "Chronic disorder*" OR "chronic infection*") AND ("healthcare" OR "health service*" OR "hospital*" OR "doctor*") AND ("United States" OR "USA" OR "America" OR "United States of America"). The search

string was developed based off of a tangentially related systematic review and applied to all five databases (Skarupski et al., 2018).

Covidence (2024) was used to manage all search results. Titles and abstracts were screened by one reviewer. After the initial review, each paper's full text was examined to further ensure that they met the inclusion criteria by A.K. Studies were excluded if they (1) only measured preventative health care, drug and substance abuse care, or Hepatitis C, (2) only measured health conditions after release or perspectives of healthcare outside of prisons, (3) were conducted only in jails, or (4) focused on solitary confinement. All studies must have been: (1) conducted in the United States, (2) presented a population or sub-population of inmates that were explicitly classified to have a chronic disease, and (3) measured incarcerated individuals' direct perspectives of healthcare inside of prisons. Retrospective accounts of care in prison from released individuals were included. Included studies were observational, and either quantitative, qualitative or mixed-methods. In an ever-changing healthcare landscape, this review seeks to be reflective of the current healthcare practices in prisons, thus my systematic review was limited to the past 10 years. The final selection of studies and inclusion criteria are demonstrated in Figure 1.

Screening and preventative care studies were inapplicable, because the aim of this paper is to explore the treatment of prisoners with known chronic diseases, not prior to diagnosis. Although Hepatitis C (HCV) is a chronic disease, a HCV diagnosis itself requires a completely unique and targeted intervention, thus needing a separate review (Akiyama et al., 2021; Assoumou et al., 2019). Similarly, studies that focused only on special populations were excluded, such as veterans, those with end of life and hospice care, juvenile detention facilities, and solitary confinement. However, the older inmate population was not classified as a special population because chronic diseases are heavily prevalent in this specific cohort and eliminating this special population would eliminate any

remaining studies. Studies met quality levels if they utilized anecdotal accounts, interview responses, or focus group data. Interview guides had to either be standardized or approved by some prison director or ethics committee. In addition, interviews had to be led by trained interviewers that have experience in the correctional setting.

After identifying all eligible studies, common themes and important information was extracted and consolidated into the framework in NVivo. A preliminary coding framework was implemented, following procedures similar to what would be used to analyze qualitative data using directed content analysis and based on a review of existing literature (Hsieh et al., 2005). An iterative process to code generation and framework refinement occurred throughout data extraction. Due to the number of identified included studies and the heterogeneity across studies, a quantitative analysis was not conducted. The final codebook is demonstrated in Table 1.

RESULTS

Searches yielded 376 results. After duplicates were removed, 234 studies remained. After abstract screening, 29 studies remained, and 5 studies were ultimately included in the analysis after full-text screening. The studies encompassed different states and regions across the United States including, Florida, Connecticut, New Orleans, California, and others within the Southeastern region. Study characteristics are shown in Table 2. All studies included examinations of the perspectives of individuals on their healthcare access and barriers in prison and used personal narratives and interviews. The five qualitative studies indicated a clear trend in significant barriers to chronic disease healthcare access. The most common themes for reported barriers include inability to afford co-pays, issues with medications, fear of punishment, negative provider attitudes and actions,

distrust towards providers, and other administrative obstacles. A summary of the results is consolidated into Table 3.

Co-pays

Across all five studies, participants reported that cost was a large barrier in receiving care. Co-pays ranged from $3 per visit to $20 per visit. Unfortunately, those without any outside financial assistance were left to their own hourly wages, where some received as little as 17 cents/hour. Though California ended co-payments in 2022, 40 state prisons still charge co-pays for medical visits across the United States (James, 2023; Herring, 2022). Furthermore, co-pays deter individuals from making appointments because they are fearful that their money will be taken away from them (Vail et al., 2017). Administrators in prisons have the authority to apply money that is sent by family members to unpaid healthcare bills (Vail et al., 2017). A participant reported that this was the very reason he did not make sick calls anymore (Vail et al., 2017). Women also face a unique challenge where these co-payment policies and costs force them to decide whether to purchase necessary hygiene items or access medical care (Aday and Farney, 2014).

