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Authors

Ekaireb, Rachel
Ahalt, Cyrus
Sudore, Rebecca
et al.

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"We Take Care of Patients, but We Don't Advocate for Them": Advance Care Planning in Prison or Jail

Rachel Ekaireb, BA[1], **Cyrus Ahalt, MPP**[1], **Rebecca Sudore, MD**[1], **Lia Metzger, BA**[2], and **Brie Williams, MD, MS**[1]

[1]University of California San Francisco Division of Geriatrics

[2]New York Medical College

Abstract

Background: Despite rapidly aging populations in prisons and jails, evidence suggests that advance care planning (ACP), an essential component of geriatric care, is not widely conducted in correctional healthcare settings.

Objectives: Investigate correctional health care providers' ACP knowledge and experience, their perspectives on barriers to ACP in correctional settings and how to overcome those barriers.

Design: Qualitative Study

Setting: Four prisons across two states and one large city jail in a third state.

Participants: 24 correctional healthcare providers (e.g. physicians, nurses, social workers) participated in individual semi-structured phone interviews about ACP in correctional settings.

Results: Participants demonstrated low baseline ACP knowledge; 85% reported familiarity with ACP, but only 42% provided accurate definitions of ACP. Fundamental misconceptions included the belief that ACP was done by providers without soliciting patient input. Multiple ACP barriers were identified, many of which are unique to prison and jail facilities, including provider uncertainty about the legal validity of ACP documents in prison/jail, patient mistrust of the correctional healthcare system, patients' isolation from family/friends, and institutional policies that restrict use of ACP. Clinicians' suggestions for overcoming those barriers included ACP training for clinicians, creating psychosocial support opportunities for patients, revising policies that limit ACP, and systematically integrating ACP into healthcare practice.

Corresponding Author: Brie Williams, MD, MS, Professor, Division of Geriatrics, University of California San Francisco, 3333 California Street, Suite 380, San Francisco, CA 94118, 415-514-0720, Brie.Williams@ucsf.edu; Twitter: @briewsf.

Author Contributions: Dr. Williams and Dr. Sudore designed the study interview guide. Ms. Ekaireb and Ms. Metzger consented subjects and conducted interviews with study participants. Ms. Ekaireb, Mr. Cyrus Ahalt and Dr. Brie Williams analyzed and interpreted the data and prepared the manuscript. Ms. Metzger and Dr. Sudore revised and edited the manuscript. All authors meet the author criteria and have given final approval of the manuscript for submission.

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Conclusion: Despite an increasing number of older and seriously ill patients in prisons and jails, many correctional healthcare providers lack knowledge about ACP. In addition to ACP barriers found in the community, unique barriers to ACP exist in prisons/jails. Future research and policy innovation are needed to develop clinical training programs and identify ACP implementation strategies for use in correctional settings.

Keywords

Advance care planning; Prisoners; Geriatrics; Vulnerable Populations

INTRODUCTION

Correctional healthcare professionals practicing in prisons and jails provide care for a rapidly growing number of patients of advanced age and/or facing serious illness. For example, over 10% of incarcerated patients are age 55 or older, an increase from 26,000 in 1993 to 160,000 in 2016.[1-3] Incarcerated patients are considered “geriatric” in their 50s due to early onset of chronic disease and disability.[4-6]In 1976, the U.S. Supreme Court ruled that incarcerated patients have a constitutional right to community-standard healthcare.[7] Therefore, correctional providers must deliver community-standard geriatric and palliative care to a growing number of patients.

A bedrock of geriatric and palliative care is advance care planning (ACP), “a process that supports adults at any age or stage of health in understanding and sharing their individual values, goals and preferences for future medical care.”[8,9] ACP reduces patient anxiety, promotes autonomy, and improves quality of life.[10–12] Primary care providers are encouraged to engage patients in ACP before acute illness or hospitalization. Patients in prisons and jails generally receive primary care from in-house providers and are transported to community hospitals for emergency or specialty care. Jails house individuals awaiting trial or serving shorter sentences while prisons house persons with longer sentences. Barriers to ACP exist in all healthcare settings,[13,14] and include discomfort with ACP, uncertainty about when to initiate conversations, fear of causing patient anxiety, insufficient training, and limited time.[15-20]

Despite increasing older and seriously-ill populations, research describing ACP in jails and prisons is limited. One study found fewer than 1% of incarcerated patients had discussed ACP with a provider,[21] and only one pilot prison-based ACP program has been described in the literature.[22]Understanding the ACP barriers correctional providers face is critical for optimizing care. Therefore, we investigated correctional healthcare providers’ knowledge, experiences, and perspectives on ACP.

