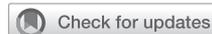


## Brief Report

# “No One Wants to Die Alone”: Incarcerated Patients’ Knowledge and Attitudes About Early Medical Release



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## Abstract

**Context.** Deaths among incarcerated individuals have steadily increased in the U.S., exceeding 5000 in 2014. Nearly every state has a policy to allow patients with serious life-limiting illness to apply for release from prison or jail to die in the community (“early medical release”). Although studies show these policies are rarely used, patient-level barriers to their use are unknown.

**Objectives.** To assess incarcerated patients’ knowledge of early medical release policies and to identify patient-level barriers to accessing these policies.

**Methods.** A cross-sectional survey of 46 male patients in two state prisons and one large urban jail who had visited a primary care provider at least three times within three months was conducted.

**Results.** Participants’ average age was 64 years, and 89% had more than one chronic illness. Fewer than half (43%) demonstrated the knowledge needed to apply for early medical release and 22% demonstrated no relevant knowledge. Participants with sufficient knowledge were significantly more likely to endorse anxiety (35% vs. 0%,  $P = .003$ ) and loneliness (65% vs. 30%,  $P = .017$ ).

**Conclusion.** Many medically complex incarcerated patients in this study did not demonstrate sufficient knowledge to apply for early medical release suggesting that patient education may help expand access to these policies. Moreover, seriously ill patients with knowledge of early medical release may benefit from enhanced psychosocial support given their disproportionate burdens of anxiety and loneliness. Our findings highlight the pressing need for larger studies to assess whether improved patient education and support can expand access to early medical release. *J Pain Symptom Manage* 2019;57:809–815. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

## Key Words

*Prison, serious illness, palliative care, complex care, vulnerable populations*

## Background

The number of deaths among incarcerated people in the U.S. has increased every year that the Bureau of Justice Statistics has tracked these data and now exceeds 5000 annually.<sup>1</sup> Nearly nine in 10 (88%) such deaths are due to medical illness (most commonly cancer, heart disease, or liver disease), reflecting the rapid aging of the incarcerated population.<sup>2</sup> Despite these trends, palliative care services are typically

limited in jails and prisons and most correctional facilities are not optimally designed to provide community-standard patient-centered care for patients with life-limiting illness.<sup>3</sup>

The growing population of incarcerated patients of advanced age or with serious illness has brought renewed attention to policies originated during the AIDS epidemic that allow some patients to apply for early release from prison or jail to receive care and

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die in the community (“early medical release”). These policies vary by jurisdiction but generally fall into two categories: “compassionate release” for patients with a terminal illness and “medical parole” for gravely ill or disabled patients who have high-intensity nursing care needs but may live for years in a state of poor health. In addition to medical criteria, many early medical release policies set a minimum age for eligibility and all require a multistage review process during which criminal justice officials consider additional factors such as the length of sentence served and the patient’s estimated public safety risk.<sup>4</sup>

Early medical release policies are a critical component of care planning for incarcerated patients with serious life-limiting illness. They also aim to reduce the high costs of incarcerating seriously ill patients and are associated with very little public safety risk; recidivism rates for those receiving early medical release are 3.5% compared with 41% for former prisoners overall.<sup>5</sup> Yet early medical release is profoundly underutilized.<sup>6</sup> Two recent reports found that early medical release applicants were approved at rates of 3% (2621 requests) and 7% (3030 requests) in samples of federal and state prison populations, respectively.<sup>7,8</sup> Although many unsuccessful applications for early release are rejected, some patients die while their application is pending. Several studies and government reports suggest that flawed medical eligibility guidelines, unclear procedures, and failure to adequately train and empower medical providers all play a role in the underutilization of these policies.<sup>6,9,10</sup> To date, however, patient-level barriers to early medical release have not been studied. To address this knowledge gap, this study assessed knowledge and attitudes regarding early medical release among incarcerated patients with high medical needs.

## Methods

### *Study Design and Sample*

This cross-sectional, in-person survey study enrolled 46 incarcerated men in two state prison systems and one large urban jail. Study eligibility included speaking English and having seen a correctional physician at least three times in the three months before participation. Three or more physician visits in three months were used to identify patients with serious illness without disclosing health status as a reason for their invitation to participate in the study. This study was part of a larger research project on advance care planning in correctional settings. Only men were enrolled in this study because men represent 93% of the incarcerated population<sup>11</sup> and including additional facilities to enroll women was beyond this study’s scope.

