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Patients' Experiences Managing Cardiovascular Disease Risk Factors In Prison

Emily Herron Thomas
Yale School of Medicine, emily.thomas@yale.edu

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Patients' Experiences Managing Cardiovascular Disease Risk Factors in Prison

A Thesis Submitted to the

Yale University School of Medicine

In Partial Fulfillment of the Requirement for the

Degree of Doctor of Medicine

By

Emily Herron Thomas, M.S.

2015

PATIENTS' EXPERIENCES MANAGING CARDIOVASCULAR DISEASE RISK FACTORS IN PRISON

Emily H. Thomas, Emily A. Wang, Leslie A. Curry, Peggy G. Chen. Section of General Internal Medicine, Yale University, School of Medicine, New Haven. CT.

Despite greater risk of cardiovascular disease (CVD) mortality in patients with a history of incarceration, little is known about how prisons manage CVD risk factors (CVR-RF) to mitigate this risk.

We conducted in-depth interviews with men and women with CVD-RF and who had been recently released from prison (n=26). Using a grounded theory approach and applying the constant comparative method, we inductively generated themes about CVD-RF care in prison. Data collection and analysis occurred iteratively to refine and unify emerging themes.

Four themes emerged from patient perspectives: (1) Access to care for chronic conditions is present, yet complicated in prisons. (2) Patient-provider partnerships can be undermined by providers' competing correctional and medical roles. (3) Informal support systems can improve self-management education and skills development. (4) The trade-off between prisoner security and patient autonomy influences opportunities for self-management.

Correctional policies pervaded patients' CVD-RF management, which undermined care delivered by providers and the development of critical self-management skills. Our findings support interventions to engage peers, providers, and care delivery systems in routine care to cultivate effective self-management strategies unique to prison.

Acknowledgements

"I am voiceless, but perhaps people will listen to you because you went to college and will be a doctor." The intensity of his gaze made me a bit uneasy. I often elicited BF's eloquent lamentations about the criminal justice system at our follow-up visits. He deftly described managing diabetes, hypertension, and coronary artery disease (his insights pepper this thesis). In these moments, when BF shared his stories, I would forget that I was, in fact, different and deeply privileged. And my uneasiness revealed this.

Before this study began, I was fortunate to have never visited a prison in my life; fortunate to have been born to an affluent family who valued education above social status; fortunate to have loving parents like Jim and Martha, who set examples of unrelenting tolerance for my sister and me; fortunate to have a sister, with whom I can share my aspirations and work. As of product of these fortunes, I hope that I can honor BF's invitation for action and in the process affect social change to restore BF's voice.

This task, though daunting, seems realizable through the mentorship of Emily Wang, who lives into these commitments daily through the rigor and zest she brings to her work. With invaluable collaboration from Peggy Chen and Leslie Curry, our qualitative gurus, we were able to develop participants' narratives into the robust themes presented in this thesis. My research team, Nathan Birnbaum, Jerry Smart, and Jenerius Aminawung, provided immeasurable assistance recruiting participants and collecting and analyzing study data.

Last, but not least, I am in awe of the participants in this study. My sole aim is to provide a space where you, the reader, will be transported (as I was) by their stories, candor, and resilience. I dedicate my thesis to these participants and their voices. With a

heavy heart, I would also like to acknowledge the three participants (RP, NR, and MT) who died during this study.

I would like to thank the Yale School of Medicine Office of Student Research for providing short-term research funding to support my salary; acknowledge the National Institutes of Health for Dr. Wang's K award that funded this study; and deliver a special thanks to Patti Cavaliere, who provided cheery administrative support for this project.

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Preface

Correctional populations suffer from poor cardiovascular health. Cardiovascular disease (CVD) is the most common cause of death in prisoners,[1] and cross sectional studies show that cardiovascular disease risk factors (CVD-RF) are more prevalent in U.S. incarcerated as compared to non-institutionalized populations.[2-5] Upon release from prison, individuals with a history of incarceration are twice as likely to die from a cardiovascular event as compared to never-incarcerated peers.[6] Yet the association between CVD and incarceration has not been explored systematically.[7] Correctional populations have a higher prevalence of behavioral risk factors, like alcohol and illicit drug use,[8,9] smoking,[10-12] poor diets,[13-15] and limited physical activity,[16-18] that may predispose them to poor CVD outcomes. Another posited mechanism is that patients with a history of incarceration have limited or discontinuous access to health care that contributes to gaps in treatment and inadequate control of CVD-RF.[19] A further hypothesis is that increased social stressors stemming from a history of incarceration or the social antecedents of incarceration, including poverty and racial discrimination, may increase allostatic load and promote adverse cardiovascular events.[20-23]

To elucidate the etiology of poor CVD outcomes in correctional populations, researchers must overcome two major challenges. First, correctional populations are difficult to study.[24-26] In 1978 the federal government designated prisoners a protected research group. Additionally, prisoners are often members of transient populations.[27] Once released to the community, recidivism rates are high, and patients return communities to which they are no longer socially connected.[28] Many prisoners are

members of traditionally "hard to reach" populations, including the homeless and those with mental health or substance use disorders.[29]

Second, environmental and social exposures influence health through complex and multifactorial mechanisms. The correctional system in the US predominantly affects individuals who are already at risk for health disparities. Prisons, as institutions, are not designed to promote health and in some cases can facilitate disease transmission.[30,31] Furthermore, incarceration can have health consequences even after release through direct collateral consequences,[32] indirect social stigma,[33] and forced migration between prisons and communities.[34] These consequences erode access to care, health promoting resources, and social capital that collectively support patients in seeking care, following through with medical treatments, and adopting healthy lifestyles.

In spite of the limitations to studying correctional populations and identifying plausible mechanisms of action without being overly reductionistic, we embarked upon a pilot study to explore the relationship between incarceration and poor CVD outcomes. Two theoretical lenses informed this study. Our first lens was inherently transformative, as we aimed to improve the social conditions that contribute to poor health outcomes in correctional populations.[35] Our second lens was pragmatic – we aimed to study plausible mechanisms and define workable solutions to improve cardiovascular outcomes in correctional populations. [36-38]

Given our motivation behind this study, we employed a longitudinal mixed methods approach to explore many predictors of poor cardiovascular outcomes, while contextualizing these findings in rich qualitative data. These data captured diverse patient perspectives about daily management of their CVD-RF both in prison and upon release

and allowed us to probe into the complex social interactions in each of these contexts. This thesis represents a small portion of these qualitative findings and elucidates how correctional systems support self-management practices for CVD and CVD-RF. We used these experiences to guide recommendations to realign correctional practices with best outpatient practices for CVD-RF control.

Introduction

Mass Incarceration

The United States has 25% of the world's prisoners but only 5% of the world's population.[39] Two point two million people currently live in U.S. prisons and jails or 1 in every 100 adults[40,41] – this is the highest incarceration rate in the world. From 1972 to 2002, the US correctional populations grew by 705% largely reflecting criminalization of drug offenses and stricter sentencing policies.[42] This tough on crime approach discriminates against poor, urban minorities, and the racial make-up of correctional facilities is correspondingly skewed.[43] One in 17 white men, 1 in 6 Hispanic men, and 1 in 3 black men will be incarcerated at some point in their lives in the US.[44]

Incarceration, therefore, tends to impact populations already vulnerable to health disparities, including people who are racial minorities, live in poverty, do not have stable jobs or housing, or have substance use and psychiatrics disorders.[45] Studies suggest that incarceration has profound downstream impacts on prisoners' future employment, income, and health, as well as the health of prisoners' family members and communities.[28,32,46-48] Incarceration may not only be a marker of risk for poor health status, but also may magnify vulnerability to poor health outcomes for patients and communities most affected by the criminal justice system.[23,33]

Disease Burden in Correctional Populations

The health status of correctional populations is complicated by the same risk factors that often contribute to their incarceration. As such correctional populations face a disproportionate burden of disease compared to community members. Prisoners are 17 times more likely to have HCV,[49] 4 – 6 times more likely to have serious mental illness,[50]

and 5 – 7 times more likely to have a diagnosable substance use disorder (SUD) than the general population.[8] While the burden of psychiatric, infectious, and SUDs has been well described in correctional populations, less attention has been paid to non-communicable medical conditions and their relative contribution to poor health status in these populations.