Three qualitative studies included participants who reported that they and many of their peers in prisons rely on family members for financial help (Aday and Farney, 2014; Vail et al., 2017; Mohammad et al., 2023). Older individuals, however, have access to less financial assistance because they tend to have no children and their families tend to have passed away (Aday and Farney, 2014). Furthermore, inmates are reluctant to ask their family members for financial assistance due to feelings that they may be a burden (Vail et al., 2017). Accordingly, these co-payments extend beyond financial barriers, but add to emotional burden due to concerns over family members.

Provider action and attitudes

All five studies also reported that provider actions and attitudes deter incarcerated individuals from seeking out or receiving proper care. Many inmates reported that providers and other medical staff refuse to acknowledge medical history, lack patience because of prisoner complaints, or do not believe their legitimate medical needs (Aday and Farney, 2014; James, 2023; Thomas et al., 2016; Mohammad et al., 2023). Unfortunately, this may stem from providers' views that their patients are faking their symptoms (James, 2023; Mohammad et al., 2023; Vail et al., 2017). In one anecdote, a participant explained that she tried to ask a question about her mammogram, but the provider dismissed her question while threatening to push an alarm (James, 2023). Interactions such as these demonstrate why participants feel that their sincere concerns are not met with understanding. Thus, because patients don't believe that their medical needs or concerns will be met, they push off care all together.

Provider actions are also barriers to receiving proper healthcare. First, physicians may not comply with outside provider recommendations for patients, in which a condition will worsen (Aday and Farney, 2014). Second, providers will not treat an individual until it's clearly an emergency, such as when a patient is dying or bleeding (Mohammad et al., 2023; Vail et al., 2017). As a result, chronic conditions may be overlooked because its symptoms are often gradual and non-specific. This delayed diagnosis can be further exacerbated by the brief medical visits where patients have little time or ability to discuss all their concerns. One participant described that during her routine once-a-year visit with her primary care provider (PCP), the PCP asked only three questions, and she was not allowed any further discussion (James, 2023). Short and limited clinic visits make it difficult to discuss other issues such as aging and chronic illnesses (James, 2023).

Physicians can also be gatekeepers for healthcare management that is not directly related to clinical care. For example, physicians have permission to prescribe bottom bunks, an important benefit especially for inmates with physical needs (Thomas et al., 2016). Among those with pain related to aging and chronic illnesses, which includes trouble standing on one's legs for long periods of time, walking up stairs, or climbing into the upper bunk, these privileges are incredibly crucial for pain management (Aday and Farney, 2014). Physicians can also prescribe specific diets that are not available to all incarcerated individuals (Thomas et al., 2016). These diets can benefit those with hypertension who need a low sodium diet or individuals with diabetes who need specific foods to help maintain their blood sugar (Thomas et al., 2016; Mohammad et al., 2023).

Distrust towards providers

Provider actions and attitudes can cause patients to distrust them. All five studies reported that distrust towards providers was a barrier to seeking out or receiving care. Sources of this distrust stem from a lack of transparency with medications, fear that providers will be non-responsive and have ulterior motives, and a one-size fits all approach (Aday and Farney, 2014; James, 2023; Mohammad et al., 2023; Thomas et al., 2016). One participant noted that she was suspicious about "everyone" seeming to have high blood pressure, taking a specific drug, or being treated for cancer (James 2023). Regardless of validity, she was suspicious that providers had underlying motives which deterred her from seeking care (James, 2023). In addition, participants used words like "neglectful" or "suspicious of malingering" to describe providers, further reinforcing their wariness towards prison medical personnel (Thomas et al., 2016). Because of these suspicions, some individuals may delay care for nearly ten years, and this may cause inmates to deny care in life-threatening situations (James, 2023). For example, one participant noted that she observed several inmates pass away in their rooms because they assumed providers were not going to do anything about their situation

(James, 2023). Other incarcerated individuals will take their health into their own hands instead of seeking out medical care because of distrust (Vail et al., 2017). For example, they may exercise more or find ways to obtain medication from other inmates (Vail et al., 2017).