METHODS

Study design, setting, and participants

This qualitative study enrolled 24 providers from four state prisons in two states and one large city jail in a third state for individual, semi-structured phone interviews between March 2017 and January 2018. Because high-quality geriatric care is interdisciplinary,[23] we

enrolled primary care (physicians, physician-assistants, nurse practitioners) and other healthcare professionals (nurses, social workers, psychologists, case managers, chaplains). Eligibility included employment for >6 months. Sixty-three potential participants, identified by institutional medical directors, were invited via email to complete an individual 45-minute phone interview about "caring for patients with serious illness". The University of California, San Francisco Institutional Review Board approved this study.

Measurements

We assessed ACP knowledge by asking participants to define "advance care planning." We then provided a consensus ACP definition[8] and gave participants the opportunity to ask clarifying questions. The interview included open- and closed-ended questions, including about participants' comfort discussing ACP, how and when ACP conversations occurred, and barriers they encountered (follow-up prompts explored "patient-level", "provider-level" and "system-level" barriers). Additional questions included whether the correctional environment influenced ACP conversations and what interventions would help facilitate ACP.

Data Analysis

Interviews were conducted by two researchers, recorded, and transcribed. Closed-ended responses were analyzed using descriptive statistics. Providers' ACP definitions were evaluated using 3 criteria from the consensus definition[8]: 1) Supports patients at any age or stage of health, 2) Elicits values, goals and preferences, and 3) Focuses on decision-making about future medical care. Definitions reflecting all three elements were considered correct. Incorrect definitions were categorized according to missing criterion/a. Two reviewers analyzed interviews using iterative thematic content analysis to identify themes. Disagreements were resolved by consensus with a third reviewer. Interviews were conducted beyond the point of thematic saturation to achieve representation from all states.

RESULTS

Provider Characteristics and ACP Knowledge

Participants included physicians, nurse practitioners, psychologists, nurses, licensed clinical social workers, case managers, a physician-assistant and a chaplain from a state prison (69%) or a large city jail (31%) (Table 1).

While 85% of participants reported familiarity with "advance care planning" and 58% reported "regularly engaging" patients in ACP, only 42% offered an accurate definition (Table 1). Incorrect ACP definitions fell into three "misconception" categories: 1) ACP is exclusively for terminally ill patients (*"[only] if the patient was nearing death"*); 2) ACP means provider planning without patient input (*"making a treatment plan for a prisoner"*); and/or 3) ACP means planning for release from prison/jail (*"a plan to get them paroled out and set up [in community care]"*).

Provider-Level Barriers to ACP

Provider-level barriers fell into three themes: uncertainty, fears, and negative attitudes (Table 2).

Uncertainty—Participants described uncertainty about whose "role" it is to engage patients in ACP and about how to conduct ACP conversations. Some expressed uncertainty about legal considerations unique to prison/jail, such as the validity of ACP documents signed before incarceration.

Fears—Providers reported fears of litigation, specifically that following ACP wishes might be perceived as negligence; (*"[We] can be perceived as withholding treatment unnecessarily as opposed to acknowledging patient preference"*). Others feared discussing future decisions could exacerbate patients' suffering (*"I don't think [prison/jail] is a great time to remind them of their illness"*). Providers also feared patients' healthcare decisions might be influenced by incarceration ("*We worry someone's making a decision from a place of depression"; "Sometimes [patients] will take chances… I've had patients with cancer foregoing treatment until they were released"*).

Negative Attitudes—Several participants expressed negative attitudes about ACP, including that ACP is unnecessary for prisoners because "none would want to be DNR": *"[Prisoners] are different from us…they have a different desire to live."* Others said prisoners cannot participate in ACP because they *"owe time to the state… Therefore, the person can't choose to be DNR or forego treatment that would result in an early death"*. Others believed community providers are responsible for ACP.

Patient-Level Barriers to ACP

"Patient-Level" barriers fell into 4 themes: poor understanding, mistrust, lack of psychosocial support, and facing the end of life while incarcerated (Table 2).

Poor Understanding—Participants identified low health literacy and severe mental illness as barriers to ACP engagement, ("*Depending on their level of psychiatric stability, they may be more or less able to understand the information"*).