The Chief Medical Officer at each facility was given the aforementioned criteria and referred potential participants to study researchers who then approached each individual to gauge their interest in the study. For those who expressed interest, consent was obtained using the teach-to-goal method, which has been used in correctional research and described elsewhere.<sup>12,13</sup> All interviews were conducted in a private room. The questionnaire included closed-ended and Likert scale questions and several open-ended items. Responses to open-ended questions were transcribed by interviewers (recording devices were not permitted in the facilities).

Consistent with relevant federal regulations and ethical considerations, participants were compensated for their time with \$10 deposited to their commissary account.<sup>14</sup> The Human Research Protection Program at the University of California, San Francisco, approved this study.

### *Measures*

*Sociodemographic and Criminal Justice Factors.* Self-reported sociodemographic characteristics included age, race, and educational attainment. Risk of post-release homelessness was assessed using the question: “If you were released tomorrow, would you have someone to stay with or would you be homeless?” Criminal justice factors included whether participants were serving a life sentence and the number of years incarcerated.

*Health Conditions.* Self-rated health was measured using a validated item from the SF-12 that has been used with other vulnerable populations.<sup>15</sup> Chronic conditions were assessed by self-report using questions from the nationally representative Health and Retirement Study.<sup>16</sup> Self-report of medical conditions is well validated in older and medically vulnerable populations, including individuals who are homeless.<sup>17</sup> Serious mental illness was defined as a diagnosis of any major depressive, manic, or psychotic disorder using the Bureau of Justice Statistics definition.<sup>18</sup> Positive screens for depression and anxiety were defined as a score of 4 or higher on the Patient Health Questionnaire-2 and Generalized Anxiety Disorder-2 scale, respectively.<sup>19</sup> Cutoffs of 4 were used to improve specificity (compared with the standard cutoff score of 3) in acknowledgment of the known stressors of living in the unique correctional setting.

*Geriatric Conditions.* Geriatric conditions included multimorbidity (having two or more chronic medical conditions) and functional impairment (reporting difficulty with one or more activities of daily living [dressing, bathing, eating, transferring, and toileting]). Participants were also asked if they had experienced

a fall within the past month and if any reported fall resulted in an injury requiring medical treatment. Loneliness, a risk factor for premature mortality and depression, was measured using the validated three-item loneliness scale.<sup>20</sup>

*Social Determinants of Health.* Social factors included health literacy (a response of somewhat or less to "How confident are you filling out medical forms by yourself?"),<sup>21</sup> poor trust in correctional health care providers (selecting "You do not trust the prison health care staff" as a factor influencing communication with their provider), and lack of social support inside and outside of prison/jail (defined as having no friends or family or having friends or family who could be relied on for a serious problem only "some," "a little," or "not at all").

*Knowledge of Early Medical Release.* "Early medical release" policy was defined as any state or correctional policies that provide for early release from prison/jail for serious life-limiting illness or grave physical disability. Knowledge of early medical release was defined as demonstrating the minimum information needed to make use of the policy, including knowing that it 1) is a policy to provide early release for medically eligible individuals and 2) can be requested by speaking with a correctional medical provider, correctional official, or legal counsel. Knowledge was assessed using two closed-ended and four open-ended questions:

- "Have you ever heard of compassionate release, early medical release, or medical parole?"
- "Do you know what compassionate release or early medical release or medical parole is?"
- "What have you heard about it?"
- "How would you describe it?"
- "Who can be released from prison through [these] policies?"
- "What does a prisoner need to do to start the ... process?"

Participants were then read a definition of early medical release for subsequent questions.

### Analysis

Sociodemographic, health, geriatric, and social determinants of health factors were analyzed using descriptive statistics. Knowledge of early medical release policies was determined by consensus of three researchers based on responses to the aforementioned six questions. Chi-squared tests were used to identify associations between knowledge of early medical release and sociodemographic, health, geriatric, and social factors. Study data were collected and managed using REDCap electronic data capture.<sup>22</sup>

## Results

During the study period, 54 people in prison or jail were referred to researchers by health providers. Of these, six (11%) declined and four (4%) could not provide informed consent using the teach-to-goal method, resulting in a final sample of 46 participants.

### Participant Characteristics

Participants had an average age of 64 years; 63% were white, 17% black, and 10% Native American or Alaskan Native. One in three (33%) were serving a life sentence (Table 1).

