

Care in the End:

Understanding Incarcerated People's Decisions about End-of-Life and Best Practices for Prison Hospice

White Paper



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Executive Summary

Across the United States, as state prison systems contend with rising numbers of older adults, they find themselves in the position of needing to reimagine and redesign services for this rapidly growing population. These demographic shifts require new resources, policies, and practices to ensure that adequate safety and care is provided and that end-of-life care needs are met. In this white paper, the study team presents the top concerns and solutions to the problem of a rapidly increasing older adult population. These findings and policy recommendations are based on extensive interviews and observations with doctors, medical staff, and patients conducted at 11 institutions across the California Department of Corrections and Rehabilitation (CDCR).

Top Policy Recommendations

Geriatric Specialization and Training

It is recommended that CDCR increase the number of geriatricians and increase trainings in older-patient and end-of-life care for all medical staff. Individual doctors in facilities are often designing their own version of end-of-life best practices, and there could be more coordination and uniformity on how end-of-life care is practiced in CDCR. Medical staff often expressed that they lacked clarity in end-of-life best practices and wished to receive more support, policy, and training.

Geriatric Housing

It is recommended that multiple geriatric yards or geriatric facilities be established in CDCR to better support and protect vulnerable older adults. Patients expressed high levels of concern for their personal safety with cellmates and on the yard as they experience increased comorbidities. Medical staff also reported safety concerns for older adults housed in yards and expressed frustrations about their lack of knowledge about yard conditions and ability to provide safe environments for vulnerable patients. This form of designated housing could also provide an environment in which geriatricians and other medical staff with geriatric and end-of-life training could be concentrated.

Replication of the Hospice

The hospice at CMF is able to deliver upon many of the desires for improved care expressed in patient interviews across the state, including respectful and dedicated care from medical staff and custody staff, high quality peer support, family visits, and diet and comfort accommodations. One of the largest barriers to more patients being able to utilize these quality services is the location of the hospice and its distance from Southern California, which causes patients and medical staff to be hesitant to transfer Southern Californian patients there. This is due to a number of factors, including the difficulty of long transport for vulnerable patients, distance from family members, and a general lack of knowledge about the hospice in other facilities. It is recommended that CDCR replicate the CMF hospice model at a medical facility in Southern California.

Standardized Older Adult Care Policies and Practices

It is recommended that institutional policies relating to accommodations and access to support items for older patients with chronic medical conditions be further developed and followed uniformly across all facilities. Patients reported that they may obtain accommodations—such as walkers, wheelchairs, single cell or lower bunk, and medications—with one doctor or at one facility but subsequently lose access when transferring doctors or facilities. These items and accommodations are crucial to patient functioning and symptom management. In general, it is recommended that CDCR prioritize trainings with both custody and medical staff on the standard policies and practices concerning support items and accommodations to ensure routine and standardized care across institutions.

Background

In recent decades in US prisons, the number of incarcerated people aged 55 or older has grown dramatically, and so has the number of older adults dying in US prisons each year [1,2,3]. Aging and dying in prison pose problems for penal institutions. As health experts and criminologists emphasize, aging in a prison context presents profound physical, psychological, and social difficulties [4,5]. Penal institutions, which are designed principally to confine, are challenged to adjust their routines and institutional infrastructures to accommodate the aging population [4]. In short, older adults have unique needs that alter the nature of imprisonment for the individual as well as the demands that are placed on the prison.

In California, where life sentences generate more than thirty percent of the prison population [6], age-related illnesses have long overtaken other health and climate factors as the primary causes of death in prisons. In this context, the needs of incarcerated people approaching the end-of-life and the factors that contribute to their health decisions become critical points for research [7]. Also relevant are ways in which prison facilities, staff, and associated specialists are able to meet the needs of those with serious, life-limiting illness. Practices of geriatric and palliative care, the capacity of prison facilities to provide such care, and the standards to which penal institutions adhere in doing so are of utmost importance.

The overarching goal of this study is to contribute to generalizable knowledge about the health care challenges and health decision-making of a growing population of criminal-justice-involved adults with age-related and other serious illnesses who are nearing the end of life, as well as the role of correctional medical services and an onsite hospice in providing care for them. The study may serve to raise awareness of the needs of aging incarcerated persons, improve understanding of the correctional system's capacity to provide palliative care across institutions, and potentially equip CDCR/CCHCS and other correctional systems with ideas and options for addressing individual and systemic needs. This information may then be used to improve the health and social outcomes of incarcerated people as they age as well as contribute to best practices for providing end-of-life care in prison.

Our Goal

Report on the common challenges and decision-making practices of incarcerated adults in CDCR who are 50 years old or older and have at least one chronic health condition as well as the care available to them and the perspectives on care held by their medical providers.

Our Purpose

Provide information and recommendations for institutional actors about how patients and staff imagine elderly and end-of-life care can be best delivered in a carceral setting.