Issues with medications

All five studies indicated that incarcerated individuals were dissatisfied with medications because of the amount, quality, or lack of choice. Unfortunately, prisons cannot afford expansive drug formularies which may force inmates to take multiple medications as opposed to one (Aday and Farney, 2014). Moreover, incarcerated individuals are sometimes forced to continue medications even after recovering because providers must adhere to treatment protocols. One participant suffering from diabetes achieved normoglycemia due to exercise and weight loss but was forced to continue and finish their medication (Thomas et al., 2016). The need to follow rules was at the expense of an individualized and possibly more effective treatment plan. This lack of choice may also mean that incarcerated individuals are forced to decide between a specific medication or none at all (if given the option to do so). One participant reported that a medication for her high blood pressure caused her to "feel high", but she wasn't provided another option for a different drug (James, 2023). As such, she decided to take no medication at all, risking her cardiovascular health (James, 2023). In contrast, an inmate may choose to take medications because there is no other choice to improve their health by other means such as modifying their diet (Mohammad et al., 2023).

While some participants reported receiving too many medications, some reported not receiving any. Because of the limited drug formulary, doctors may prescribe medications, but inmates will never receive them because they are not on the approved formulary (Aday and Farney, 2014). Furthermore, some inmates may be erroneously taken off medications. One participant with

hypertension noted that she was taken off her medications by the physician, despite the medication being the reason for her lowered blood pressure (James, 2023). Eventually, she was put back on the medication after her hypertension rose again, and she needlessly suffered from unnecessary stress and poor health (James, 2023).

Rather than proper medical tests or diagnostics to provide individualized medication and uncover causal issues, inmates are provided a short-term solution. Participants described that ibuprofen is the "drug for everything" but "doesn't work" (Aday and Farney, 2014). Due to the liberal distribution of Motrin, among the seven women's' prisons spread across the southeastern United States, two-thirds of the women reported sometimes or frequently having difficulty sleeping because pain was a major factor (Aday and Farney, 2014). These chronic pain symptoms occur despite inmates on average, taking 4.9 over the counter or prescription medications daily to manage pain or other chronic illnesses (Aday and Farney, 2014). As a band-aid solution, some incarcerated individuals are given these over-the counter drugs in lieu of an appointment with a physician as well (Vail et al., 2017).

Fear of punishment

Three studies included participants who feared punishment for not taking their medications and refusing care, taking control of their own health, or not having symptoms upon a clinic visit. Although patients in carceral settings have the legal right to refuse medical care, they can face punishment upon care refusal (James, 2023). One participant with a traumatic experience in a skilled nursing facility was threatened to get written up after refusing to attend her medical appointments for a period of time (James, 2023). A write-up can be severely detrimental because it stays on an inmate's record, lengthening their prison stay or limiting privileges (James, 2023). Similarly, an inmate can be written up for a false report if they do not present the symptoms that they initially reported during their clinic visit (Mohammad et al., 2023). If an individual doesn't adhere to their

medications, they may also be sent to solitary confinement, lose recreation time, or have delayed parole, ultimately hindering self-management behaviors for good health (Thomas et al., 2016). Patients are also scared to ask too many questions or report a problem that wasn't already "preapproved" (James, 2023). Some are worried about being too aggressive but also not getting the help they need, necessitating a fragile balance between self-advocacy and fear of punishment (James, 2023).

Inmates also desire to take care of their own health without medications which can include a modified diet by secretly keeping nutritious foods like oranges, apples, or bread (Mohammad et al., 2023). However, fruits from the dining hall are considered contraband in prisons, but fresh fruits are not offered in commissary (Mohammad et al., 2023). For individuals with diabetes and suffering through hypoglycemic episodes, fruit can be a quick solution, but with barriers to keeping these on hand for fear of punishment, incarcerated individuals can't manage their health in this way.