Many chronic medical conditions are overrepresented in prisoners. Between 30 – 50% of prisoners are diagnosed with a new chronic condition during their intake medical visit in prison, and these numbers are projected to increase.[51] Elderly prisoners (greater than 55 years old) are among the fastest growing groups of prisoners, with a 550% increase from 1990 to 2012.[52] Because of extensive medical co-morbidities, prisoners are estimated to be 10-15 years older physiologically than their chronological age,[53] similar to estimates for the homeless.[54] Harzke et al. estimated that two-thirds of elderly prisoners have at least one chronic medical condition,[55] and close to 80% of prisoners overall have at least one condition requiring long term care, including psychiatric and substance use disorders.[56]

Cardiovascular Disease in Prisoners

While CVD is the most common cause of death amongst inmates, the correctional research agenda has not focused on cardiovascular disease (CVD) in prisoners and how incarceration impacts CVD progression and outcomes. In the US, inmates are disproportionately affected by many CVD risk factors, including diabetes, hypertension, hyperlipidemia, and obesity. According to Binswanger et al, in an adjusted model that accounted for socioeconomic status (SES) and alcohol consumption, prisoners were more likely than non-institutionalized adults to have hypertension (AOR 1.17, 95% CI 1.09 to

1.27) and diabetes (AOR 1.12, 95% CI 0.98 to 1.26), yet were less likely to be obese (BMI > 30; AOR 0.80, 95% CI 0.72 to 0.88).[4] In women, however, the converse may be true. Several studies have demonstrated that incarcerated women were much more likely to be overweight or obese than women in the community.[18,57] Similarly, Wilper et al. found that prisoners had higher age-adjusted rates of hypertension (30.8% vs. 25.6%), diabetes (10.1% vs. 6.5%), and prior myocardial infarction (5.7% vs. 3.0%) than the general population.[2] International epidemiologic studies have shown elevated rates of CVD and CVD-RF as well.[5,58,59]

The burden of CVD and its risk factors in prisoners is substantial and disproportionate to the community. Few studies have assessed directly what mediates this relationship. Prisoners have many risk factors for poor cardiovascular health including low socioeconomic status,[22,60,61] illicit drug use,[62-64] and high smoking rates.[65] Incarceration itself can contribute directly to poor lifestyle factors for CVD, including physical inactivity, poor diet, and generalized declining health status[12] and health efficacy.[66] In a retrospective analysis of the CARDIA cohort, Wang et al. identified incarceration as an independent risk factor for hypertension (AOR 1.6, 95% CI 1.0 to 2.6) and left ventricular hypertrophy (AOR 2.7, 95% CI 0.9 to 7.9) upon release even after adjustment for smoking, alcohol and illicit substance use as well as SES.[19] Therefore behavioral risk factors for CVD, like illicit drug use and smoking, may not fully explain elevated risks in correctional populations.

The relationship between CVD risk factors, incarceration history, and CVD outcomes is not straightforward. Retrospective cohort studies have demonstrated that compared to patients in the community, prisoners have decreased mortality, particularly

in racial minorities, described as the "healthy prisoner effect." Rosen et al. showed that black prisoners had 36% and 80% lower than expected mortality from CVD and diabetes respectively.[67] Spaulding et al. similarly found that black prisoners had a lower than expected mortality, even though they did not assess mortality secondary to CVD.[68]

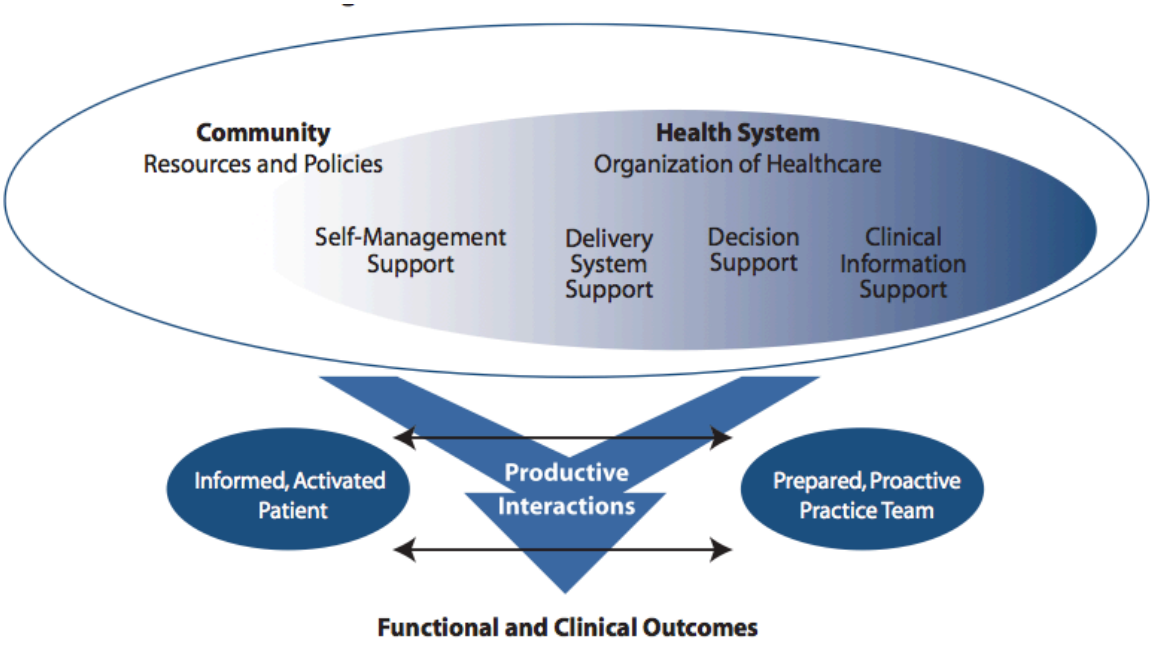
A precipitous decline in health status upon release from prison, however, far outstrips any gains from the "healthy prisoner effect." As a group, releasees face higher mortality from CVD. Binswanger et al. engaged in a retrospective analysis of 30, 237 releasees (excluding those with compassionate release) and found a significant mortality penalty that peaked within the first 2-weeks post-release at 12.7 times greater than predicted.[6] The second most common cause of death among released prisoners was a cardiovascular event. Within the study period (1.9 +/- 3.1 years post-release), cardiovascular mortality was 2.1 times greater in those released from prison as compared to age, sex, and race matched peers in the community. Little is known about what promotes these poor health outcomes following release from prison and how the correctional environment and medical care within prisons influence CVD progression.

Chronic Care Model and Correctional Settings

In the community, studies have shown that tight control of CVD-RF slows progression of CVD;[69,70] however there is a treatment gap – efficacious therapies exist, but are less effective when translated into clinical practice.[71] Many strides have been made to improve the delivery of CVD-RF treatment, particularly through multimodal interventions, like the Chronic Care Model (CCM).[72,73] The CCM enhances chronic care delivery by re-designing health care systems to enable providers to deliver pro-active, patient-centered care. This system facilitates patients in building the necessary resources

and skills to manage their conditions outside of the clinical setting (Figure 1. Chronic Care Model).[74,75] The CCM has been shown to improve management for many chronic conditions, including hypertension, diabetes, and congestive heart failure.[75-79] In a study of patients with diabetes, Vargas et al. demonstrated that implementation of the CCM across 13 health care organizations reduced the 10-year risk score for cardiovascular events by 2.1% (95% CI – 3.7 to – 0.5).[80] Therefore successful implementation of the CCM has the potential to reduce cardiovascular events through effective risk factor control.

Figure 1. The Chronic Care Model



The burden to care for CVD-RF in the correctional settings is exceptionally high and growing, according to a 2002 report by the National Commission of Correctional Health Care (NCCHC) about the "The Health Status of Soon-To-Be-Released Inmates."[81] Because medical care is constitutionally guaranteed, many patients in prison will be diagnosed with chronic conditions for the first time. Consequently, correctional settings

have a unique opportunity to not only treat, but also to educate patients about the long-term management of their chronic conditions. The NCCHC responded to the influx of chronic conditions by issuing guidelines to assist correctional settings to deliver high quality care for hypertension and diabetes.[82,83] These guidelines incorporate several key elements of the CCM, most notably patient education and self-management. However, correctional settings are unique settings that may pose challenges to implementation of the CCM and in particular self-management skills.

