

# Incarcerated Individuals' Perspectives on Living with Serious Illness

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## ABSTRACT

The object of this study was to elicit patient perspectives on the experience of living with serious illness while incarcerated. The study was conducted at the Rhode Island Adult Corrections Institutions (ACI) in both the men's medium security and women's (all levels) facilities in June of 2016. Semi-structured interviews were conducted with participants, who met study criteria for serious illness. Interviews were coded following the template organizing style. Eighteen participants were enrolled, 13 males and five females with majority Caucasian (n=11) and ages 40-59 (n=9). Incarcerated individuals with serious illness perceived diverse healthcare deficits, including access to care, quality of care, and accommodations for medical needs and physical disabilities. Deficits were somewhat mitigated through prison programs and support from community advocates. The findings of our study support a quantitative needs assessment of available physical accommodations in prisons, national standardization of what constitutes adequate care, and reevaluation of the prison co-pay system.

**KEYWORDS:** correctional health care, incarceration, chronic illness, user's views, qualitative research

## INTRODUCTION

The United States incarcerates a higher proportion of its population than any other country in the world. Although the nation has less than 5% of the world's population, it is home to 25% of the world's incarcerated individuals.<sup>1</sup> One rapidly growing subset of the incarcerated population is individuals over the age of 55. Since 1990 the number of incarcerated individuals over the age of 55 has doubled, bringing with them a high prevalence of chronic illness.<sup>2,3</sup> Approximately 40% of the incarcerated population suffers from at least one chronic medical condition, with a higher rate of diabetes, hypertension, and asthma than their non-incarcerated counterparts.<sup>4</sup> All incarcerated individuals are legally guaranteed health care "at a level reasonably commensurate with modern medical science and of a quality acceptable within prudent professional standards."<sup>5</sup> This requirement places pressure on the penal system to provide community equivalent health services in an environment historically built for the purpose of punishment.<sup>6-8</sup>

Existing research on illness among incarcerated individuals has identified multiple factors that complicate the delivery of health services in prisons, including security protections for providers, formulary and other limitations on medications available to providers and their incarcerated patients, co-pays for often indigent prisoners, and overcrowding with limited resources for an increasingly large population.<sup>7-11</sup> However, there is a paucity of data analyzing the prisoner perspective on the quality of and barriers to care provided in this setting. The critically important voice of the seriously ill incarcerated individual is largely missing from prison health research despite being the most important stakeholder perspective.<sup>12</sup>

Through interviews with inmates with serious illness, this study seeks to understand the experience of seriously ill, incarcerated individuals and how the prison system in one state meets or fails to meet the healthcare needs of these individuals.

## METHODS

This study was conducted within The Rhode Island Adult Corrections Institutions (ACI) in the men's medium and women's (all security levels) facilities. In June and July of 2016, the principal investigator (PI) conducted semi-structured oral interviews with seriously ill, incarcerated individuals. Participants were eligible for the study if they had a chronic serious illness, defined as "permanent or long-term conditions (such as Amyotrophic Lateral Sclerosis (ALS), Chronic Obstructive Pulmonary Disease (COPD), or cancer), chronic conditions requiring complex treatments (including chemotherapy or dialysis), and/or chronic conditions requiring recurring inpatient care in a hospital setting (such as congestive heart failure)." These criteria were developed to capture participants with chronic, serious illness who have frequent interactions with the prison health care system.

### Participant Recruitment

All primary care practitioners working in the prison facilities were briefed on the study and asked to refer eligible individuals using a permission-to-be-contacted sheet. Contact sheets were collected until providers no longer had additional referrals. Prior to beginning the interview, informed consent was obtained and participants were assured of confidentiality.

### Interviews

Interviews were single sessions conducted in a clinical suite without prison or medical staff present, and were audiotaped

without including any identifying information. Questions for the interviews were designed to elicit participants' experiences with, perceptions of, and attitudes toward the health care system while incarcerated. The questions focused on concepts of autonomy, access, and quality, as identified in prior studies.<sup>7,8</sup> The interview guide was reviewed and approved by both the medical director of the prison system, and a human rights lawyer with extensive experience in prison health. The guide was composed of eleven open-ended questions. Each participant was asked these core questions, followed by unscripted questions for clarification or to probe more deeply into participant answers.

### Data Analysis

Data was analyzed following the template organizing method.<sup>13</sup> A codebook was created based on an initial literature review, interview questions, and preliminary scanning of the text, and was then used to assign codes to interview transcripts. Interview transcripts were analyzed and segments were assigned relevant codes. The two authors coded groups of three transcripts independently and met to reconcile inconsistencies as well as add, remove, or refine codes. This process was repeated until all transcripts had been coded. After completing the coding process, focused coding was used to group codes into largest segments, identify relationships between segments, and then derive overarching themes.