Administrative barriers

All five studies reported administrative barriers to receiving proper healthcare. Various individuals in authoritative positions act as gatekeepers that can lead to delays in receiving care. For example, correctional officers (CO) could pose as gatekeepers before inmates are allowed to see a physician based on if they disbelieve symptoms due to perceptions that an inmate is too aggressive or have a negative assessment of their character (James, 2023; Vail et al., 2017). Sometimes, emergency medical technicians (EMTs) can be gatekeepers to healthcare as well, where they are often the first line of treatment and have a role in determining who gets to see a physician (Vail et al., 2017). EMT's were described as trying to keep inmates from seeing providers by offering other support such as ibuprofen, a bandage, or sugar water (Vail et al., 2017).

Another administrative burden is the lengthy process for medical requests to be approved and medical forms that must be filled out before seeing a physician. Aside from emergency situations, inmates must describe their symptoms in a form to go to the medical center (James, 2023; Mohammad et al., 2023; Thomas et al., 2016). These forms can be held by CO's, in which once again they serve as gatekeepers to care (James, 2023). Moreover, an inmate may have to submit multiple medical requests before they eventually see a physician (Thomas et al., 2016). These forms are also limited in the number of issues a patient can list, where they are allotted only two medical issues at one time (James, 2023). This limitation can be a detriment to those with multiple chronic health conditions, where they must prioritize which problems to list and discuss with their provider (James, 2023).

The location of prisons, lack of care coordination with outside providers, and overburdened clinics can also present barriers to proper healthcare. First, many prisons are in rural areas where healthcare services are not easily accessible (Aday and Farney, 2014). As such, this leaves many inmates fearful about emergency situations in which they need to travel to a hospital (Aday and Farney, 2014). Second, inadequate coordination with outside hospitals can lead to interrupted or delayed treatment and rescheduled surgeries, leading to recurrent and unaddressed chronic pain (Vail et al., 2017). Last, clinics are overburdened and as a result, providers can only see patients based on urgency, similar to an emergency department (Thomas et al., 2016). This emergency room-like process means that inmates are not able to have regular checkups for their chronic conditions (Thomas et al., 2016).

DISCUSSION

The five qualitative studies demonstrate that incarcerated individuals have clear barriers to healthcare and a lack of chronic disease treatment has implications to deteriorating health. Impediments to

chronic disease healthcare delivery in prisons consists of four primary facets: costs, providers, medications, and administrative burdens. The barrier of costs is two-sided: prisons themselves cannot afford a wide range of medications on their formulary, while inmates cannot afford to seek out care on a regular basis because of co-pays. These co-pays deter individuals from seeking out care because 1) they fear that money their families send will be confiscated to pay off medical debt, or 2) they choose to spend their money for other needs. Moreover, these payments are especially harmful for women who must choose between paying for health care or feminine hygiene products. At present, only 10 states do not require co-pays, and Virginia is piloting a program to suspend these payments (Herring, 2022). During COVID-19, twenty-eight states altered their co-pay policies, but only suspended co-pays for visits related to COVID-19 symptoms (Herring, 2022). As of 2022, at least 22 states continued with these modified policies (Herring, 2022). A cost associated with each physician visit is a dangerous practice because there is a higher likelihood of disease spread and worsening chronic conditions as inmates delay care (Herring, 2022). And although these co-pays are meant to reduce healthcare costs in prisons by discouraging unnecessary medical visits, there is insufficient evidence to suggest that this is the case (Herring, 2022). The remaining states ought to follow the few who have already abolished co-pays for medical visits and reduce this cost barrier for good.