Mistrust—Participants described patient mistrust of correctional providers and the correctional healthcare system. One physician explained, *"Our policy does say we take care of patients, but we don't advocate for them…[Patients] see me as an agent of the state. If I'm not thoughtful in the way I present [ACP], it sounds like the state wants to rub you out."* Participants also suggested incarceration might cause patients to doubt ACP: *"[Patients] may be skeptical about…the ability of the healthcare system to acknowledge their autonomy because the system really undermines people*".

Lack of Psychosocial Support—Patients' lack of psychosocial support was identified as a barrier to ACP engagement (*"Their tremendous minute-to-minute isolation from family is a big issue...that's part of what is difficult in (ACP) discussions"*). Participants contrasted this with ACP in community settings, where families can attend appointments.

Facing the end of life while incarcerated—Several participants described facing the end of life while incarcerated as a unique barrier, including patients' fear of dying while incarcerated ("*[In ACP] we're bringing them the thought that they may die in prison, which I think is a great underlying fear*"). Some also expressed concern that patients' wishes might not be realizable, (*"Incarceration [means] many of the patients' preferences around end of life care cannot be fulfilled"*).

System-Level Barriers to ACP

Participants identified system-level barriers, including restrictive institutional policies and lack of standardized ACP delivery and documentation (Table 2).

Restrictive Policies—Restrictive institutional policies posed barriers to ACP, including policies requiring providers to talk with patients through bars and others impeding family visitation. Some policies explicitly limit ACP: one state only allows patients diagnosed with a "terminal illness" to sign ACP documents and another state requires ACP forms be signed by a person outside the facility.

Lack of Standardized ACP Delivery and Documentation—Participants described a lack of standardized delivery contributing to low prioritization (*"We don't have an organized system for dealing with [ACP]…so it gets neglected"*). Participants also stated that ACP documents oftentimes were not transferable to outside healthcare facilities.

Overcoming ACP Barriers

Participants' suggestions for overcoming ACP barriers (Figure 1) included: training clinicians, providing patient education and psychosocial support, standardizing ACP delivery, and revising restrictive policies (Table 3).

Provider Training—Participants identified ACP training needs, such as clarification about each provider's role in the ACP process and education about the legal implications of ACP in prisons/jails.

Patient Education and Psychosocial Support—Participants suggested that ACP engagement could be enhanced through patient education, ACP peer-support groups, involving families in ACP discussions when possible, and/or providing patients with an independent advocate. Several underscored the importance of empowerment during ACP conversations, (*"I'll often [say], 'You have control over so little in your life here, but you have control over this, so let's talk about that'"*).

Standardizing ACP Delivery and Documentation—Participants suggested standardizing ACP and integrating it into routine correctional healthcare delivery. Others called for integrating standard ACP documents into electronic health records that could be shared with outside hospitals.

Revising Institutional Policies—Participants suggested ACP policy revisions, including modifying eligibility criteria so that all patients could participate in ACP and allowing more

visitation for patients with serious illness. Additionally, participants recommended that compassionate (early) release be included in ACP discussions, since most patients would prefer to die outside of prison/jail.

DISCUSSION

In this qualitative study, misconceptions about advance care planning (ACP) were prevalent among correctional healthcare providers; fewer than half provided an accurate definition of ACP. Common misconceptions included that ACP does not require patient input and that ACP should be initiated only when patients are terminally ill. In the community, one national survey found that 91% of physicians describe several barriers including lack of knowledge about when to initiate ACP.[24] Yet, lack of ACP knowledge among correctional providers may be uniquely detrimental to patients who, unlike free persons, cannot choose their provider. This study also identified provider-, patient-, and system-level barriers to ACP in prisons/jails. Some echo barriers in the community; for example, uncertainty about who should engage patients in ACP, [24] and a lack of standardized ACP documentation systems.[25] Other barriers were unique to prison/jail, such as uncertainty about the legal validity of ACP documents for incarcerated patients, negative attitudes about incarcerated patients, and policies that limit family/friend support during medical decision-making. These themes were consistent with specific barriers identified in a pilot study of ACP in a single prison (Sanders et al.), where providers identified staff buy-in and adequate systems for documenting and sharing patient wishes as critical to success.[22]