Self-Management and Correctional Settings

A majority of care for chronic conditions occurs outside of the clinical setting, and therefore chronic care depends critically on fostering patients' self-management skills.[84] For the purposes of this study, we will use Clark's definition of self-management, "the day-to-day tasks an individual must undertake to control or reduce the impact of disease or physical health status." Clark suggests that these activities "are undertaken with the collaboration and guidance of the individual's physicians and other health care providers," and we propose to expand this definition to include collaboration with any people who facilitate patients in undertaking these daily tasks.[85]

Self-management, therefore, is a set of practices that are learned and enacted by patients, and often facilitated by other actors, most often by medical providers, but also peers and family members. These practices are not standardized, and a systematic review of 145 interventions defined several key components of self-management, including disease education, symptom management, medication management, psychosocial support, lifestyle changes (diet, exercise, and smoking cessation), and provider communications.[86]

Consequently self-management outcomes are diverse and related to skill development, self-efficacy (the patient's confidence in his capacity to manage his chronic condition), and clinical outcomes. Several meta-analyses have demonstrated that self-management skills enhance clinical outcomes for diabetes and hypertension.[87-89] Few analyses have been able to distinguish which intervention components are most effective.[90] It is important to consider, therefore, that most self-management interventions are multifaceted and are more effective when implemented as such. In fact, when the Diabetes Initiative of the Robert Wood Johnson Foundation constructed an evidenced-based framework for diabetes self-management, they used an ecological model, underscoring that self-management practices are inextricable from the social and environmental contexts in which patients care for their conditions.[91]

This model may be useful in deconstructing how correctional settings, their unique environments, and social structures influence self-management practices. This model posits that patients should optimally be engaged in individualized and collaborative providers relationships, in a health care system that enables routine and continuous follow-up care, and embedded in an environment that promotes access to resources that allow patients to enhance these skills. There are few, if any, studies in the correctional literature that address self-management of CVD-RF in particular. Vast knowledge gaps exist about how patients self-care for their medical conditions in prison and how the "controlled and restrictive environment" of prison constrains patients' access to providers, medication, and education. [92] Nonetheless correctional settings have begun to address these limitations by developing and assessing interventions for chronic care and in particular self care in correctional setting.[93-96] Using the framework from the

Diabetes Initiative, we will briefly review the correctional literature related to self-management practices in prison.

Routine and Continuous Follow-Up Care

Medical care in U.S. correctional settings has been constitutionally guaranteed since the Supreme Court decision, Estelle v. Gamble, in 1976. Historically, medical care, particularly preventive and chronic care, has not been prioritized in correctional systems.[97-99] The primary mission of correctional settings is to securely detain prisoners, not to promote health. [100] Therefore prisons largely conduct health visits through a "sick call" system where prisoners apply for triage-based care. Notably, there is large variability in correctional systems and in particular in health care,[97] which have allowed models of chronic care delivery to emerge. In Texas, an academic correctional health care system reformed its health care delivery to include chronic care clinics, resulting in significant improvements in clinical measures of CVD-RF.[101] In California, a study demonstrated that implementation of the CCM for asthma was feasible in prisons.[102] Yet models of chronic care delivery rely largely on patients' active engagement in care, and in qualitative studies of prisoners, perceived access to care was constrained by delays, correctional gatekeepers, and even co-pays.[20,103-105] In models of self-management, routine care is essential to provide feedback on skills, like medication adherence or self-monitoring.[91] Therefore these findings indicate that research, both evaluative and interventional, is needed to explore and integrate patient-level perspectives for chronic care delivery.

Individualized and Collaborative Relationships with Providers

Patients' relationships with medical providers play a key role in the development of self-management skills to tailor care to individual patients and set attainable goals for care.[106] As compared to outpatient studies, there are no correctional studies that assess how tailored care improves patient outcomes, perceptions of care, or health care utilization. However, several interventions suggest that nurse-led partnerships can facilitate education and screening for HIV and HCV and promote risk reduction behaviors upon release.[107,108] Additionally qualitative interviews of patients tend to explore patient-provider relationships two-dimensionally, meaning that providers are good (caring, compassionate, trusting)[109] or bad (neglectful, hostile, suspicious).[20,105,110,111] More studies are needed to describe not only what patient-providers relationships look like, but also how patient-provider interactions influence chronic care management, particularly related to health education, self-monitoring practices, medication administration, and care seeking. Measures, like the Assessment of Chronic Illness Care (ACIC), adapted by Wang et al. to correctional settings, may improve provider awareness of these chronic care metrics.[112]

Access to Resources to Enhance Self-Management Skills

Patients in prison face distinct constraints to enacting their self-management skills. Correctional settings have ultimate control over many aspects of self-care, and patients have little choice about their diets, movement, or access to health resources.[104,113,114] Therefore patients may not practice skills to select nutritious diets or exercise routines for CVD-RF control. Several studies of group-based interventions that teach patients exercise and nutrition habits have produced improvements in key clinical outcomes for CVD, like weight, body mass index (BMI), and blood pressure,

demonstrating that the challenges of correctional settings may be overcome to reinforce lifestyle changes for CVD prevention.[115-118]

Because of security concerns, prisons may also constrain patients' ability to access and administer their medications or self-monitor risk factors for CVD.[119] Security constraints may be particularly relevant to diabetics, who are not allowed to keep needles to inject their insulin.[120,121] To overcome these limitations, the NCCHC's diabetes guidelines, specifically, recommend that patients be able to "prepare and administer their insulin under supervision." Studies have not been conducted to assess the uptake or feasibility of these guidelines in prisons. Several studies suggest that prisoners may safely perform self-management practices. One study in Connecticut demonstrated that self-performed peritoneal dialysis is effective and safe in the correctional setting.[122] Future research is needed to determine how particular correctional settings can adapt these self-management practices to improve educational and adherence outcomes.

In qualitative studies, patients often report a need for greater programming and education for their chronic medical conditions. There is a wealth of literature supporting group-based and peer-led interventions to improve knowledge and practices related to HIV+ prevention.[123-126] These interventions also improve key psychosocial domains and self-reported health status. One intervention has been conducted in women's prisons to educate patients about CVD-RF with improvements in knowledge domains, yet this study did not assess how these interventions impacted patient-level behaviors.[127] These findings demonstrate the need to determine whether interventions can overcome the challenges related to self-management in correctional settings, foster sustainable skills for CVD-RF control, and consequently improve CVD outcomes.

Studying Self Management for CVD-RF in Correctional Settings

Correctional settings pose particular and largely unexplored challenges to CVD-RF self-management that may negatively impact future CVD outcomes. In sum, patients in prison often face a disproportionate burden of risk factors, unresponsive medical care to the needs of chronic conditions, and limited opportunities for self care. There are many assets in the correctional settings for patients with chronic conditions. Prisons offer a stable environment and guaranteed access to care, where patients may be screened and treated for chronic medical conditions for the first time.[29] An estimated 95% of prisoners are ultimately released back into the community,[81] where their mortality risk from CVD is greatest. Upon release from prison, patients face poor access to care, gaps in insurance coverage, medication discontinuities, and immeasurable transitional stress.[128-131] But prisons may be able to mitigate these risks by fostering practices for self-management that patients continue to enact in the community upon release.

Regardless of the implications for patients following release from prison, studies have shown that the implementation of chronic care delivery can improve risk factor control and reduce costs in the correctional system.[101] These outcomes are particularly salient for prisons, as these health care systems struggle with the growing number of elderly prisoners and their burgeoning chronic conditions. In light of this background, we aim to explore how correctional settings influence patients' CVD-RF management. By interviewing releasees, we will elucidate how correctional systems foster the development of self-management practices both in prison and upon release. These processes are complex and interactional and would be difficult to capture using quantitative methods. Therefore we chose to conduct qualitative interviews to assess

diverse patient-level perspectives and practices, explore how varying correctional settings approach these practices, and capture interpersonal interactions between prisoners, providers, and correctional staff. These findings will be used to make recommendations for interventions that not only enhance self-management and chronic care delivery across correctional settings, but also may improve CVD outcomes following release.

Statement of Purpose

The purpose of our study was to explore patient experiences managing CVD and CVD-RFs in prison with a particular focus to how correctional systems facilitate or constrain self-management practices.

Specific Aims

1. To explore diverse patient perspectives on informal and formal management of CVD and CVD-RFs in correctional settings.
2. To describe how interactions with medical providers, correctional officers, and prisoner peers informed patients' acquisition and enactment of self-management practices.
3. To develop recommendations for patient-centered interventions to improve CVD-RF management in correctional settings.

Methods

The current study reports on findings from a series of qualitative interviews that we conducted as part of a larger mixed methods study.