Methods

Group Interviews

Group interviews were conducted at ten CDCR institutions. Institutions were selected for their geographic diversity, security level, number of medical beds, admissions received in hospice, medical risk classification patient numbers, expected death numbers, and gender. Individuals were qualified to participate in the study if they were 50 years or older and had a chronic illness. Recruitment of qualifying participants was conducted based on recommendations from medical staff as well as response to flyers circulated by Inmate Advisory Councils. Interviews were typically conducted with between five and twelve patients for 90 minutes.

Medical Staff Interviews

At the ten facilities selected for group interviews, three or more medical staff were also interviewed on site or virtually by phone or video connection. Medical staff study participants include doctors, nurses, and mental health staff. Individual interviews were typically conducted for one hour.

Hospice Study

The study team visited the CMF hospice on two occasions, including one two-week visit, and employed three methods:

- Interviews with doctors, nurses, PCS workers, social workers, dieticians, chaplain, volunteers, and patients. Interviews were typically conducted individually for approximately one to two hours.
- Observation of daily hospice practices.
- Document gathering, as approved and permitted.

Interview Topics

Below are the topics that were discussed during individual and group interviews.

Patients

Aging in prison, health needs and resources, family and peer relationships, end-of-life care and desires, spiritual needs, knowledge of CMF hospice, end-of-life transfer considerations, COVID-19, best practices for information sharing.

Medical Staff

Older adult population, older adult treatment and care, care team composition, philosophy of care, older adult programming, CMF hospice referral process, COVID-19, ideal support for older and end-of-life prisoners.

Hospice

End-of-life care, end-of-life goals, referral process, philosophy of care, resources, expansion, differences between hospice and palliative care, care team, hospice history, hospice benefits and concerns.

Limitations

For all interviews conducted with medical staff and patients, we are reporting what was told to us without the ability to independently corroborate claims. However, claims made in this report have been reported to us by multiple sources. This report makes note when an event was witnessed first-hand by the study team.

Participant Demographics

Group Interviews

The study team spoke with 110 group interview participants, collected from 20 group interviews at 10 institutions.

Demographic Table of Group Interview Subjects (n=110)

Variable	n (%)
Gender Identity	
Male	85 (77.27)
Female	22 (20)
Transgender	3 (2.73)
Race / Ethnicity	
White	44 (40)
Black / African American	24 (21.82)
Hispanic or Latino/a	17 (15.45)
Asian / Pacific Islander	2 (1.82)
Native American	5 (4.55)
Mixed race / Other	18 (16.36)
Age	
Range	50-92
Mean	65
Median	65
Education	
8 th grade or less	5 (4.54)
9 th to 11 th	14 (12.73)
12 th (high school diploma/GED)	31 (28.18)
Some college	32 (29.09)
Associates	19 (17.27)
B.A.	4 (3.64)
Master's Degree	3 (2.73)
Professional/Doctorate	2 (1.82)
Total Years Incarcerated	
Range	1-63
Mean	29
Median	30

Medical Staff Interviews

The study team conducted individual interviews with 35 medical staff (primarily physicians, but also nurses and mental health practitioners) across 10 institutions.

Hospice Study

The study team conducted individual and group interviews with 47 participants at the hospice.

By Position:

Patients: 10
 Pastoral Care Service Workers: 10
 D-yard Incarcerated People: 7
 Nurses: 6
 Physicians: 3
 Volunteers: 3
 Dietician: 2
 Medical Social Worker: 2
 Chaplain: 1
 Mental Health Care Social Worker: 1
 Psychiatrist: 1
 Incarcerated Janitorial Worker: 1

Study Team



Dr Christopher Seeds

Associate Professor

Christopher Seeds served as an attorney for people on death row and people serving life sentences for more than a decade. As a sociologist and sociolegal scholar, his current research focuses on life- and long-term sentencing and sentencing policy and he continues to work with incarcerated people serving life and long-term sentences.



Joanne DeCaro

PhD Candidate

Joanne DeCaro is in the final year of her PhD program. She researches life sentencing and the re-entry process. She is the co-founder of three archival projects that document the experiences of incarcerated individuals and facilitates a legal clinic for lifers.



Medical Staff Interviews

We interviewed 35 medical staff across ten CDCR institutions about how geriatric end-of-life care is practiced at their facility. This is a summary of what those participants reported in these individual interviews.

Medical Staff Interviews

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Care Team

This section discusses the care team, which medical staff emphasized as an essential ingredient of effective care for patients approaching the end-of-life.

● Organization

Participants reported that end-of-life requires a holistic perspective on care that will involve a team of physicians, nursing staff, and more, including psychiatrists, pharmacists, social workers, mental health, spiritual counselors, and dietitians. Participants reported the most successful construction of a holistic care team will also have support from top to bottom—from the warden on down.

● Team Integration

Participants emphasized the importance of strongly integrating mental health care team members and medical team members to provide the best possible care to patients. One participant particularly stressed the importance of warmly introducing mental health care providers to their patients to avoid the stigma some patients attach to mental health care. A mental health provider, utilized as a member of the care team in this way, may serve patients as a resource for discussing concerns about health and dying in prison.