Providers are also perceived as lacking empathy, patience, or delivery of individualized care. Inmates are hesitant to seek out physician visits for fear that the providers will be quick to judge and punish, without sincerely listening to their concerns. These findings are consistent with other studies that have demonstrated that stigma from providers may lead to psychological distress, social withdrawal, and deterrence from healthcare utilization (Abbott et al., 2017; Martin et al., 2020; Swan, 2016). Furthermore, many justice-involved individuals have intersecting identities (e.g. incarceration and

HIV; incarceration and substance misuse), and qualitative studies have shown that stigma related to this multiplicity discourages individuals from seeking out care (Abbott et al., 2017; Swan, 2016). As a result, stigma against criminal justice involved individuals can lead to poorer health outcomes. For example, individuals recently released from prison who reported discrimination due to their criminal record had increased odds of fair/poor health (Redmond et al., 2020). Within prisons, there are limited studies analyzing the direct effects of provider stigma on healthcare utilization, so future studies can investigate this relationship (Martin et al., 2020).

In addition, many distrust their providers and believe that they don't have the necessary skills and capability to treat their concerns. Unsurprisingly, an exploratory analysis demonstrated that older incarcerated individuals were moderately more likely to distrust the healthcare system, and this was statistically significant (Vandergrift and Christopher, 2021). These findings may be explained by the fact that older individuals need more healthcare or have had more negative experiences while incarcerated. Distrust in the healthcare system is a real and relevant issue for incarcerated individuals, and is exacerbated by age, acting as a significant hurdle for older inmates living with chronic diseases.

Physicians may also serve as gatekeepers for privileges that allow inmates to manage their own chronic conditions. For example, a modified diet or living accommodations requires special permission from providers, which may be necessary for those living with diabetes or suffering from chronic pain where simple daily tasks are difficult. These gatekeeping practices enable physicians a degree of authority over an inmate's social determinants of health, known as the "cause of causes" where medical care can only account for 10-15% of preventable mortality (Braveman and Gottlieb, 2014).

There are many issues with medications in prisons as well. Often, inmates are given ibuprofen that only targets acute pain symptoms rather than the chronic disease itself. Even worse, over the counter drugs may be distributed to prevent inmates from seeing a physician. Some patients are given too many medications because of the limited formulary, never receive their medications, or are incorrectly taken off a prescribed medication. In a comparison of the use of medications for chronic diseases in jails and state prisons versus in community settings from 2018-2020, prescription medication use was significantly lower in jails and state prisons, ranging from 1.9 to 5.5 times lower than in the community setting (Curran et al., 2023). This disparity can be attributed to a variety of factors including underdiagnosis of chronic diseases, distrust towards the medical system, lack of regular care, and more. Secondary and tertiary prevention of chronic conditions is difficult when correct or effective medications are not properly distributed.

Lastly, incarcerated individuals face several administrative barriers to healthcare. Many prisons are in rural areas, which make it difficult for inmates to reach necessary care at outside hospitals if needed. There is also poor coordination with these outside hospitals that result in interrupted or delayed treatment. Overall, prison clinics are overburdened and being seen by a provider in the first place can be a challenge, further exacerbated by staffing shortages in prisons (Hefferfan and Li, 2024). Staffing shortages extend the process of obtaining medical care, with individuals having to submit multiple forms before being seen by a clinician. In Georgia, prison staffing decreased by 33% which led to long waits for medical visits, and for women, it led to difficulty obtaining feminine hygiene products because not enough prison staff were available to help with distribution (Hefferfan and Li, 2024).

This review demonstrates how many of the barriers are intricately intertwined such as distrust in the medical system leading to low medication use. Thus, the barriers to healthcare in prisons is

tremendously nuanced and requires solutions that acknowledge these complexities. Telemedicine could be an interesting intervention because of its cost-effectiveness (Krsak et al., 2020; Rappaport et al., 2018). Rappaport et al. (2018) investigated the cost savings of telemedicine and calculated that the cost of an average trip to a medical facility was approximately $370. As such, prisons could accumulate around $37,500 per month of savings by adopting telemedicine, in part by reducing the expenses needed for the guards' time and transportation (Rappaport et al., 2018). These cost savings from adopting telemedicine could also potentially address the shortage of staff issues by re-allocating that money to hire more employees.

These results should be analyzed in light of several limitations. No second researcher participated in screening and coding, that may have allowed for a more rigorous identification of themes. In addition, screening was restricted to five databases and may have missed other pertinent articles.