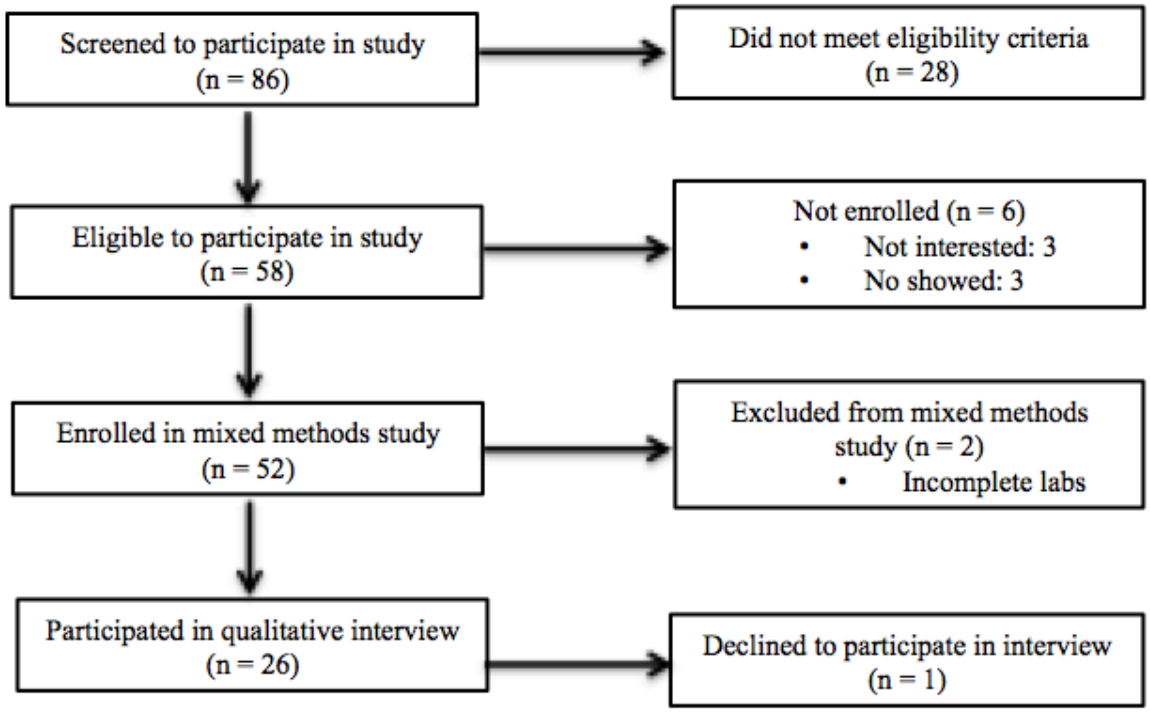
Mixed Methods Study

The purpose of our mixed methods study was to examine how knowledge, attitudes, beliefs, and practices of patients recently released from prison impacts future control of CVD-RF. The findings from this study will inform future studies and interventions that address the specific determinants of poor CVD outcomes following release from prison. A member of our research team (EHT) recruited 52 participants with a history of incarceration in the New Haven community. Participants were eligible if they (1) had been released from prison within 6 months; (2) had been diagnosed with CVD or CVD-RFs, including diabetes mellitus (type 1 or type 2), hypertension, hyperlipidemia, or obesity (BMI > 30); (3) spoke English; and (4) planned to remain in the greater New Haven area for 12 months. EHT confirmed patients' stated chronic disease status by review of prison and community medical records.

Recruitment was multi-pronged and included direct engagement at the Transitions Clinic, a primary care clinic for patients with a history of incarceration, participant word of mouth, and flyer distribution at re-entry organizations in the New Haven community. Participants received an honorarium in the form of a $50 gift card for study participation. Of the 86 individuals who contacted EHT to participate in the study, 67% met all four eligibility criteria, of those 90% were consented to participate in the study and 10% refused to participate or did not attend their enrollment appointment. Two individuals participated in the qualitative interviews, but did not complete the quantitative surveys at

enrollment and were, therefore, excluded from quantitative strand of the study (Figure 1. Study Flow Diagram).

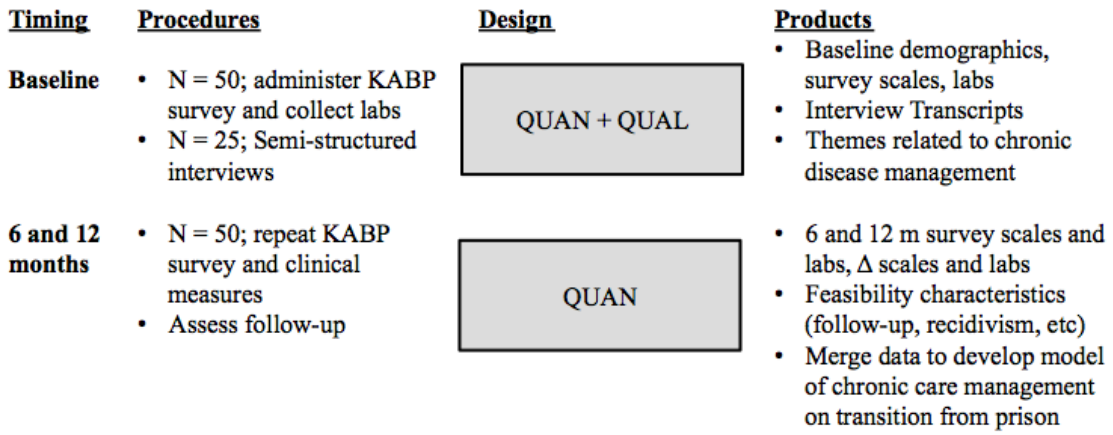
Figure 1. Study Flow Diagram



Upon enrollment in this study, we concurrently conducted qualitative interviews (EHT and EAW) and collected quantitative data at baseline, 6 months, and 12 months after enrollment to assess patients' clinical parameters, health care utilization, and KABP using validated surveys (EHT). We collected many quantitative parameters about patients' KABP and disease outcomes to identify possible mediators of CVD-RF control following release from prison. The use of qualitative methods was essential to this study, because patient-level interactions about CVD-RF management practices in correctional and post-correctional settings are complex and have rarely been explored in an in-depth manner.[132] Therefore, by merging these data strands at the conclusion of the mixed

methods study, we aim to elucidate the process of developing knowledge and practices for CVD management in the correctional setting, translating these skills into community settings, and contextualizing clinical outcomes through patients' KABP following release from prison (Figure 2. Mixed Methods Diagram).[38,133,134]

Figure 2. Mixed Methods Diagram



Study Design and Sample

From among the 52 participants in the mixed methods study, we utilized a purposeful sampling strategy to ensure both representativeness and diversity within our qualitative sample.[135] Twenty-six participants participated in these interviews. These participants were selected to capture diverse perspectives from key groups of interest (gender, race/ethnicity, disease status). Compared to the proportion of women in Connecticut prisons, we over-sampled women to account for differences in correctional facilities, which are sex segregated. Of the 27 participants asked to participate in qualitative interviews, only one declined. The Human Investigation Committee at Yale University, the Connecticut Department of Corrections Research and Advisory

Committee, and the United States Office for Human Research Protection approved this study.

Data Collection

Two members of our research team (EHT and EAW) led semi-structured interviews using a standardized interview guide (Table 1. Interview Guide). The interview guide included open-ended questions to elucidate how prison facilitated or constrained self-management of CVD-RFs.[136] In addition, we asked participants to reflect on how their CVD-RFs are managed in the community immediately post-release. The interview guide also included non-standardized probes to provide clarification and elucidation of the concepts that emerged in these interviews.[137] Interviews were recorded, professionally transcribed, and review for accuracy. The interviews averaged 42 minutes with a range between 12 to 71 minutes.

Table 1. Interview Guide

Questions
Tell me about when you were diagnosed with X.
What is it like to have your chronic condition in prison?
What made it easy to manage your chronic condition in prison?
What made it hard to manage your chronic condition in prison?
In prison, what personal strategies did you develop to take care of X?
What makes it easy to manage X now that you have been released from prison?
What makes it hard to manage X now that you have been released from prison?
General Probes
Can you tell me more about that?
What did you mean when you said…?
Can you walk me through that process?

Data Analysis

Our research team was composed of a mix of content and method experts as well as a trainee (EHT). Our interdisciplinary team included a medical student with prior experiences in caring for correctional populations (EHT), an internist with expertise in

the care and research of corrections populations (EAW), a pediatrician with expertise in qualitative methods (PGC), and a health service researcher with expertise in mixed methods research (LAC). The team worked collaboratively to develop the concepts in the guide based on our experiences working with patients recently released from prison and performing qualitative research around individual experiences in health care systems.[138,139]

Three members of our research team (EHT, EAW, and PGC) met regularly and performed the analysis of these interviews.[140] We initially reviewed 5 transcripts to develop a preliminary coding structure through inductive coding in accordance with grounded theory. Developed by Glaser and Strauss, grounded theory is an approach to qualitative analysis that allows themes to emerge inductively from the perspectives of participants rather than from the preconceptions of the researchers.[141,142] LAC reviewed this preliminary coding structure and interviews to assure that we were unbiased and comprehensive in our approach.[143]

After developing a preliminary code structure, we coded the first 6 transcripts independently, meeting weekly to negotiate consensus and refine our code structure using constant comparative analysis. This iterative process supported refinement of the coding structure to clarify extant themes and introduce new themes as they emerged from the data.[144] We maintained a thorough audit trail, adding refinements to our code structure and eliminating or consolidating codes where needed.[145] The remaining 20 transcripts were coded iteratively, as each coder reviewed the transcripts and codes from the prior coder. We reconciled differences in codes at weekly meetings.