● Communication & Resource Sharing

Participants reported that, given the frequent coexistence of physical and mental health needs, resource sharing, collaboration, and communication between medical staff and mental health was very important. Participants also recognized the importance of communication more broadly: for example, participants emphasized the importance of maintaining close ties with local hospitals and of talking regularly with representatives of an institution's Inmate Advisory Council.

“This model that we’ve been trying to implement here for a long time is the care team model, this multi-disciplinary model. I’m talking about medication management and having someone to check in on the pills. Maybe having a geriatric referral clinic. It takes multiple members of a multi-disciplinary team to be able to do this successfully, it can’t rely just on the doctor.”

- Physician

Philosophy of Care

This section discusses the different philosophy and approach that end-of-life care requires, and what that orientation to medical practice demands from individual medical staff and care teams.

● End-Of-Life Care Philosophy

Participants emphasized differences between the philosophy and approach to end-of-life care, which is focused on pain management, comfort, peace, and standard medical practice, which is centered on treatment. With the change in approach, participants reported, important aspects of day-to-day practice also change—for example, routine testing and referrals may not be appropriate and the use of certain medications may no longer be necessary.

● Compassion

One participant explained that effective communication between care team members, including between medical and mental health providers, was largely about personality and compassion. Participants reported that hiring people with compassion is important because as a prison medical worker you do not select what patients you see and have to be willing to care for people regardless of their crimes. Compassion is particularly important for end-of-life care, participants explained, in part because of the added stress that dealing with death involves, and not all medical staff are trained to deal with death. End-of-life care, as one physician put it, “is not for everybody—you have to have that inside you.” Another physician explained that end-of-life care demanded “a special training” as well as “a special heart.”

● Care-Team Cohesion

Participants emphasized the importance of a united philosophy of care among the care team for end-of-life situations. Communication between different team members is critical. Participants reported that morning huddles and weekly team meetings in part served as opportunities to foster cohesion and communication and put everyone “on the same page.” Effective end-of-life care also depended on custody staff who work with end-of-life patients to understand the palliative philosophy of care.

● Care-Team Dissonance

Without an agreed upon philosophy of care, there may be a clash of treatment philosophies; without effective communication, it is hard to foster a group understanding. Participants reported that one significant challenge with providing end-of-life care is the tension it can raise with nursing staff who are trained to keep people alive and are uncomfortable with taking responsibility for allowing a patient to die. Participants emphasized the importance of paying attention to this during recruitment and in the training of nursing staff and other members of the care team.

“In most of the instances they have some dignity, some control, and compassion and comfort. We meet them where they are and do what we can. Not in the face of jail or prison, but in the face of death. We do a good job.”

- Physician

"Not many physicians can handle end-of-life. Yes, we are doctors and nurses but if we're not trained to handle end-of-life we don't do a good job of handling patient pain and suffering in their last minutes to days and hours to days and weeks. The hospice is a subspecialty. And not only that, you need a special training but you [also] need a special heart. So, you recruit specific doctors, specific nurses, specific inmate helpers so that the program's successful."

- Physician

"I think that having people that have compassion to be able to work with this population is important. You don't want to put the person—you know, you're just a number to me and I'm just checking the boxes of what I have to do at my job—that would not be a good person to meet with a terminally ill patient. And that's an unfortunate thing here because you don't select what patients you're going to see."

- Mental Health Provider

"Even though we are physicians, in general a majority of physicians cannot handle death. Meaning a physician's job—because we are trained to face life, we are trained to not let patients die. So, you really need to train the caregivers, including the physicians and the nurses, the LDM, the psytech and everybody, that what they are getting into and where they can give the most to patients, and also so they don't get burned out. No matter what, your patient is going to die. We see a lot of burn out. We see a lot of nurses leaving. It's not easy."

- Physician

End-of-Life Protocol

This section discusses the steps that medical staff take to implement an end-of-life philosophy of care, including taking the initiative to learn and seek out training and innovate to help patients die comfortably and peacefully.

● No Defined Protocol

Participants recognized the palliative care guide provided by CCHCS was very helpful. Participants also noted that recent trainings on compassionate release and medical parole were very helpful. Some participants also reported recent trainings concerning palliative care. But participants reported that there remained no defined end-of-life protocol at most institutions. As a result, in cases where it was not possible or not advisable to transfer patients nearing the end-of-life, individual medical staff and local care teams developed their own ways of adjusting the care for patients who no longer want treatment.

● Innovation

Participants also shared accounts of innovative efforts by individual medical staff and care teams to be as flexible as possible in order to respond to patient wishes—including not applying CPR, providing extra medicine to reduce pain, physicians spending more time bedside with patients, providing 24/7 nursing, changing linens and clothing as necessary, applying more flexibility in meal requests, and taking extra steps to find family.

● Training and Learning

Participants shared with us examples of initiatives they took on their own to learn about palliative care, often despite a lack of specific professional experience or training in palliative care, including reaching out to CMF hospice and local hospitals with questions or concerns.