CONCLUSION

Individuals with chronic diseases are a neglected population in prisons, treated with little human decency and a one-size fits all approach. This review reveals that the most perceived significant barriers to health care among those in United States prisons who have been diagnosed with any chronic diseases are costs, attitudes and actions of providers, distrust towards providers, issues with medications, fear of punishment, and administrative obstacles. To contextualize this review, future research can investigate the perspectives from providers and prison staff on these identified barriers, which will help to understand why these obstacles exist in the first place. Furthermore, potential future interventions should focus on eliminating co-pays, reducing provider stigma, expanding prison medication formularies, streamlining medical request processes, and ameliorating prison staff shortages to ultimately improve chronic disease healthcare in prisons.

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APPENDIX

Figure 1. PRISMA flow diagram

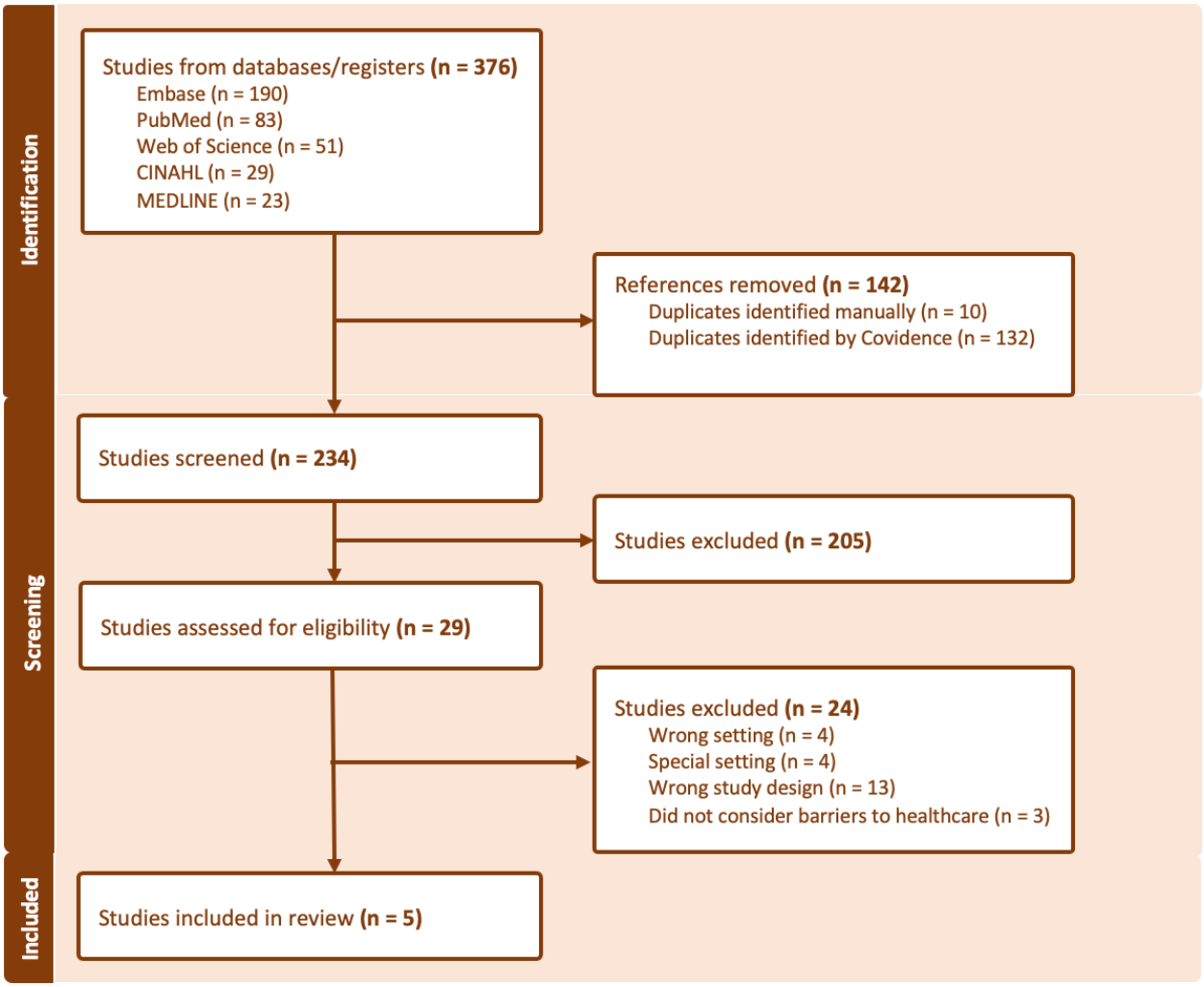

Table 1. Coding framework

Codename	Definition	Example
Barriers to healthcare		
Administrative and Staff	Other administrative and staff barriers	"We are out here in the boonies and miles from a hospital. I lie in my bed at night and think about what if I had a heart attack or something. How long would it take to get a guard to call for assistance? How long would it take for an ambulance to get me to a hospital? This thought really scares me" (Aday and Farney, 2014).
Forms	Any mention of medical request process and medical forms	"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" (James, 2023).
Gatekeepers	Any individual that is a barrier to an inmate seeing a physician or receiving healthcare	"Many voiced concern that emergency medical technicians (EMTs) and correctional officers provided most first-line medical triage, serving as healthcare gatekeepers that determined who got to see a physician" (Vail et al., 2017).
Cost	Other cost barriers	(Occasionally, we will run into a nurse who will just tell us the truth. To be honest with you, they will look at you and just say, "Honey, they're not going to do that because it costs too much money" (Aday and Farney, 2014).
Co-pay	Cost of co-pays; how co-pays deter inmates from seeking out care	"We do not have the money to go to medical all the times that we really need to. We need medical to care and stop charging three dollars on the seventeen cents we make an hour. It takes three days to work to pay for this" (Aday and Farney, 2014).