Most (65%) reported being in poor or fair health and most (89%) had more than one chronic health condition (Table 1). More than one in three (37%) reported activities of daily living impairment(s). Loneliness (50%) and lack of social support inside prison/jail (67%) were common while 20% had a positive screen for anxiety. Thirty-seven percent of participants reported low health literacy, and 46% expressed poor trust in their correctional health care providers.

### Knowledge of Early Medical Release

Fewer than half of participants (43%) demonstrated the knowledge needed to request early medical release. Of the 26 participants who did not have adequate knowledge, 15 (33% of the overall sample) demonstrated partial knowledge of early medical release, including 13 (28% overall) who understood the medical release policy but did not know how to start the process (Fig. 1). The remaining 10 participants could not accurately describe early medical release policies.

### Patients Perspectives on Early Medical Release

Approximately three in four (76%) participants said they would want to apply for early medical release if they were seriously ill. The most common reasons cited were to die surrounded by friends and family and the belief that they would receive better care in the community. Among those who said they would not seek medical release if seriously ill, the reason most commonly given was that they believed they were ineligible based on criminal justice factors (e.g., due to a life sentence without the possibility of parole). A small number believed that early medical release was not actually granted to applicants and so perceived that any application would be fruitless (Table 2).

### Characteristics Associated With Medical Release Knowledge

A positive screen for anxiety (35% vs. 0%,  $P = .003$ ) and loneliness (65% vs. 30%,  $P = .017$ ) were each significantly associated with having knowledge of early

Table 1  
Participant Characteristics According to Early Medical Release Knowledge<sup>a</sup>

Baseline Characteristics	All (N = 46)	Early Medical Release Knowledge, n = 20	No Early Medical Release Knowledge, n = 26	P-value
Age (mean, SD)	64.2 ± 9.8	63.2 ± 9.6	65.8 ± 10.2	.381
Location				
State Prison System 1	15 (33)	9 (35)	6 (30)	.080
State Prison System 2	21 (46)	8 (31)	12 (60)	
Major City Jail	10 (22)	9 (35)	2 (10)	
Race/ethnicity				
African-American	9 (20)	3 (15)	6 (21)	.391
White	29 (63)	14 (70)	15 (52)	
Latino/Hispanic	1 (2)	0	1 (3)	
Asian	1 (2)	0	1 (3)	
Native American/Alaska Native	5 (11)	3 (15)	2 (7)	
Other	1 (2)	0	1 (3)	
Education < high school	6 (13)	5 (19)	1 (5)	.212
Post-release homelessness risk	12 (26)	7 (27)	5 (25)	1
Self-rated health poor or fair <sup>b</sup>	30 (65)	18 (69)	12 (60)	.515
Criminal Justice Factors				
Life sentence	15 (33)	5 (19)	10 (50)	.055
Years incarcerated <5	21 (46)	14 (54)	7 (35)	.203
5 or more	25 (54)	12 (46)	13 (65)	
Chronic Health Conditions				
High blood pressure or hypertension	31 (67)	19 (73)	12 (60)	.348
Diabetes	18 (40)	11 (42)	7 (35)	.615
Cancer (excluding minor skin cancer)	7 (15)	5 (19)	2 (10)	.446
Chronic lung disease	14 (30)	8 (31)	6 (30)	.955
Heart attack, coronary heart disease, angina, or CHF	21 (46)	13 (50)	8 (40)	.500
Stroke	8 (17)	7 (27)	1 (5)	.113
Arthritis or rheumatism	26 (57)	14 (54)	12 (60)	.348
HIV/AIDS	1 (2)	0 (0)	1 (5)	.435
Hepatitis C	8 (17)	3 (12)	5 (25)	.267
Cirrhosis or end-stage liver disease or liver failure	3 (7)	1 (4)	2 (10)	.572
Geriatric Conditions				
Multimorbidity <sup>c</sup>	41 (89)	22 (85)	19 (95)	.262
Recent fall <sup>d</sup>	22 (48)	15 (58)	7 (35)	.149
Functional impairment <sup>e</sup>	17 (37)	13 (50)	4 (20)	.064
Mental Health				
Positive Depression Screen (PHQ-2)	7 (15.21)	6 (23)	1 (5)	.119
Positive Anxiety Screen (GAD-2)	9 (19.57)	9 (35)	0 (0)	.003
Serious mental illness <sup>f</sup>	23 (50)	16 (62)	7 (35)	.136
Factors Related to the Social Determinants of Health				
Low health literacy <sup>g</sup>	17 (37)	12 (46)	5 (25)	.219
Poor trust in health care providers <sup>h</sup>	21 (46)	12 (46)	9 (45)	.938
Loneliness <sup>i</sup>	23 (50)	17 (65)	6 (30)	.017
Lack of social support inside prison/jail <sup>j</sup>	31 (67)	19 (73)	12 (60)	.348
Lack of social support outside prison/jail <sup>k,l</sup>	17 (37)	9 (35)	8 (40)	.708