The barriers and facilitators to ACP identified in this study offer insights into future directions for policy and research. Participants suggested provider training could help clarify when and how to initiate ACP conversations. ACP training increases providers' knowledge, confidence and engagement with patients.[25-27] Other recommended interventions such as integrating ACP delivery and documentation into healthcare protocols hold great promise since such interventions in the community have increased patient engagement in ACP.[27,28] Participants recommended addressing lack of psychosocial support by integrating family into ACP discussions when possible and providing a patient-advocate and/or peer support. Sanders et al. also noted that effective ACP was contingent on psychosocial support[22] but further research is needed to understand incarcerated patient's unique psychosocial needs during ACP. Future research should also explore whether knowledge of historical instances of unethical treatment of prisoners could affect patient decision-making[29] and the extent to which provider distrust, a barrier to ACP found among ethnic minorities and the homeless, [30, 31] is a challenge in prisons/jails. Since participants identified the need to address policies that limit ACP, the development of a guide that describes exemplary correctional ACP policies could benefit all systems.

Our study had several limitations. Agreement to participate in this study could indicate a particular interest in older, seriously ill patients. However, fewer than half adequately defined ACP. Second, our study was qualitative and therefore not powered to investigate differences between types of settings or providers. Third, we used individual interviews to elicit candor on a potentially sensitive topic. Future research using focus groups could reveal additional themes through in-depth discussions. While this was the first multistate study of

multidisciplinary providers to assess ACP in jails and prisons, policies that restrict the availability of ACP differ by state and not all are reflected in this study. Instead, our findings serve as a first step to inform larger studies designed to improve ACP use in prisons/jails. Future research should also explore patients' perspectives about ACP in correctional settings.

This study offers provider perspectives on challenges to delivering ACP in correctional settings and starting points for overcoming these barriers. Provider training, provision of psychosocial support for patients, and modifications of restrictive policies represent potential avenues for increasing ACP engagement among the growing number of incarcerated patients who would benefit from ACP.

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IMPACT STATEMENT:

We certify this work is novel clinical research. The potential impact of this research on clinical care and health policy includes the following: The identification of unique barriers to advance care planning (ACP) in prisons/jails and the need to address these barriers; the need for training in ACP for providers working in these settings, and the identification of policies that hamper appropriate provision of ACP, so they may be revised.