Wage per hour	How much inmates get paid in prison	"The only money… that I had, was from working, and I made 75 cents a day" (Thomas et al., 2016).
Fear of punishment	Any fears while receiving care or about seeking care	"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" (James, 2023).

Medications	Any other problems with medications	"When recounting her newly developed cardiovascular disease, Aaliyah stated that she was "put on Lipitor, which I really resisted. I did not want to take it, but couldn't control my diet," ultimately leading her to use medication to treat her condition rather than having the choice to modify her diet" (Mohammad et al., 2023).
Inadequate Medications	Too many, too little, or inappropriate medications	"Women with gout often go for over a week without any medication. The doctors may prescribe a medication, but the prisoner never receives it because it is not on the approved formulary" (Aday and Farney, 2014).
Motrin	Specific mention of ibuprofen/Motrin	"They won't give anything for pain but Motrin [ibuprofen], and lots of women experience much pain. Motrin is the drug for everything here and it doesn't work" (Aday and Farney, 2014).
Providers	Any other provider related issues	"I go to sick call and see one doctor and the next time we see a different one" (Aday and Farney, 2014).
Distrust towards providers	Any mention of lack of trust for providers	"Kenneth described the taxing mental health trauma associated with the lack of transparency in what medications they were being administered, citing feeling "unsafe from the staff" and expressing concern that he "can't identify what [medications] they were giving him" (Mohammad et al., 2023).
Provider actions	Provider actions that are obstacles to healthcare	"One woman stated, "Most of the time they go against what the outside provider recommends for our needs which causes our conditions to worsen" (Aday and Farney, 2014).
Provider attitudes	Provider attitudes that are obstacles to healthcare	"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" (James, 2023).
Study characteristics		
Chronic Conditions	Any mentioned chronic conditions that inmates or participants have	"The most common chronic illnesses mentioned were arthritis (61percent), hypertension (53 percent), issues related to menopause (30 percent), digestive disorders/ulcers (29 percent), and heart conditions (26 percent)" (Aday and Farney, 2014).
Study Sample	The study sample	"Thirteen formerly incarcerated Black women participated in interviews for this study" (James, 2023).
Study Setting	The study setting	"This research was conducted in seven women's prisons in the Southeastern United States" (Aday and Farney, 2014).