At weekly meetings, we regularly examined how our personal perspectives influenced our coding interpretations (for example, PGC's lack of exposure to correctional settings or EHT's and EAW's relationships with the participants as patients). This process of reflexivity allowed us to explore and establish distance from our preconceptions to strengthen trustworthiness of our coding interpretations.[143] Our final code structures included 12 codes, each with discrete sub-codes to capture a broad range of experiences in prison and upon release (Table 3. Final Coding Structure).

EHT then systematically applied the final coding structure to all transcripts. We used qualitative analysis software, (ATLAS.ti 5.0; Scientific Software Development, Berlin, Germany) to facilitate data organization and retrieval for the purposes of data analysis.

Table 3. Final Coding Structure

In Prison
The Role of Institutional Control in patient's health Sub-codes: institutional policies that enhance or limit choice, affect coping, or reinforce "prisoner-hood"
The Role of Individual Agency in patient's health Sub-codes: individual choices contribute to positive or negative health behaviors or affect coping
The Role of Care Delivery in patient's health Sub-codes: issues to initiating new care or follow-up care, unpredictability of or delays in care, patient education, perceptions of care delivery, lack of tailored care, and cost as a factor in care
Desires for additional supports
Upon Release
The Role of Post-institutional consequences in patient's health Sub-codes: direct or indirect consequences of incarceration that limit individual choice or influence coping
The Role of Individual Agency in patient's health Sub-codes: individual choices contribute to positive or negative health behaviors or affect coping
The Role of Care Delivery in released prisoner's health Sub-codes: transitional care and discharge planning, issues related to follow-up care, barriers to care, patient education, perceptions of care delivery, tailored care, cost as a factor in care

Desires for additional supports
In Prison and On Release
Chronic Disease Management Sub-codes: medication delivery & administration, diet, exercise, self-monitoring, and multimorbidity
The Role of Interpersonal interactions in patients' health Sub-codes: interactions with other prisoners, prison staff, medical staff, family, non-prisoner peers, criminal justice staff, and no relationships
The Role of Group Membership/Affiliation in patients' health Sub-codes: influence of religious status, financial status, disease status, prison employment, and prison term duration on health
Comparisons of chronic disease management Sub-codes: prison and community, prison and prison, temporally between prisons

Results

Demographics

Among the 26 participants, the average time to enrollment in the qualitative study following release from prison was 76 days with a range 3 to 181 days. We sampled purposively for age, sex, race, and disease status to achieve a diverse range of perspectives about chronic disease management in the correctional setting. The average age of our sample was 43 years old. Participants were largely black, male, single, high school educated, and unemployed. On average, participants spent 858 days in prison prior to enrollment in this study. Of the participants, 96% saw a provider and were prescribed medication during their last incarceration. Routine health maintenance screenings were high for these participants, and 71% of participants had either medium or high health literacy (Table 3. Participants Characteristics).

Table 3. Participant Characteristics

Key Characteristic	**(n = 26)**
Mean age, years (range)	43 (23 - 61)
Male, n (%)	17 (65)
Race/ethnicity, n (%)	
Black	16 (61)
White	8 (31)
Hispanic	2 (8)
Chronic Condition	
Hypertension	16
Hyperlipidemia	14
Diabetes Mellitus	13
CAD	2
Obesity (BMI > 30)	18
Demographics	**n (%)****
Marital Status	
Never Married	13 (50)
Married	1 (4)
Separated/divorced/widowed	12 (46)
Educational Level	
Less than high school	6 (23)
High school/GED	14 (54)
Some college/college graduate	6 (23)

Housing status	
Homeless (living on streets or in shelter)	2 (8)
Doubled up (living with friends or family)	10 (38)
Facility (halfway house, drug treatment)	8 (31)
Renting or own home	5 (19)
Employment Status	
Unemployed	21 (81)
Full time/part time	3 (11)
Disable/Unable to work	2 (8)
Socioeconomic Status	
Have Access < $100	23 (88)
Have Access $100 - $500	1 (4)
Have Access to > $500	2 (8)
Incarceration History	
Mean length of most recent incarceration, days (range)	858 (77 - 3666)
Time to enrollment from release, days (range)	76 (3 - 181)
> 3 Convictions as adult, n (%)	16 (62)
Arrested as juvenile, n (%)	9 (35)
Health Care Parameters	**n (%)**
Had a routine provider prior to incarceration	21 (81)
Had health insurance prior to incarceration	22 (85)
Saw medical provider in prison	25 (96)
Prescribed medication in prison	25 (96)
Routine Health Maintenance	
Colonoscopy (eligible, n = 7)	5 (71)
Pap Smear (eligible, n = 8)	7 (88)
HIV (in past year)	21 (84)
Health Literacy	
High	9 (38)
Medium	8 (33)
Low	7 (29)

** The percentages reflect only the proportions of respondents who chose to answer the questions. Only 25 participants answered questions about housing status, and 24 completed all of the health literacy questions.

Themes

Our analysis generated insights into how patients interacted in correctional settings, in particular with correctional health care systems, to manage their chronic conditions. Our final code structure captured a broad range of experiences in prison and upon release. For this analysis, we will focus on four themes that emerged from the codes related to "The Role of Care Delivery" in prison: (1) Access to care for chronic conditions is present, yet complicated in the correctional setting. (2) Patient-provider

partnerships can be undermined by providers' competing correctional and medical roles. (3) Informal support systems can improve self-management education and skills development. (4) The trade-off between prisoner security and patient autonomy influence opportunities for self-management.

Access to care for chronic conditions is present, yet complicated in the correctional setting

Many participants reported that despite being routinely screened and treated for their chronic conditions at the beginning of their prison term, they had concerns about continuity of care, including an absence of health education, regular disease monitoring, and follow-up for complications. Patients endorsed a need for continuing education about their chronic conditions that were often first diagnosed in the correctional setting. One patient recalled that there were few opportunities to interact with medical providers for education about chronic disease management:

> "The medical units in the state prisons… need more help…[T]hey need people in there to focus and teach them about their disease, you know? You're supposed to have checkups like that. They don't got no "open door", nothing in medical. They don't have no diabetes meetings, no blood pressure meetings, health seminars and stuff like that."

Medical care in prison was largely organized using a triage system, where providers saw patients based on medical acuity, similar to the "emergency department" according to one participant's description. This acute care orientation complicated the provision of routine chronic disease management, and patients often reported barriers and a general sense of neglect from providers for needed chronic disease follow-up in prison. Patients, once diagnosed with a chronic condition, relied largely on the "sick call" system to gain access to their care providers. In such a system, patients filled out a form to

request a provider visit and deposited the form into a mailbox on the prison unit. One hypertensive patient described how the triage process contributed to delays in care even for medical complications, while similarly noting the staffing constraints in prison medical units arising from high patient volumes:

> "You have to write a medical request, first of all, and then once they see you and you get your medication and your medication acts abnormal in you, now you have to go through that medical request system all over again. And usually the doctor sees, you know, the people who need the emergency treatment or people who have already been treated and already are on medication… you're not that much of a priority to him as someone who just came in that needs to be seen. Because he's got… at least 100 to 200 guys coming in daily, so you're not a priority. "We already medicated you. You're medication's causing you side effects. When I get to you, I get to you." That's it. And then you just keep going through the process of writing medical request after medical request, and eventually they'll see you."

Additionally, gatekeepers unique to correctional settings mediated patients' access to care in prison. Many participants perceived that correctional officers (COs) played a key role in delivering medical request slips or locating patients when they were called to the medical clinic. One patient who requested a provider visit to address sudden weight loss and polyuria explained:

> "So I'm writing to medical and it'll usually take about a week to get an answer back and what was happening was I was, I worked in the kitchen, and they would call for me in the block[i] to come to medical and I wasn't there and the CO doesn't bother saying, "He's at work. Call him over in the kitchen." So it took over two months for me to be seen."

In addition to the procedural barriers to seeing a medical provider in prison, participants reported unforeseen obstacles to routine care. In some prisons, provider visits, even for sick call, required a co-pay. This fee deterred patients, especially those with limited resources in prison,[ii] from seeking education about a new diagnosis:

> "If you go to sick call, you have to pay three dollars every time you go there. The only money that you have, that I had, was from working and I made 75 cents a

> day. So to ask a question that's going to cost me three dollars, it just doesn't work out. That's, what, four days pay to go ask somebody a question."

Despite the access barriers endorsed by many patients, several participants had divergent and overall positive experiences with the sick call system. One patient expressed that sick call was "easy" and that the once a patient placed a medical request in prison "9 times out of 10 they'll get back to you the next day. So… they really did follow-up… if you've got a chronic disease such as diabetes…[they'd] see that your needs were met." These varied perspectives reflected the diversity of medical care delivery practices across prisons.