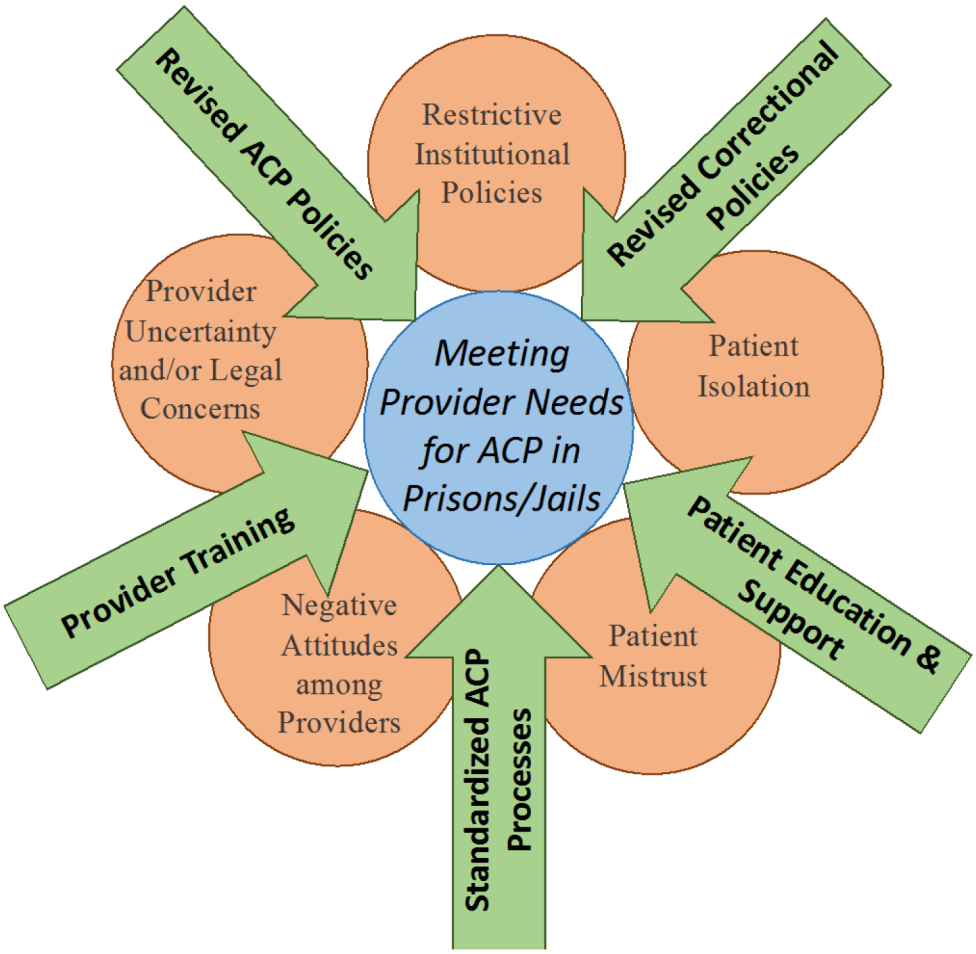

Figure 1.
Provider-Identified Facilitators to Overcoming Unique ACP Barriers in the Correctional Setting

Table 1.

Participant Characteristics and Baseline Advance Care Planning Knowledge

Characteristic (N=24)	N (%)
Gender	
Male	8 (33)
Female	16 (66)
Profession/Degrees	
Physician	5 (21)
Physician-Assistant	1 (4)
Nurse-Practitioner	2 (8)
Psychologist (PhD or CNS)	4 (17)
Nurse (RN)	7 (29)
Social Worker (LCSW) or Case Manager (BA)	4 (17)
Chaplain	1 (4)
Correctional Facility Location/Type[1]	
State 1 – Midwest, State Prison	12 (50)
State 2 – Northeast, State Prison	4 (17)
State 3 – Northeast, City Jail	8 (33)
ACP Knowledge/Experience	
Familiar with term “ACP”	20 (83)
Self-reported engagement in ACP	14 (58)
Accurate ACP definition	10 (42)
ACP Misconception	
ACP is planning for patient’s release	4 (17)
ACP is for terminally ill, dying patients	5 (21)
ACP doesn’t require patient input/participation	5 (21)

[1]Participants from States 1 and 2 worked in four state prison facilities (two in each state) ranging in size from 300-700 residents. Participants from State 3 worked in a large city jail which has an average daily population of 10,000 residents. All facilities are publicly owned and operated (non-profit institutions).

Table 2:

Barriers to Advance Care Planning

OVERARCHING THEMES	SPECIFIC BARRIERS	ILLUSTRATIVE QUOTES
Provider Uncertainty	Who should engage patients in ACP	"I can participate in (ACP) and initiate it if that becomes my role, but we have lots of counselors around here, social workers…I don't know who would do that." (Nurse Practitioner)
	How to initiate ACP	"How can we have this kind of conversation and for the patients to not feel like they're being pressured to sign off on something but let them know they have this option?" (Psychologist)
	Legal considerations	"If somebody had a healthcare proxy or some sort of community document does that apply when they're in the correctional setting? There's a lot of anxiety around forms' validity." (Physician)
Provider Fears	Litigation	"We got to…talk to our lawyers. I was involved in getting code statuses here, living wills being made available to people…it was (important) to make sure it didn't look to the public like we were trying to kill people off." (Physician Assistant)
	ACP causes suffering	"[During ACP] I don't want to make them feel worse. You know? By explaining what is going to happen." (Psychologist)
	Incarceration affects patients' decision-making	"A patient with liver cancer…said to me, 'This isn't working. I'm just gonna refuse all treatment and die…I don't want to live sick in prison … If I can't spend this time with my family, then why am I on this earth?'… That's unique to prisons." (Physician)
Provider Negative Attitudes	ACP is unnecessary for prisoners	"I haven't encountered anyone (request to be DNR) …Prisoners are hardy people for the most part. They're different from us. They have a different desire to live than we have." (Nurse Practitioner)
	Prisoners aren't entitled to ACP	"I've heard people say…if someone is sentenced to five years for a crime it's the physician's responsibility to ensure the person serves those five years. Therefore, the person can't choose to be DNR or forego treatment that would result in an early death." (Physician)
	Community clinicians responsible for ACP	"I rely on specialists to do (ACP), so if somebody has cancer, it's their oncologist (outside) that does all that." (Nurse Practitioner)
Poor Patient Understanding	Low health literacy	"Health literacy is a barrier. I think there are many individuals who feel sick…but don't necessarily understand their diagnoses" (Case Manager)
	Serious mental illness	"The biggest barrier that comes to mind is their serious mental illness. Most individuals on my unit are struggling with severe psychosis or severe borderline personality disorder." (Psychologist)
Patient Mistrust	Mistrust of clinicians	"People perceive that providers in a jail-based setting care less about them than community providers. There is a perception quality of care is poorer. I think that creates a lot of mistrust." (Case Manager)
	Mistrust of healthcare system	"For someone to believe that you are going to be able to implement advanced care directives, they need to trust that you can do that and the system overall really undermines trust." (Physician)
Patients Lack Psychosocial Support	Isolation from family during ACP	"While the doctor was speaking the patient was definitely focusing on something else altogether. Probably [thinking], "What am I going to do? How do I contact my family to tell them?"…Your support system can't give you a hug. They can't advocate for you." (Nurse) "It's challenging to have (ACP) conversations from inside correctional settings or facilitate family meetings." (Physician)
Patients Facing End of Life While Incarcerated	Patients fear dying in prison/jail	"We're bringing to them the very thought that they may die in prison, which I think is a great underlying fear." (Physician)
	Wishes not realizable while incarcerated	"Incarceration makes it such that many patient preferences around end of life care cannot be fulfilled…visitation, leisure activities, [those things] would be a priority in a hospice but (aren't possible) in jail." (Physician)
Restrictive Institutional Policies	Security policies	"As you go up in security, you're not allowed near patients. They're usually in a room with guards. They're in shackles. You can't touch them." (Nurse Practitioner)