"I feel like I'm still kind of student here. I'm still learning. The prison is a place that things are constantly changing. So as soon as you think you know something or understand a procedure or policy, it changes. I think one of the things that could be improved is that they could do a better job of educating us about the programs that are here and some of the policies and procedures that are here. Because it's hard when you get here you basically hit the ground running. Unless somebody tells you, you may not even know. So the communication about what's out there and what we need to know would be helpful. Then we would be able to help our patients—you know, if we know, then we could help."

- Physician

"As they started to need more palliation, have more and more symptoms, short of breath or delirious or just very weak or in pain, trouble moving their bowels, whatever it might be, I would usually start checking on them a couple times a week. And when it got very close to the end or if they were highly anxious and really wanted to talk to me about things, I always made myself available and I'd see them once or twice a day. My own way of being a doctor is more time intensive and I feel like it's part of good medicine and of being a healer that I make myself available in that way."

- Physician

Resources

This section discusses resources, generally available at CMF hospice, that medical staff deemed especially important for palliative care, as well as challenges that participants recognized for employing those resources at other facilities.

● Space

Participants reported that hospice has psychological as well as physical (pain-reducing) benefits for patients. Participants noted that the psychological benefits of hospice have a lot to do with the physical setting in which patients are housed. More space allows more free movement, more space for activities. Spaces such as gardens and outdoor areas have relaxation benefits. Participants reported that such space is rare and hard to create in existing institutions.

● Medication

Participants reported that they feel limited in amount of pain medications they can prescribe and administer because of their concerns over high rates of narcotic use and diversion of medication in institutions. However, other participants explained the liberal use of pain medication is central to the hospice philosophy of end-of-life care. Given the tension between these circumstances, there is the strong need for more end-of-life care training with all levels of medical and custody staff across the institution.

● Activities

Participants reported that activities that patients can participate in, individually or collectively, improve communication among patients and between patients and staff, and thereby also have a positive impact on the quality of life that patients experience at end-of-life. Activities, however, require a space set aside in which patients and activity leaders (CDCR employees or volunteers) can gather.

● Freedom of Movement

Participants reported that in palliative care and end-of-life operations not at CMF—including CTC and OHU facilities—there are restrictions on freedom of movement. Cell doors remain locked until custody opens the door and dorm-eligible patients are not allowed freedom of movement. Participants reported that this poses a barrier to the efficiency of the care team's response to an emergency and also impedes casual check-ins on a patient that might otherwise occur.

"We try to match [CMF] here. Not with the visitors as much, but with the quality of end-of-life care in terms of not doing CPR, giving extra medicine to reduce pain and suffering. There is oxygen available from the wall, nursing 24/7, changing of bed linens and clothing is as necessary 24/7.... They can ask for extra eggs or more tomato juice or less crunchy food. The food can be soft and bite sized or even pureed. We get liquid nutritional supplement, where they wouldn't get that in their regular housing.... So there's more flexibility. It's certainly not flexible, but it's better."

- Physician

"In the men's hospice they've got a whole unit that they can make open so that they're not isolated in cells and locked in all the time. Whereas here, we are dealing with custody who hasn't been, you know—these are the 'locked in' times and these are the 'unlocked times' all across the whole institution. And you have to be locked in. In fact, when they are in administrative segregation, then the nurses can't go in without a custody officer. That's extraordinarily challenging and we would have to work with the warden when that happened and try to get something set up because we have to be able to provide. You have to be able to get to them quickly and help them. Also, for many people who are in the process of dying it really helps for them to have social interaction. They don't do well without it and they do much better when they have it."

- *Physician*

Increased Needs

This section discusses what medical staff identified as key changes in the patient population in recent years as well as the impact of those changes, and challenges they pose, for medical care.

● Older Population

Participants from some institutions reported that the number or percentage of older patients in their care had increased in recent years.

Physician participants reported that for them the increase in older patients amounted to more work—and an increase in workload and added stress—but also noted that it did not appreciably change their approach to work and care.

Participants reported that the increase in older adults, however, could present more complex challenges for non-medical staff, including custody, as dealing more often and with more individuals living with age-related physical limitations and disabilities pushed them to approach health services and patients differently.

"I keep saying to my colleagues, there's just something that's been eye-opening to me over the past six months or so about our, the population. We have just medically complex, older patients. So, this is going to continue to be, this is our population now. We're going to see people continue to decline."

- Physician

● Mental Health Care Needs

Participants reported a greater number of the population having mental care needs and this intersecting with a mental health care staffing shortage. Participants also reported a greater institutional reliance on medication as a response to patients' physical and mental maladies.

Participants linked the greater institutional reliance on medication to the lack of a staffing increase sufficient to accommodate increasing patient needs. Participants expressed that in order to be better prepared to handle the continued influx of older patients, more mental health care staffing would be required.

"We went to the state capital to argue why we need more psychiatrists in prison. And part of it is we really, over time, at least over the past three years, and part of it is COVID to blame, but I would say that 95% of my appointments have been cell side and under three minutes, just checking 'are you alive' and 'are you going to be alive today'? As I said the numbers are so high, the staff are so short. I personally believe if we do therapy right, the use of medication should be, instead of now using medication 90-95% of the time, it will probably be 10% of the time. It's a broken system."