Table 2. Study characteristics

Study	Design	Sample	n	Chronic diseases mentioned
Aday and Farney (2014)	Mixed methods; descriptive aggregate data and personal narratives	Seven women's prisons in the Southeastern United States; older women with a mean age of 56.4 years	327	Arthritis; hypertension; menopause problems; digestive disorders/ulcers; heart condition; emphysema/ulcers
James (2023)	In-depth interviews; Black Feminist Epistemological Methodology	Older, formerly incarcerated Black women; all released from prison when they were aged 50 or older	13	High blood pressure; lupus; rheumatoid arthritis; back pain
Mohammad et al. (2023)	Semi-structured interview; qualitative thematic analysis	Individuals in Miami Dade County, FL released within the past year; average age not mentioned	12 (5 formerly incarcerated; 7 community providers)	Cardiovascular disease; diabetes
Thomas et al. (2016)	Qualitative; In-depth interviews	Primary care clinic in Connecticut; men and women recently released from prison with mean age of 43 years	26	CVD or CVD-RFS (including diabetes mellitus, hypertension, hyperlipidemia, or obesity)
Vail et al. (2017)	Semi-structured interviews	Formerly incarcerated men in the Greater New Orleans area; mean age of 56	24	Diabetes; high blood pressure;

Table 3. Summary of results

		Themes				
Study	**Co-pay**	**Provider actions & attitudes**	**Distrust towards provider**	**Issues with medications**	**Fear of punishment**	**Administrative**
Aday and Farney (2014)	$3 copay; $0.17/hour	Won't acknowledge medical history; looks down on patients; easily agitated; doesn't comply with outside provider recommendations	Fear that staff will be nonresponsive	Must take multiple medications rather than one because of limited drug formulary; never receive medication; Ibuprofen given liberally	Not addressed	Majority of prisons are in rural areas so health care services/hospitals are hard to access
James (2023)	$5 copay; $0.08/hour	Assume patients are drug-seeking; assess character based on education, race, gender, or gang affiliation; don't believe patients are sick	Suspect that prison doctors are doctors that can't work in society anymore; question care and intention	Taken off blood pressure medication, despite still needing it; poor reaction to medication, but it's either *that* medication or no medication at all	Can be punished for asking too many questions during appointment or reporting a problem other than what's been pre-approved	Medical forms restrict individual to list two problems at a time; medical request process is lengthy; correctional officers as gatekeepers to healthcare
Mohammad et al. (2023)	$5-12 copay; $0.20-0.55/hour	Pervasive culture to not believe patient's medical need; dehumanize patients; don't treat individual until emergency	Lack of transparency with medications leads to feeling unsafe with medical staff	No choice but to take medication because can't modify diet for diabetes management	Will get written up if symptoms don't present at time of visit; fruits considered contraband, so can't take control of diet for diabetes	Medical request process can be lengthy
Thomas et al. (2016)	$3 copay; $0.75/day	Physician as gatekeepers for privileges like a modified diet; don't individualize treatment plans	Perceive providers as neglectful or suspicious of malingering	Can't discontinue medication even after achieving normoglycemia because provider must adhere to treatment protocol	Face punishment if they don't take medications, such as loss of recreation time, delayed parole, etc.	Prison clinics overburdened; patients seen based on urgency; medical request process can be lengthy
Vail et al. (2017)	$4-20 copay; $0.04-0.10/hour	Believe that patient is faking symptoms; misdiagnosis; delayed diagnosis; don't treat individual until emergency	Asks peers not to take them to medical if they get sick; believe they must take care of themselves	Given over counter drugs to be kept from seeing a physician or nurse	Not addressed	Poor care coordination with outside hospitals; correctional officers and emergency medical technicians as gatekeepers to healthcare