<sup>a</sup>Defined as the minimum information needed to make use of the policy, including knowing that medical release 1) is a policy to provide early release from incarceration for individuals with a serious or terminal illness and 2) can be initiated by speaking with a prison-based medical provider, correctional official, or legal counsel.

<sup>b</sup>A response of "poor" or "fair" to the question: "In general, would you say your health is excellent, very good, good, fair, or poor?"

<sup>c</sup>Two or more of the above-listed chronic medical conditions.

<sup>d</sup>Defined by self-report of a fall in the last month.

<sup>e</sup>Self-report of difficulty with one or more activities of daily living, including dressing, bathing, eating, transferring, and toileting.

<sup>f</sup>Defined as any major depressive, mania, or psychotic disorder using the Bureau of Justice Statistics' definition.

<sup>g</sup>A response of "somewhat" or less to the question: "How confident are you filling out medical forms by yourself?"

<sup>h</sup>A response of "You do not trust the prison health care staff" as a factor holding them back from talking with their doctor about their care wishes if they were to get very sick.

<sup>i</sup>Defined as a positive screen on the validated Three-Item Loneliness Scale.

<sup>j</sup>A response of "some" or less to the question: How much can you rely on friends and family outside of [prison/jail] if you have a serious problem?

<sup>k</sup>A response of "some" or less to the question: How much can you rely on friends and family outside of [prison/jail] if you have a serious problem?

<sup>l</sup>Of total of 46, those who answered "yes" to having friends and family inside or outside of prison but did not answer the follow-up question are coded as having no social support.

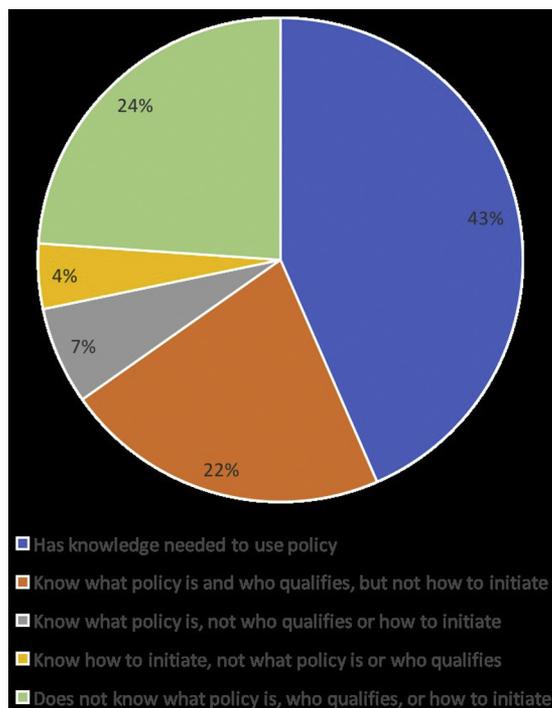


Fig. 1. Distribution of early medical release knowledge. "Medical release knowledge" was determined based on participants' response to three open-ended questions asking them to describe 1) what the policy is, 2) who is eligible to use it, and 3) how they would initiate the process. To be assessed as having knowledge, participants' responses had to convey that medical release is a policy to provide early release from incarceration for individuals with a serious or terminal illness and that for incarcerated individuals with serious or terminal illness, medical release can be initiated by speaking with a prison-based medical provider, correctional official, or legal counsel.

medical release policies. Participants with a life sentence were less likely to demonstrate knowledge of early medical release than participants without a life sentence (50% vs. 19%,  $P = .05$ ), Table 1.