- Mental Health Provider

Classification

This section discusses the importance that medical staff place on classification and the ways in which classification decisions play a role in health management and health outcomes.

● Medical Levels of Care

Participants reported that a challenge in the care of older and chronically ill patients was identifying and providing the appropriate medical level of care for a patient. Participants reported that the medical risk classification sometimes poses challenges because it creates tension between where a patient desires to live and their ability to be housed in that facility.

● Medical Bed Availability

Participants reported that when patients are identified at certain levels of care, which demand particular care conditions, the number of beds meeting those needs are often limited and not immediately available. Participants accordingly recognized the need for more placement options appropriate to multiple levels of care. Lack of bed availability can also limit continuity of care because patients may be moved unit to unit until a place with the appropriate care conditions becomes available.

● Safety

Some participants reported that safety for a patient was a factor they felt should be taken into consideration when assessing a patient's health and health classification. The philosophy of care for some participants included helping patients be in a safe environment in which basic needs are being met and they can access help when they need it. Yet, participants reported, even if safety was recognized as a factor in evaluation, it could be challenging to know about a patient's day-to-day safety, such as the conditions or what kind of supports they have on the yard, because the medical team generally does not encounter them there.

● Limitations of Evaluations

Participants reported that what is very challenging to medical providers is that they see patients in clinic, but that patients spend most of their lives in the general population, and the doctors do not know what the officers see day to day. The medical team, accordingly, may not have a vantage point for identifying gradual declines in health. This is particularly a challenge for new patients in an institution, or patients with new housing, whose cellmates or peers are not familiar with their condition. Participants also reported that patients may make an effort to avoid a certain classification—for example, an effort to avoid using a wheelchair—because such a classification would necessitate a move to another institution. This also can contribute to later identification of patient conditions.

"As we're seeing patients here slowly decline, how we can best support them and how they have to fit into certain categories—I might see someone with mild cognitive impairment, right. But in order to get them to a better setting you need to categorize them. That piece, I do see that there are, with our aging population—it's been eye-opening to me over the past six months or so just seeing how our population is getting much older, we're getting transferred in a much older population. I'm looking at their release dates, you know, they're going to die with us. These are elderly people, 70s, who have multiple life terms."

- Physician



"I had a patient who was both bladder and stool incontinent, and they had, in addition, mobility issues. And she was underweight and frail and she had a roommate. When she would get up, stool would run down her leg. She was being worked up to find out what was going on, why she was having the stool incontinence. To me, that patient needed a higher level of care because we don't have RN or standing nurse CNA overnight in the [supportive unit.] There were various concerns. One, the roommate was upset because she would smell, obviously of stool. And the roommate might get violent. And if she go up to try to clean herself, she could slip and fall in her own stool because she is so frail in her wheelchair. And she could end up, if she couldn't get attention—she wouldn't be able to get attention of custody and change clothes and linens overnight. Those kinds of things. This is somebody you need to keep your eye on, so she doesn't end up getting hurt by others, so she doesn't slip and fall, that she doesn't end up with a pressure ulcer or some kind of issue because of the medical issues that are going on. Sometimes space is an issue and sometimes it's hard to place people. There isn't always an ideal spot."

- *Physician*

Hospice Transfer

This section discusses what medical staff identified as important considerations in making decisions to transfer patients to the CMF hospice or outside hospitals, including health-related barriers to a transfer and challenges that arise during transfers.

● Health Status

Medical staff reported that for transfer for medical care to an outside hospital or to hospice, if a patient is unstable, it is not well advised to transport them. With respect to decisions to transfer to the CMF hospice in Vacaville, geography therefore can play a role. For some institutions that are far from Vacaville, if a patient is not in stable condition, it is not a good idea to transfer them, for example, halfway across the state. For this reason, early referrals were noted as important, so that the transfer could take place before the patient's health declined.

● Local Care

Health status combined with the distance to be traveled and social conditions during transfer may deter some patients from wanting to transfer. But even if transfer itself is not perceived as a challenge, participants reported that sometimes patients wish to stay at the institution. Participants reported occasions where patients had become so accustomed to the care team, including doctors and nurses as well as other staff and peer workers, that they wanted the same caretakers at end-of-life. Participants also reported occasions where patients had personal attachments—including family nearby or incarcerated peer family—that held them to their current institution.

● Social Conditions

Participants reported that transfer to an outside hospital or to hospice may also be socially challenging, as it involves not only sustained interactions with custody staff involved in the transfer, but also exposure to society outside of the prison. For example, one participant explained, transfer can involve social interactions during stops for gasoline or food, in which by-standers or onlookers may interact negatively with the patient.