This study was approved by the Institutional Review Board of Brown University and the prison system's Medical Review Advisory Group.

## RESULTS

### Participant characteristics

A total of 18 interviews were conducted, 13 identified as male and five female. Participant decade of life ranged from 20s–80s, with the greatest number of participants (9 out of 18) between 40–59. Participants' self-reported medical conditions were diverse; the most common included cancer, poorly controlled/complicated diabetes, and severe mental health conditions requiring frequent hospitalization (Table 1). Interviews ranged in length from 10:09 to 48:18 minutes, with an average length of 27:03 minutes.

During interviews, three major themes emerged: accommodations, access to care, and quality of care.

### Theme 1. Accommodations

Multiple participants discussed the availability of appropriate accommodations for their illness or disability, particularly those related to structural deficiencies of the physical environment.

Based on participant comments, the physical structure of the prison was not equipped to accommodate numerous inmates with physical limitations. Many participants with impaired ambulatory conditions had trouble navigating the prison facilities. For example, accessing bathrooms and showers was a common challenge. Most importantly, the need for handicap accessible cells far outstripped the supply. One inmate summarized the discrepancy:

"The biggest problem is this facility holds 1200 people

**Table 1.** Participant Characteristics

Baseline Characteristics	Number of Participants (n=18)
<b>Gender</b>	
Male	13 (72%)
Female	5 (28%)
<b>Age</b>	
20-39	4 (22%)
40-59	9 (50%)
60-79	4 (22%)
80 or >	1 (6%)
<b>Race/Ethnicity</b>	
Caucasian	11 (61%)
Hispanic/Latino	2 (11%)
African American	4 (22%)
Other	1 (6%)
<b>Medical Condition<sup>a</sup></b>	
Amyotrophic lateral sclerosis	1 (6%)
Cancer	3 (17%)
Chronic osteomyelitis	1 (6%)
Congestive heart failure	2 (11%)
Chronic obstructive pulmonary disease	1 (6%)
Diabetes mellitus	3 (17%)
Epilepsy	2 (11%)
Inflammatory bowel disease	1 (6%)
Severe Mental Health Condition	3 (11%)
Other	2 (11%)

<sup>a</sup>Includes multiple conditions for each patient if present, percentage indicates percent of total study population

and there are only two handicapped cells in the whole place. I was fortunate to get one of them, but there are other people here that have similar disabilities like me and cannot get the same level of care."

Inmates requiring higher levels of care can elect to have a fellow inmate serve as a 'caretaker.' Caretakers were paid by the prison to provide a broad range of services, including transporting wheelchair-bound participants around the large facility. Caretakers also assumed greater care for their fellow inmates by becoming cellmates.

### Theme 2. Access to Care

Multiple factors, including cost, wait times, social supports, and a lack of health-related educational materials influenced inmates' ability to access appropriate health care.

#### Cost

Participants focused on two distinct forms of cost related challenges: 1) prison cost-saving policies, and 2) co-pays for medical visits as a financial burden. Many participants felt that cost was the prison administration's largest barrier to

providing medically-indicated pharmaceuticals or assistive devices such as canes or walkers. Some described being denied their previously prescribed medications upon prison entry. Substitute prescriptions were often considered by the participants to be less effective or inferior. Due to cost, participants also struggled to access devices including outdoor wheelchairs, lumbar support pillows, and night guards.

"I grind my teeth at night. I have told [the provider] I grind my teeth at night, I need a night guard. Night guards cost a lot of money and he doesn't want to order me a night guard. He is telling me put a towel between my teeth or something crazy."

Seven of 18 participants specifically mentioned co-pays, charged by the prison, as a barrier to care. Generally, co-pays are charged for medical visits, medications, and trips to outside appointments, and range in price from \$3 to \$6. There are several exemptions for which the co-pay requirements are waived, including emergency services, initial intake physical, immunizations, dressing changes, visits initiated by medical staff, yearly dental cleaning, and prenatal care. Multiple participants, who predominantly relied on wages from prison jobs (\$1–3 dollars per hour) for income and amenities, reported deferring care due to the co-pay. However, individuals with outside sources of income, primarily from family members depositing money into prison accounts, did not perceive co-pays as a significant barrier.

#### Wait times

Many participants discussed long wait times and delays for in-prison medical care and outside visits to specialists, particularly for non-emergent chronic care or specialty health care needs. To access healthcare services, an incarcerated individual would "put in a slip" to the medical unit and wait for their name to appear on a "med unit list" indicating they would be seen that day. Inmates described wait times for non-urgent needs ranging from a few days to a few weeks. Non-urgent specialty appointments took even longer given the need for a minimum number of patients before an outside specialist would come to the prison. However, even though inmates were frustrated with wait times, many voiced an understanding that delays were inevitable and providers were doing their best given the limited resources.