## Discussion

In this study of early medical release knowledge and attitudes among 46 medically vulnerable incarcerated men, fewer than half (43%) knew enough about their state's early medical release policies to initiate a request if they were or became medically eligible. Of those without adequate knowledge, nearly half knew nothing about the policy. Among those who had heard of it, a majority could not describe how to initiate the application process. Health status did not appear to correlate with knowledge; for example, those with life-limiting illnesses (e.g., cancer, end-stage liver disease) were equally represented in the groups who did and did not know about early medical release. When participants were given the definition of early

medical release, most (76%) endorsed a desire to apply for it. These findings suggest that patient education may be an important factor in addressing the underutilization of early medical release policies.

This study's findings also suggest that incarcerated patients considering or near eligibility for early medical release may benefit from additional psychosocial support. Among the 76% of participants who said they would like to apply for early medical release if eligible, the most commonly cited reason was a desire to die at home in the company of family. This wish is consistent with well-documented preferences of community-dwelling older adults who express a wish to die at home rather than in an institution (e.g., hospital, nursing home).<sup>23–25</sup> In addition, participants with knowledge of medical release were more likely to endorse loneliness and anxiety possibly reflecting the common occurrence of existential distress, including a fear of dying while incarcerated, that has been documented in this population.<sup>26</sup> As incarcerated individuals approach eligibility for medical release, referral to mental health care and/or greater access to peer or family support may be of benefit. However, more research is needed to better understand the psychological effects associated with early medical release, including whether psychological or existential distress reduces the number of applicants.

A lack of trust in correctional health care providers identified by nearly half of the patients in this study, and in correctional systems more broadly, may also undermine early medical release policies. Such mistrust is well documented in correctional health care settings<sup>27–30</sup> and suggests a need to normalize applications for early medical release among potentially eligible patients, ensure that medical release applications are acted on in a timely and transparent fashion and consider creative approaches to increasing access such as engaging an independent advocate to facilitate applications (e.g., via a Pro Bono Program) or filing early medical release applications for eligible patients on an "opt-out" basis.

Our findings should be interpreted in the context of several limitations. This was a relatively small, exploratory study that used a convenience sample. As a result, the precision and generalizability of our findings should be considered preliminary. However, this is the first multistate study to enroll incarcerated older and/or seriously ill participants to assess their knowledge, attitudes, and perspectives about early medical release policies. Our finding that at least some patients who likely are (or will soon be) eligible for early medical release have limited or no knowledge of early medical release suggests a critical opportunity for patient education in this area and a pressing need for research to expand our knowledge about patient-level interventions that could improve access to early

Table 2

**Patient Perspectives on Early Medical Release**

Themes: Why or Why Not Would You Apply if You Were Seriously Ill?

Family	To be with my family. No one wants to die alone. I would rather be home with my wife. The thought of her and what she would go through if I passed here are too much.
Better care	Medical inside prison is not as good as it is outside. Like you have a stroke, reaction time to an incident is bad if not nonexistent. I have a lot of health issues. I don't think they can handle. I feel like my life is in jeopardy because of infections here. I was getting proper care in the street. My immune system is not as strong as it used to be—it's easier for me to catch things. Dialysis takes a lot out of you
Ineligibility and distrust in the CR process	I'm not eligible they would have to make an exception. They'd never release me. The only way I'm getting out is with a DNA test. Because I know it's not going to happen. I think I'm ignored because my stroke is not a serious illness, so I think I would just be ignored.

medical release. Although we used a proxy for serious illness (having three or more visits with a physician within three months), participants had overall high rates of multimorbidity and geriatric conditions, suggesting that knowledge of early medical release policies is important in our study participants. However, it is possible that our sample included some individuals who were in relatively good health, and as a result, our findings may under-report the lack of knowledge about early release policies among the seriously ill.

Overall, this study identified an important opportunity to ensure that medically appropriate incarcerated patients have the information and support they need to access early medical release policies. This study is of particular importance given the growing number of incarcerated older adults<sup>31,32</sup> and builds on prior work that has identified a number of administrative and clinical barriers that likely impede the use of early medical release.<sup>6,9,33–35</sup> Our findings underscore a critical need for larger studies that address barriers to patient trust in correctional health care and investigate the role that psychological and/or existential distress may play in limiting access to early medical release. Most importantly, this study suggests that patient education and support, as well as creative approaches to addressing patient trust in the correctional setting, are potentially promising areas of opportunity to expand access to early medical release.

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The data for this study may be made available on request.

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