“One of the biggest things is they’ve been here for years; this is their home. To uproot them is very hard. Yeah, that has come up many, many times where patients just say no, I don’t want to go. For those that have an attachment to this place, it’s a very hard thing. It would be wonderful if we could take care of those patients here, so they don’t have to leave the place they know. Not just their friends and buddies, its staff. They get to know the officers, or it’s their psychologist, their social worker, these people that they’ve lived with here for years.”

- Physician

"There's been a couple instances where I've had a patient who I thought might be a good candidate to be transferred to a hospice unit and there's just not enough beds available. We've been successful on some occasions to send a patient up north for a hospice program. But often it is very difficult and it's hard to do. It is very far. Sometimes we find ourselves in a case where a patient is just so ill and so unstable at the end-of-life that we don't even think it's a good idea to have them transfer all the way across the state in that condition when it's not really comfortable for them. It kind of defeats the purpose of giving them comfort care at the end-of-life. So that's one big barrier. It would be great to have access to more beds and maybe a closer facility."

- Physician

"As good as the medical staff tries to be in terms of treating an individual patient with respect, custody does not always do that, medical people do not always do that, transportation does not always do that. So, there's a lot of meanness out in the world that you can avoid by not transferring. Often, they'll say [about an outside hospital] the doctor was great, the nurses were wonderful, but there's accusations of racism all over the place and it was miserable on a level that it did not have to be."

- Physician

"Over the years we've had this discussion with many patients. I clearly remember this patient we had the same discussion with in end-of-life stage and advised this man that we have a hospice in the system, that he was in a condition he could be moved in—he's not too sick. So, we gave him the option of that. I wasn't ready for the answer he gave me. That's why I still remember. He said, 'doctor you know I've been to the hospital, they send me to the hospital when I'm short of breath, and I go to the emergency room, and I don't know anybody there. All these nurses are strange to me, doctors are strange to me. You guys have taken care of me for so long.' He was in the CTC for a number of years, two or three years. 'I know all of you. I know all the nurses here. Don't send me to the hospital, and don't send me to any other hospice either. I'd rather die.' So, we become the hospice."

- Physician

Trust

This section discusses ways in which medical staff recognize that trust between the medical team and the patient affects medical care and also the challenges of establishing trust with patients in the prison setting.

● Establishing Trust

Participants acknowledged the importance of establishing trust in the medical-patient relationship and the difficulty of doing so with patients who have had negative past experiences with medical care in prison. Participants reported that consistently communicating genuine care for the patient's wellbeing was essential. Participants emphasized that an effective approach was to listen and take what patients said at face value; and rather than dismiss a patient whose claims seem ungrounded, take an inquiry stance and get more information.

● Effects on Care

Participants reported that one result of a lack of trust in the medical-patient relationship can be failed communication, and that this could have a detrimental effect on medical care. Such as a failure of a patient to accept a treatment or a failure of a medical team member to speak up about what they perceive as a medical need or symptom.

"It's a negative environment, so we [the staff] tend to stick together. Because we're dealing with violence and bad guys, I think that's what makes it—you want to be safe all the time. Safety is a priority. We deal with violence all the time, and it is very negative. Inmates are cursing, calling names and all that. I've had experiences but I've never felt unsafe, there's always somebody. I think about it for a few days and then try to move on, try to accept that these are inmates. You have to accept, there's limits to how you interact with them."

- Nursing

● Obstacles to Trust

Participants recognized obstacles to trust in the medical-patient relationship coming from both sides. Participants reported that patients may lack trust in the medical system—to the point of consistently refusing medical check-ups and refusing medical treatment. In some institutions, noncompliance with medical was prevalent. Some participants reported that concern over safety and fear of the patients could also affect patient care, and that a good support system among a care team could help with that.

"I think where I've done well with patients, and it's just my approach, is that you listen to them, you meet them where they're at. You take what they say at face value.... I think ultimately my approach that has worked well is people just understanding that you're there to care for them.... If you're getting new patients in, it's going to take some time to build that trust.... Just showing that that's why you're here... You just always have to take everything into consideration. And even the most difficult patients, you know we've got quite a few here, you just still sometimes have to step back or sometimes you have to have a colleague take a look for you."

- Physician

Recommendations from Staff

1

Trainings in Palliative Care

Participants stressed the need for more training in palliative care. End-of-life care is not so straightforward as treating illness; it involves a change of mindset. Also, people have different views, different philosophies on end-of-life care. Participants report doctors sending people to outside hospitals because they don't want to deal with end-of-life, or don't think it's their job, or don't know how to. Participants also reported that because palliative care can be a contentious issue among staff it doesn't get addressed as much as it could in team meetings. Without end-of-life training, staff burnout is more likely, as it is not easy encountering death, especially when one has been trained to treat illness and save lives. One participant recommended that working in palliative care in prison only come after medical staff have developed a feel for medical care in prison generally.

2

Care Team Model

Participants emphasized the importance of having a multi-disciplinary team involved to properly provide end-of-life care. The breadth of the team, from medication management specialists to dietitians and peer care workers, is important. So is stability of the team, people working with the same population over time, so that the team is best equipped to recognize decline in condition. Participants also reported that communication across the care team was essential, and therefore the training recommended above should extend across the members of the care team as well as to custody staff who are working in facilities providing end-of-life care.