OVERARCHING THEMES	SPECIFIC BARRIERS	ILLUSTRATIVE QUOTES
	Policies limit ACP eligibility or enactment	"Currently, you must be seriously ill and probably dying for folks to engage (in ACP). There's still a (policy) if you're gonna change your code level we have to write you have a terminal illness." (Physician)
ACP Delivery, Documentation Not Standardized	ACP not prioritized	“So many urgent issues need to be addressed…abstract, long-term ACP issues aren’t a priority in that space.” (Physician)
	Poor communication of ACP wishes	"[It’s difficult] to communicate (ACP) wishes to the hospital where some of the more advanced care would be provided and where it's probably most important people's wishes be known." (Physician)

Table 3:

Potential Interventions to Overcome Advance Care Planning Barriers

OVERARCHING THEME	SPECIFIC FACILITATOR	ILLUSTRATIVE QUOTES
Provider Training	Clarify clinical roles, Empower team	"We could teach our entire medical team that (ACP) could be brought up by anybody…Maybe give folks more freedom or empower them to begin that conversation." (Physician)
	Formal training in ACP	'I think training is extremely helpful…I think people definitely need…a level of familiarity and encouragement to have these conversations when appropriate' (Physician)
	Education on laws	"I would really like to know what has worked well and what can I do that isn't going to cause legal problems" (Physician Assistant)
Patient Education	Provide patients information about ACP	"Doing a lot of advanced education and normalizing, 'This is something we all need to think about.' Doing education up front before we attempt advanced care planning." (Social Worker)
Psychosocial Support During ACP	Include family or patient-advocate	"If there was more of precedent set system-wide on how to allow for a more robust support system for individuals that would change the (ACP) conversation." (Case Manager)
	Offer optional groups	"Group settings are always helpful…they allow for a sense of camaraderie, belonging and shared experience." (Social Worker)
Standardize ACP Delivery, Documentation	Create protocols for ACP initiation	"We screen people for mental illness, suicide and things like that. It may be a point where we're…just making (ACP) part of our admission." (Physician Assistant) "Make it a priority as part of discharge planning that everybody gets a healthcare proxy form filled out and takes it with them into the community." (Physician)
	Create standardized ACP documents	"Incorporate (ACP) into this new [EHR] system where everyone knows where to go if the need arises. 'Okay, we click and here is the advanced directive.'" (Social Worker)
Revise Policies to Allow Enactment of ACP Wishes	Modify security policies	"We made accommodations…the warden allowed (the patient's) parents to stay at his bedside for the last several weeks of his life. His mom and dad basically were part of our team." (Nurse)
	Modify policies to expand ACP eligibility	'My personal thought is there are many people who may be 40 or 45…who may say, 'I already have strong feelings about wanting to be resuscitated or not regardless of the fact I'm not currently seriously ill'" (Physician)
	Include compassionate release in ACP discussions	"Patients ask for (medical parole) because…they want to be closer to their family and those who care about them, and I think they just want to die with dignity." (Chaplain) "The conversation very quickly becomes around the legal circumstances… essentially, people facing the prospect of dying in jail almost universally their preference for end-of-life care is not to die incarcerated." (Physician)