Patient-provider partnerships can be undermined by providers' competing correctional and medical roles

Patients reported interactions with a range of health care providers in prison. Most often, their medical interactions were with medical assistants or nurses. They interacted much less frequently with physicians or specialists at diagnosis, initiation of treatment, and interval follow-up. The relationship between medical providers and patients in prison was multifaceted. Patients often portrayed physicians in multiple roles as gatekeepers to ostensibly non-medical privileges such as the coveted bottom bunk or clearance for certain jobs. Participants were not at liberty to simply change their diet:

> "The doctor has to [write for diet changes]. And you know how long it takes you to get to it… once I put a slip in and let them know, you know, that I'm trying to get a low-sodium diet, then I gotta go down and see the doctor…so it take a process of maybe two weeks and I'll have it."

At the same time, correctional policies shaped their function as medical providers. Participants described how medical providers exerted punitive correctional roles, by

sending patients to the box (another name for solitary confinement) or issuing tickets[iii] for refusing to adhere to medication regimens, for example:

> "They have a med line[iv], and you have to go get your meds. If you don't get your meds, you get a ticket. So you got no choice but to go get the meds… [taking medications is] a routine for me, and, you know, that's the reason why, because you get a ticket if you don't."

These correctional roles shaped patients' perceptions of their medical care. While some providers were described as caring and attentive, others were described as neglectful, hostile, or suspicious of patients' malingering. One patient reported that he found it difficult to convince providers that he "needed attention [and] at the same time trying to have [the provider] understand that you're not there for something that he doesn't want to give you." In one patient's assessment, the correctional setting influenced not only access to providers, but also framed providers' interactions with patients, treating them as collective prisoners rather than individual patients:

> "[W]hen you're incarcerated, it's a lot different. Medical is a lot different. And, I mean, the care there is not the best of care… [Medical providers are] in a place, they're in a hostile environment, so I believe it's a lot harder and difficult for one to deal with people. Because…they'll look at each individual as the same, instead of looking at each individual differently, you know what I'm saying?"

Furthermore, participants perceived that prison providers were required to treat per protocol, which also limited individualization of care. This diabetic patient reported:

> "I bring it to my doctor and I say, "Listen, I want to get off medications because I think it's helped keep it under control, but I think because of losing weight I think I'm doing well." "Yeah, you probably did help yourself by losing weight, but you're still going to take the pill." I was like, "Why?" He was like, "Because it's been ordered for you, so you gotta take it until where it runs out." There was an indefinite order."

Alternatively, several participants described how medical providers successfully tailored interventions to patients in the correctional setting. These divergent experiences

reflected opportunities to improve patient-provider partnerships in prison and foster patient collaboration in their medical care. Rather than ignoring the "Catch-22" that many patients faced to improve their diets in prison, one overweight woman described how a medical provider taught self-management skills tailored to prison:

> "[I]t was called Women Overweight group …I did go to a couple of those groups and [the nurse] would lay out everything that was on commissary[v] that was like good for you... Like they used to sell peanuts and things like that, so she taught us like how to rinse off the peanuts from the salt so it's not high in sodium…[S]he would have a whole class based on like your options… in the chow hall, she would go over that, like what is good for you, how many calories are in that..."

In another collaborative intervention, inmates were trained to become certified nursing assistants (CNAs) and share the caregiving role for routine monitoring of chronic diseases. One participant remarked that that "…the CNA's that were inmates, they were great... they were more caring than those nurses ever were, and these were men caring for men…"

Informal support systems can improve self-management education and skills development

Patients sought informal resources from fellow prisoners, family members, and even correctional officers to enhance their education and skills. Many participants read books in the prison library and looked to other prisoners, such as those encountered in medication lines, to share books or knowledge:

> "[Y]ou talk to other people that have the same things that you have that…one of the conversations was I didn't know the difference between Lantus and regular NPH...that one was a long-acting and one was a fast-acting…but I found that out from another prisoner that was, you know, in jail."

Fellow prisoners also played a role by identifying new diagnoses or complications from chronic diseases and informing correctional staff, as this new-onset diabetic patient explained:

> "I passed out coming out of the chow hall, and honestly it was another inmate who suggested that when I go to the medical unit that they check me, check my sugars because she said it seemed like the way I was explaining to the CO… [it]seems like you got - do you have diabetes?"

Participants noted that peer education and support were particularly valuable. Removed from community support systems, patients in prison shared the experience of managing their CVD-RFs through unique correctional challenges:

> "[Y]ou gotta be each other's support system, so…your doctors tell you to do stuff, but you know in that environment you can't really do anything. It's easy for them to tell you to do it, but, you know, being as different procedures and lock downs and all that stuff, you can't really do nothing."

Beyond peers, participants identified family members and correctional officers as educators, when medical providers were not easily accessible or informative. One woman newly diagnosed with hypertension reported that "[t]he only… education I did have was from my family because… a lot of people in my family had suffered from high blood pressure." On the units,[vi] correctional officers provided support to patients. A diabetic man noted that his "my block officer[vii]… used to be a nurse. [S]he would ask me every day how I was doing, how I'm feeling, how my sugar was. She was the one who explained to me what ketones were. Not the medical staff."

The trade-off between prisoner security and patient autonomy influences opportunities for self-management

The policies of correctional settings dictated patients' ability to self-manage their chronic conditions. This tension between correctional control and patient autonomy was illustrated most saliently in patients' opportunities to self-monitor their condition, administer medication, and manage complications. These opportunities were often conditional and varied by correctional facility, medication type, and patient education. In

some, but not all facilities, diabetic patients were taught in medication lines to prick themselves and use glucometers to measure their blood sugars. No diabetic patient in our study reported that he had learned how to administer insulin while in prison. One patient noted the repercussions he faced when he was released from prison:

> "One of the major problems I had was, obviously they don't give you needles in prison, they inject you with the insulin, and so I never learned how to inject myself. They do give you like a crash course the day before you leave on how to do it, but they never told me, they never gave me information on how much insulin I'm supposed to use compared to what my sugar is. I have insulin at home now and never used it, even when my sugar was high, because I don't know how to do it, how much to take…"

Prisons differed in their processes of administering lower risk medications (i.e. those not injected or controlled substances). In some prisons, patients received their medications at clinic, where the staff "check your mouth…and make sure you swallow the pill…" In contrast, other prisons allowed patients to have KOP (keep on person) medications, often dispensed "on a strip [or] a bulkie." Patients endorsed that KOP medications gave them the opportunity to practice self-administrating medication and reinforce adherence behaviors. Medical providers, however, reluctantly delegated these self-management practices to patients:

> "In the beginning, because they don't know you, they don't know if you're responsible enough to take your meds, because a lot of people don't, you have to see the nurse to get your medication. And then that went on for like three months and I finally said, you know, on one of my blood pressure checks I said, "Why do I have to keep going? Like, it's blood pressure medicine." It's not, you know, because they let you, they allow you to keep certain medications on you… So they finally called me down for my physical, like three months later, and the doctor was like, "Well now that I've seen you, I can tell them that you can have your medication on you."

Despite restrictions on formal processes of self-management, patients invented strategies for CVD-RF management. Patients learned to manage hypoglycemic

complications that frequently occurred at night, when access to correctional officers or medical providers was limited by smuggling sugar packets from the cafeteria to the unit, or as this patient, who could afford commissary,[viii] described:

> "I wouldn't even try to go to medical. I would just go in my locker and eat out of my locker… I'd be having candy and stuff… all ready, Snickers, Little Debbie cakes and stuff that I have that I don't eat for snacking… I keep them for, to preserve them for like if I ever be in a predicament like that, and I'd eat that and then, I'd probably eat two of them just to get my sugar up there real fast."

Similarly, participants developed many strategies unique to the correctional system to advocate for improved self-care. Patients described formal channels that they perceived enhanced access to follow-up care, including barraging the system with medical requests or filing formal grievances against medical providers. Additionally some patients enlisted their family members to call the correctional facility to request that a medical provider see their family member. Ultimately the compromise between patient autonomy and prisoner status to facilitate self-management was a negotiated one:

> "It was more of a debate, you know? You would verbally have to stress firmly, you know, and aggressively that you are entitled to an hour of rec[ix]. You demand it or you would demand to see a higher chain of command. That's about it."