"[A] multi-disciplinary team... It's clear that is what's needed and were still just not there. It's like we all know this and a lot of it just has to do with staffing, unfortunately, you know, getting stability. If you have a really stable clinic team, nursing staff, medical assistant, these different components, they can start to notice those things too. How do you create these models when you don't have the people to do it?"

- Physician

"To me caring for someone dying is as important as caring for them living. But a lot of doctors don't see it that way. I think they see it as a failure. Or they're so uncomfortable with it they just don't want to deal with it. Some of the doctors the first thing they want to do is send them back to the hospital—I'm like what, why would you do that? So, it does come up sometimes [in team meetings], but it can be pretty contentious. I think it needs to be talked about. There needs to be training for everyone, from the custody staff, the medical staff, the doctors and the nurses. For end-of-life care, it's not as straightforward as treating diabetes or hypertension."

- Physician

3

More Palliative Care Units

Participants stated that what was most needed was not full-on hospice facilities but more palliative care units. They reported that patients who are independent with little need for help from nursing but getting closer to end-of-life are the largest population requiring palliative care. One physician recommended two or three more palliative care units of moderate size (e.g., ten-bed units) in existing institutions as regional hubs for nearby prisons to refer patients to.

4

Prison Hospice in Southern California

We asked physicians and other members of the care team about what patients had expressed to them, during conversations about end-of-life, as concerns or considerations in deciding on whether to go to CMF hospice. Participants stated that patients often had a mistaken view about the nature of hospice. After patients were better informed, participants stated, then much of the resistance to hospice had to do with location. Participants in Southern California locations reported that many people are agreeable to a transfer to hospice, but not agreeable with going upstate, because it involves being far away from family, peers, or their care team. They also mention the difficulty of a long transport due to their physical condition. One physician stated that the major improvement needed was a hospice in the Southern region, and that ideally there would be a hospice in Southern, Central, and Northern California.

"The difficulty here mainly is geographic. So the patients don't have a problem with hospice, they have a problem with their families down here going 400 miles away or however far that is to a place where their family can't see them. So part of the issue is in my judgment is we need a Southern hospice, so patients who are from LA or Orange County or San Diego, San Bernadino, Riverside, or the lower desert can be sent here and that is still a realistic trip for the family to be able to get to them. So that's the issue. I've had people that just weren't interested in hospice. But more often than not that's not the case. They're down with hospice, once I explain to them what it is. But they're not down with going up there."

- Physician

"I think the need is mostly for palliative care. And it is twofold. One, in the current setting, that is the biggest need, for patients who are mostly independent with little help from the nursing staff but who are getting closer to end-of-life. This is the biggest population, patient population who requires palliative care. Need is to have more units like CHCF palliative care unit. Two or three more units throughout the state or in each region to work as the regional hub. They don't have to be as big as thirty beds, they can be a ten-bed unit. If we had three or four more dedicated, palliative care ten-bed units that would definitely help significantly."

- Physician

5

Facilities For Older Patients

Participants supported the idea of a single institution or multiple housing units across the state designated exclusively for older patients, an arrangement that would allow patients to remain independent, but also provide a space in which they would be less vulnerable to victimization and more easily attended to should their physical condition decline. Participants noted that providing institutional spaces specifically for older patients may also include changes in thinking about the use of group spaces and cells and housing units.

6

Facilities For Patients With Cognitive Impairment

Many participants stressed the need for more housing and programming for patients living with acquired cognitive impairment. Specifically, participants noted a need for more memory care units for patients with mild to moderate dementia, which would also entail a care team trained to provide the appropriate level of care.

"Imagining a space that's safe where people can still remain independent and do some activities, that allows them to do that on their own. The majority of people want to maintain their independence. But we get in the position if we see someone who's really failing and you can't expect a cellie to really take care of them, that's when you have to really start putting them in OHU or CTC. But I think there's other ways to do that. It would probably take reinventing how we think about housing units."

- Physician

"Dementia's difficult here. You really have few opportunities to advocate for yourself in prison. And if that moment flows by without you taking advantage of it, that can be difficult. And of course, you don't remember it just flew by but when there's an opportunity to make your life better and it's gone, and you missed it, that's sad. None of our patients are so demented that they need hospice right now. But we have transferred patients with dementia to hospice and they're gonna need more hospice because there's a lot of old folks whose memory is failing."

- Physician

"Providing housing where they would be safe from predators or people that might hurt them. We don't have enough help. A lot of programs are great but if we don't have the help to manage that then it's a problem and that includes nursing and doctors. To imagine a housing unit for older people with activities and exercise programs that center around them. Where they can go to a class, and they can do a wheelchair exercise class and they can do activities that center around their interests and that kind of thing that would be kinda nice for them."