"You got to understand, there is 1200 guys here so you know things don't just happen at the snap of a finger. But with a little bit of patience, you will get whatever treatment you need done."

#### Health Information

Due to security concerns, inmates had access to medical literature available in the library, but could not freely access the Internet or outside books. Inmates relied on providers and family members for information related to their illness. Some participants described apathetic providers who ignored requests for health education, while others described positive experiences with providers who worked to educate them about their illness.

"She [my NP] will go over anything you want to go over and she is very helpful in pointing out side effects and advantages and disadvantages; she will give you the total lowdown of any situation."

Family members often served as sources of medical information, financial supports, and essential advocates for accessing necessary medical accommodations. One participant described the importance of her family supports:

"They try to do whatever they can. They have called here. Like I said, now they are calling lawyers. They do whatever they can for me. If I have a problem, I call them. Because I got nowhere else to turn, no one is going to listen."

#### Theme 3. Quality

Some of the factors impacting the perceived quality of healthcare in the prison were 1) the quality of healthcare providers, 2) limited choice of providers and 3) inadequate pain management.

Participants' health care teams often changed due to high provider turnover; participants commented on discrepancies in quality of care between different providers. Well-regarded providers were those who were perceived to be patient-centered and knowledgeable.

"She was thorough. She listened to me. She tried everything she could to help me. She treated the whole person. She was really, really good. The best doctor I have ever had."

Conversely, participants considered providers to be of poor quality if they were perceived to be primarily concerned about cost or were perceived to be burnt out. This perceived poor quality was compounded by the limited number of providers available to inmates.

Ineffective pain management also impacted perceptions of quality for multiple inmates. One common experience among participants was the transition from their community pain regimen when entering prison:

"Yeah, they cut out a lot of the meds...dealing with the pain, you just tough it out. I mean they are giving me some [pain meds], but very little. There is a huge difference, I mean I was on a lot of pain meds on the outside."

#### DISCUSSION

Our study contributes important qualitative data to the understanding of the seriously ill, incarcerated individuals' lived-experience. Study participants perceived deficits across multiple healthcare domains, including access to care, quality of care, and medical accommodations. Many participants experienced substantially limited healthcare resources in prison, including inadequate structural accommodations and limited access to healthcare staff.

Importantly, the findings of our study highlight that both prison authorities and incarcerated individuals need to rely on third parties to mitigate the larger structural and bureaucratic barriers that impact healthcare delivery. In prison, authorities hire other incarcerated individuals, or "caretakers," to transport immobile, seriously ill inmates across penitentiary grounds, or to serve as caretakers for those with conditions in need of monitoring, including epilepsy. These "caretakers" are largely considered a positive component to participants' care. Incarcerated individuals also benefit from social supports outside of prison who would advocate on their behalf for items such as outdoor wheel chairs and drugs that were not on the formulary. With legal requirements

to provide a community standard of care for incarcerated individuals,<sup>5</sup> third parties appear to be one means through which prison authorities attempt to fill gaps in services and incarcerated individuals can obtain the care they need. Our study supports prior research findings that seriously ill inmates face multiple barriers to receiving care that meets their health needs. These include co-pays, long wait times, and prison facilities that offer inadequate accommodations for illness-related needs.<sup>8,14</sup> To keep up with a growing population of aging and chronically ill inmates, prisons would ideally need to design or retrofit facilities that accommodate the complicated serious diseases of incarcerated individuals. This is an expensive proposition that is unlikely to happen without external incentives including legal challenges based on the Americans with Disabilities Act, among other laws that have been successfully used to change prison policy and practice. Also, further efforts could be made to expand and utilize polices including those that facilitate the medical release of elderly and terminally ill inmates.<sup>15</sup> In the interim, given the enormity of undertaking large structural changes, expanding alternative programs such as the “caretaker” model where able-bodied prisoners provide simple services to inmates who have special care needs could provide immediate and widespread benefit. Additionally, prior studies suggest that interventions designed to empower patient autonomy through self-directed education, peer education, or group education visits can benefit incarcerated individuals.<sup>8,16</sup>

## LIMITATIONS

There are several limitations to consider when interpreting this study. First, the study took place in a single state that uses a unified system for all incarcerated individuals; its conclusions may not be generalizable to other facilities that utilize a dual system (with separate prisons and jails). However, given that this is a novel qualitative study, it provides information upon which future studies could expand. Second, the study has a small sample size, with heterogeneous gender and disease status. Prior research has focused on single genders and diseases; more research is needed to examine the population of seriously ill incarcerated individuals.<sup>8,12</sup>

## CONCLUSION

To summarize our findings, incarcerated individuals with serious illness face numerous challenges including poor accommodations, long wait times and prohibitive costs while incarcerated, and rely on programs such as peer caretakers and advocacy from family members to meet their health care needs.

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