Discussion

Because correctional populations are often underserved and lack adequate access to health care in the community,[52] prisons provide a unique opportunity to screen and manage CVD-RFs in patients at higher risk of CVD mortality. Ninety-five percent of patients in prison will ultimately be released to the community. Therefore the treatment of CVD-RFs in prison is not only a matter of individual health, but also one of public health.[81] As such, correctional facilities are ideal locations to design interventions to improve cardiovascular health.[146]

We conducted a qualitative study to determine how prisons support self-management practices for CVD-RF. Our participants largely voiced that correctional policies and security concerns limited their access to care, interactions with providers, and self-management practices. However, divergent accounts about CVD-RF management suggested that in some settings, chronic care was readily available; providers were responsive to follow-up; and correctional policies enabled patients to establish routines to adhere to their medication regimens. Additionally, participants strongly approved of group education sessions that tailored dietary recommendations to prison and peer-based care, where inmates were trained to be CNAs. These experiences suggest that many correctional settings have implemented strategies that support CVD-RF self-management, and these practices warrant further investigation. In addition to identifying best practices of chronic care delivery in correctional settings, our findings suggest that prison health care systems may strengthen CVD-RF management by focusing on three key areas of care delivery.

Systems-Level Recommendations

At the systems level, a paradigm shift from acute care visits to routine chronic disease monitoring may overcome many access barriers that patients endorsed. Our participants noted that guaranteed access to care was undermined by delivery processes that were unpredictable and often delayed, rather than proactive and continuous, which is necessary for optimal chronic care.[74,79] As a consequence patients with chronic conditions defaulted to the sick call system for medical issues like education for a new diagnosis and medication complications that were better addressed in routine visits. Regularly scheduled chronic care visits may reduce well-documented triage-based delays[105,147] for chronic conditions that are by their nature sub-acute. These shifts towards chronic care not only improve treatment outcomes, but also may be cost-effective, as demonstrated in the Texas prison system.[101]

In an effort to reform the sick call system, correctional systems should also eliminate co-pays for patients who particularly benefit from continuity of care. Co-pays were originally implemented to limit frivolous health care seeking; however, there is evidence to suggest that co-pays for any condition are harmful. Case studies document that co-pays contributed to MRSA outbreaks in correctional facilities across the US.[148] Additionally, co-pays create a two-tier system for care in prisons and unfairly penalizes or restricts health care access for those patients without outside financial support.[103,105,110,111,149] As such, the NCCHC advise against co-pays in prisons and provides recommendations for regular oversight of these unfair practices, if implemented.[150]

Additionally, by coupling chronic care visits with self-management education, prison health care systems may improve patients' capacity to self-care for their conditions

and reduce their reliance on medical providers. Studies have demonstrated that patients in prison sought care more frequently than community-dwelling patients.[151] The antecedents of elevated health care utilization in prison are complex. As opposed to communities where an abundance of health resources exist outside of the medical setting, medical providers are the most reliable source for disease-based education, yet our participants endorsed concerns that there was "no open door" policy to meet their needs. Additionally, a qualitative study of Belgian prisoners suggested that prisoners seek access to medical care to exert control over their lives, where they have little.[152] Self-management interventions have been shown to reduce health care utilization[153] and may have the potential to restore patient's sense of control by diffusing CVD-RF management back to patients. This concept is similarly reflected in Barlow et al.'s comment that "[s]elf-management may be one means of bridging the gap between patients' needs and the capacity of health and social care services to meet those needs."[86]

Provider-Level Recommendations

At a provider-level, the medical and correctional roles of medical providers in prison should be clearly delineated. Dual loyalty is a concept that is common in the human rights literature and has been applied to describe the competing roles that medical providers fill in prisons to force feed prisoners who undergo hunger strikes or to certify that prisoners are "mentally fit" for imprisonment.[154] Many prisoner advocates support "an uncompromising separation of medical roles in prisons,"[154,155] and our findings support this separation, especially in an effort to realign patient-provider partnerships with best practices for chronic care and to improve patient perceptions of care in prison. Our study demonstrated that these conflicting roles were exerted in various ways, as

medical providers assumed responsibilities to administer formal sanctions and become gatekeepers for non-medical privileges.

Providers administered formal correctional sanctions, like solitary confinement or tickets, for medication non-adherence. These punishments not only reinforced patient experiences as prisoners, but also diminished autonomy for self-care. While Stoller et al. described how providers barred one patient from performing her prison job because of non-adherence to psychiatric medications,[105] our study, to our knowledge, is the first to report that providers sent patients to solitary confinement for non-adherence to medications, in this particular case for insulin. Medical providers undoubtedly face numerous ethical and administrative challenges in the correctional setting,[154,155] yet studies have repeatedly demonstrated adverse physical and psychiatric consequences from the use of solitary confinement.[156] Punishment for medication non-adherence violates the notion of provider non-maleficence and may in fact be counter-productive. Participatory approaches that engender patient trust and foster communication between patients and providers are suggested to most effectively cultivate adherence.[157-159] Therefore we recommend that formal sanctions for medication non-adherence be eliminated from correctional settings primarily for ethical concerns, but also because more effective evidenced-based alternatives exist[159,160] and may be applied in prisons to encourage adherence behaviors.

Participants also perceived that providers were suspicious about patient malingering, an assumption that is well documented in the correctional literature.[161,162] In fact, providers in prison are taught to recognize the signs of "invented illness."[163] One chart review of diabetic complications in prisoners in New Zealand revealed high rates of

self-induced hypoglycemia. [164] While provider suspicions were in some cases valid, we posit that preoccupation with malingering may stem from systemic problems in the prison health care system. Providers were gatekeepers for many resources in prison, medical and non-medical.[114] Patients may learn to seek out a provider for secondary gain, like bunk status or diet orders, because that was often the provider's function. Similar to pseudo-addiction, when under-treatment of pain contributes to pain-seeking behaviors that mimic addiction behaviors,[165] patients in prison may engage in excess health-seeking behaviors for secondary purposes or even for necessary chronic care follow-up care that is under-addressed due to delays in access to care or co-pays. These health-seeking behaviors may mimic malingering, but are, in essence, pseudo-malingering. As a result, we extend our recommendations that medical providers cease to perform these gatekeeping functions in order reduce pseudo-malingering in the prisons.

Additionally patients perceived that protocolized care undermined collaboration to individually tailor care. Participants identified several possible limitations to these types of interactions. First, providers had too many patients to adapt care and engage in disease-based discussions. Second, there was an absence of provider willingness to collaborate with patients. Third, care protocols limited provider flexibility. While these characterizations were patient suppositions, these perspectives underscored that care discussions can be improved in the correctional setting. Models for chronic care emphasize changing relationships with providers that steer away from paternalistic models towards patient-centered ones.[72] Through collaborative care discussions, providers and patients establish care plans that are feasible for individual patients and have been shown to improve self-management practices and clinical outcomes.[166]

Correctional settings should encourage providers to engage in patient-centered care discussions and consider amending care protocols to facilitate tailoring care to individual patients.

Patient-level Recommendations

At the patient level, a deeper understanding of current patient-level self-management practices and informal educational opportunities can enable correctional settings to develop interventions to scale up these practices. Experts estimate that 95% of care for chronic conditions occurs outside of the clinic setting.[167] In prison, however, patients' self-care was subject to correctional oversight, which impairs self-management,[92] self-monitoring,[121] and coping strategies[149] for CVD-RF. These practices, while difficult to promote, are feasible in prison. A randomized control trial demonstrated that adherence to self-administered HIV medications in prison is comparable to that administered in medication line.[168] Self-administered medications have the added benefit of minimizing breaches of confidentiality, being more tolerable to patients, and potentially teaching self-management strategies that can be used upon release.[119,169,170] Similarly, none of our participants were permitted to self-administer their insulin and felt unprepared to care for their diabetes on release. Based on these findings, we recommend that prisons implement interventions that teach self-management practices, diffuse self-care responsibilities to patients, and encourage providers to deliver feedback to reinforce these practices.

In the outpatient community, self-management education and support is increasingly being diffused outside of the medical setting. Computer-based education and self care reminders sent via cell phones or texts messages have proven effective, but

are not accessible in correctional contexts.[171-173] Instead, study participants highlighted the endogenous resources of the correctional setting, including prisoner peers, family members on the outside, and sometimes correctional officers.

Peer-to-peer and group based education has the potential to deliver effective self-management support in prisons. Community interventions that employ lay health workers to deliver self-management interventions are equivalently effective as interventions led by medical providers.[87,174,175] Qualitative studies have shown that prisoners preferred peer educators to medical educators.[176] Peer-led models for HIV+ education are common and shown to improve disease outcomes in prison and post release.[177] Our participants reported that they were able to ask peers, encountered in medication line or on the units, about information for medication and disease prevention. Given the evidence of feasibility in prison and acceptability to patients, correctional facilities may consider formalizing these moments of peer-to-peer education by designating and/or training peer educators,[178] who have the knowledge and skills to provide reliable and trusted information about CVD-RF and management.

Our participants endorsed positive experiences with group-based education. Peer-led support groups, like Alcoholics Anonymous and Narcotics Anonymous, are abundant in the correctional setting, do not require additional resources, and provide emotional support/coping.[179] Similarly prisons could create disease-based groups for self-management strategies, like coping and self-efficacy support, without necessitating a medical facilitator. Meta-analyses demonstrate that self-management interventions that include group-based teaching foster better hypertensive control than those without.[87] Therefore, facilitated group programming, like those that have been designed for HIV+

prevention, could be adopted for CVD-RF self-management. Similar to one's participants experience with the Women Overweight program, the group-based programs are likely to be more effective, if they emphasize self-management skills specific to the correctional setting, like food choice in commissary or chow hall.

Our participants also reported that they were able to learn about and cope with their chronic conditions through interactions with family members (over the phone) and with COs. Studies have posited that the "prison code" to suppress outward displays of weakness or illness can limit substantive interactions with fellow prisoners.[180] In this vacuum, families may provide a critical role in educating prisoners about their disease practices.[111,173,181] Many studies have suggested that COs may play a "care-giving" role in prisons to educate or support patients.[112,182] While this role may complicate the correctional and medical roles that COs fill, several studies have demonstrated the COs may be instrumental in reducing suicides in prison units.[183,184] Similarly, COs could be taught critical skills to recognize and respond to patients with diabetic complications.

Finally, prisons should look to patients to design future interventions and improve care in the correctional setting. Our participants developed informal self-care practices, like storing sugar packets in their cells to treat hypoglycemia, and these practices should be studied and formalized, if effective. Similarly, a Canadian prison used community-based participatory research approach to eliciting prisoners' ideas to design a primary care intervention that educated prisoners and COs about health.[182]

Communication is a key domain of self-management that is largely unaddressed in the correctional literature; yet our participants often relied on filing grievances or outside family intervention to access needed follow-up for their CVD-RFs. These barriers

left patients feeling neglected, which complicated current and future relationships with medical providers. Medical systems in the community proactively address patient satisfaction through patient surveys and advisory boards, and one prison in Switzerland incorporated a health hotline on prison units to bridge communications between prisoners and medical units.[170] We recommend that correctional systems should consider how to elicit feedback from patients in prison about management of their chronic conditions, in order to systematically improve care delivery and minimize grievances and distrust.

This qualitative project captured a breadth of perspectives from a racially diverse cohort of men and women with many CVD-RFs, released from a variety of correctional settings in Connecticut. Based on these participants' unique experiences managing CVD-RF in prison, we aimed to produce actionable recommendations to improve CVD-RF management in prisons (Table 4. Recommendations to Improve CVD-RF Management in Prisons). Both anecdotal and empirical findings have demonstrated that correctional settings have the opportunity to improve health outcomes and "act as a stabilizing and restorative force" for vulnerable patients.[185] At present, however, this opportunity is under-utilized, and patients released from prison face many challenges that impede CVD-RF self-management practices.[131] Therefore, correctional institutions should evaluate not only the effectiveness and safety of these interventions in prisons, but also how these practices may facilitate transitions of care and improve CVD self-management in the critical post-release period.

Table 4. Recommendations to Improve CVD-RF Management in Prison

Theme and Sub-themes	Recommendations
I. Access to care for chronic conditions was present, yet complicated in the correctional setting	
Patients with chronic conditions defaulted to sick call for chronic care, health education, and follow-up.	Shift medical care delivery paradigm from acute care visits to proactive, routine chronic disease monitoring.
Co-pays created a two-tier system for access to medical care	Follow NCCHC guidelines to remove co-pays from correctional health care.
Correctional Offices acted as gatekeepers to medical visits	Educate COs about medical triaging.
Some patients reported good follow-up care for chronic conditions via sick call	Study and emulate these practices to improve care for CVD-RF management in other prison.
II. Patient-provider partnerships can be undermined by providers' competing correctional and medical roles	
Providers often face dual loyalty.	Separate medical and correctional roles.
Providers exerted punishment for medical non-adherence.	Remove sanctions for medication non-adherence
Patient's report that providers are suspicious of malingering	Pseudo-malingering may result from medical provider's gatekeeper roles. Remove non-medical permissions.
Medical protocols limited collaboration with patient to tailor care to individual patients.	Encourage providers to engage in patient-centered collaborative care discussions. Amend protocols for chronic care to facilitate these discussions.
Health programming that integrated prisoner peers were positive aspects of care.	Fill gaps in health education through interventions, like group programming and peer-educator training.
III. Informal support systems can improve self-management education and skills development	
Peer prisoners and family member were frequent sources of education about disease, medications, and self care practices.	Designate or train reliable and informed peer educators for certain chronic conditions.
Peer prisoners provided emotional support and coping in prison.	Support informal education by allowing peer-led groups (i.e. AA or NA model) for chronic conditions.
COs educated patients about their conditions on the unit.	Consider ways to use COs to enhance self-management practices.
IV. The trade-off between prisoner security and patient autonomy influenced opportunities for self-management	
Due to security constraints, patients did not learn medication administration techniques or self-monitoring skills.	Teach and allow patients to inject insulin or measure blood sugar/blood pressure in a supervised environment. Ensure that all newly diagnosed diabetics learn these key skills.
Prisons varied on whether medications were KOP or administered in med line.	Default to KOP, unless medications have potential for misuse or barter.
Patients developed unique practices to manage complications in prison.	Study how patients successfully self-manage chronic conditions in prison and formalize these practices.
Patients used the grievance system or leveraged family members to advocate for better medical care.	Consider ways to systematically improve communication between patients and medical system.

Limitations

Our findings should be interpreted in light of several limitations. First, our participants represent a relatively small sample released from prisons in Connecticut. Therefore, the study findings may not be transferable to other prisons,[143] but should instead serve as a guide for potential ways to improve CVD-RF care. Second, we interviewed participants within the first 6 months post-release and as a result, our findings may be limited due to recall bias. We believe that this recall bias has been limited to the extent possible, as the average time to enrollment was 76 days after release. Third, many participants were engaged in primary care, which reflects a narrow sample of releases, and many participants were patients under the care of members of the coding team. Although participants' views may be subject to social desirability bias, the relationship may also be an asset to framing honest discussions about patients' health care experiences. Finally, our coding team was composed of Asian American and white women from an academic medical center. Although this does not reflect the racial and ethnic diversity of participants, we note that the team routinely considered these dynamics through reflexivity.

Future Directions

As was mentioned in the preface, this thesis represents a portion of a longitudinal mixed methods study to assess KABP in patients recently released from prison in order to identify predictors of cardiovascular outcomes. We have completed iterative data collection and analysis from baseline interviews. Several unifying categories emerged in these interviews, including how prison influences self-management practices (presented in this thesis), health efficacy, and social capital formation. In the next steps, we plan to develop the themes that emerge from the latter two categories. Our ultimate goal is to develop a ground theory guided by the socio-ecological model for CVD-RF management in the correction setting that may be used to conceptualize and implement interventions in prison.

Additionally, as we continued to collect data from the quantitative strand, we realized that we were missing a key opportunity to explore how poor CVD outcomes develop in the post-correctional setting. When we conducted baseline interviews, we assessed in-prison management of these conditions, but patients were not able to reflect on their full illness trajectory in the post-correctional setting. We amended our IRB to explore these perspectives in patients who had worsening clinical measures of their CVD-RF. We will integrate these quantitative and qualitative strands to contextualize poor disease outcomes in our qualitative themes and KABP measures.

Conclusion

Correctional policies pervaded opportunities and interactions with providers for CVD management, which undermined care delivered by providers and patients' education and skill development. Our findings point to important areas for future interventions and research to develop effective self-management practices for CVD-RF in correctional settings. Assessment of these interventions should not only measure concrete outcomes for self-management, patient education, and chronic care delivery but also evaluate outcomes upon release, where knowledge gaps about the consequences of prison CVD-RF management are greatest.

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[i] The "block" is the cellblock where prisoners lives and spends most of his time.
[ii] Participants received money from a nominal wage in prison jobs or from friends and family members in the community who deposited money into prison bank accounts.
[iii] A ticket is a penalty in prison. The consequences of getting a ticket are cumulative and varied, ranging from a loss of recreation time (and other privileges), solitary confinement, or delayed parole.
[iv] The med line is the medication line, where prisoners wait for prison-administered medications (most often controlled substances).
[v] Commissary is the prison general store. Prisoners can purchase toiletries and packaged snack foods here.
[vi] A "unit" refers to area where prisoners' live and spend most of their time in prison cells. A unit is also referred to as a "block."
[vii] A "block officer" is a correctional officer who is assigned to guard a particular unit or block.

[ix] Rec is recreation time. Prisoners typically get a minimum of one hour of recreation time in the prison yard or in the gym a day.