- Physician

7

Amenities

Participants reported that older and ill patients often ask for amenities—as one physician put it, “creature comforts that we all would want.” These include extra blankets, softer mattresses and pillows, as well as specific clothing items such as shoes and hats with brims. Participants also recognized the importance of age being a factor for lower bunk assignments. Participants emphasized the importance, specifically at end-of-life, of having access to nature in the form of plants, a garden, or even just natural light. Participants also emphasized the importance of having more access to phone calls and expanded visitation, and accommodations so that one person could sit with another when they are dying.

8

Post-Death Protocol

Participants recommended greater attention to procedures that take place following death. In hospice, staff is trained in procedures for how to care for a body after a person passes away, but when a person passes on the yard, it was emphasized, respectful measures for the body should also be taken, including protective screens. Participants also noted the importance of having a normalized process for providing information about the death of an incarcerated person and allowing family and peers an opportunity to mourn.

“Ladders, right, the bunk beds. A simple thing like that. Something that really takes over quite a lot of the medical visit is the inability to get on the upper bunk. To get on the upper bunk you have to put a foot on the sink, on the little sink... and kind of hop yourself up to get on the upper bunk. And you think about someone who’s aging. Years ago, there was a soft age criteria. In my opinion, the officer should be able to say, you’re getting older here, go on the lower bunk. But that’s been removed so we’re put in this very difficult position of helping our patients understand. When I think of a major thing, it is a bunk issue. Not having little stairs to get to the upper bunk.”

- Physician

“I find that a lot of the things that some of the older patients come in and ask for are basically some of those comforts. You know they would like a softer mattress, or they would like a couple of extra blankets or a pillow you know, because they are getting arthritic and stuff. Being able to give them those creature comforts that we all would want without feeling like they’re jumping through a bunch of hoops to make that happen.”

- Physician

“So, when the person dies, in the CTC there’s no problem with this. They die in their bed, it’s an expected death, they can lay there. But for people that die in their cell, if it was expected often times they are just left in their cell on their bed until the coroner comes to remove the body. But that’s not always the case. They can die outside of their cell. And so, you’ve got this dead body, laying wherever, in front of however many people... and it can be hours before the body is moved. We are not good at putting up screens, we are not good at laying sheets, or if we do the sheet is over half the body and the legs are hanging out at an odd angle. It’s not good. That’s something we should work on, visual barriers and such.”

- Physician



Hospice Interviews & Observation

The study team spent two weeks at CMF hospice, observing best practices and interviewing medical staff, patients, and other members of the care team, including peer caregivers. This is a summary of what we observed and participants reported in their interviews.

Hospice Interviews & Observations

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Hospice Best Practices

This section discusses aspects of the hospice that study participants highlighted as positive and essential to maintaining quality care.



Stable and Experienced Nursing Team

The hospice is primarily staffed with experienced nurses who have spent many years in the hospice or plan to spend many years there. That stability allows for an environment in which there is high cohesion within the nursing staff and with the rest of the care team, especially the Pastoral Care Service (PCS) workers. We observed the nurses constantly sharing information and best practices with each other, which resulted in superior care for patients. The nurses created an environment among each other and with others that was supportive, relaxed, and full of humor and genuine care.



Experienced and Helpful Custody Staff

We observed the regular custody staff members in the hospice unit being respectful and friendly with PCS workers and patients. They trusted PCS workers to do their jobs in the manner that best met patients' needs and were flexible and helpful in the process. We witnessed some custody staff go above and beyond their required duties to help or accommodate nurses and PCS workers with aspects of their jobs. They contributed to the overall unit by helping with things like cleaning, getting areas ready for family visits, and by generally being observant and pitching in where applicable. It was the only area in a prison where we observed custody staff to be highly integrated with and contributing to mixed medical staff and prisoner worker teams.



Pastoral Care Service (PCS) Workers

We observed that peer support workers, being also incarcerated, provide a unique connection for patients that bridges a distance that otherwise exists between medical staff and patients. We heard consistently from PCS workers that they saw their job as helping patients "live" well for however many days a patient had left to live. PCS workers educate new patients about the culture of the hospice and help reassure patients coming from higher levels of security. They help overcome trust issues patients have with medical, engrained over years or even decades in the prison system. We spoke with one individual who came to hospice frail and near death and recovered to such an extent that he was discharged to the prison general population. Medical staff and PCS also emphasized the role PCS workers play in identifying subtle aspects of patient health, sometimes through non-verbal cues, that physicians and nurses might not have the cultural awareness to notice. It was also reported to us that PCS workers play an important role in maintaining a stable culture in the hospice during staff turnover.



"Out there a lot of times the family takes that role that we would take. To some degree we have that role that the family have, helping them with that acceptance. Maybe it's something spiritual they want at the end. Hey, you know, if they want to accept Jesus Christ at the end to hedge their bets, I'll help them. They want me to read the Koran, I'll read it. If they want to have somebody sit there and listen to them, tell them stories, or not say anything at all. Just be there, somebody to just be there. Nobody wants to die alone, right, I'm assuming. We're social people. Nobody wants to die alone, right? And that's part of our role, the acceptance role, helping them accept what's happening to them."

- PCS Worker

"They're us and we're them. And they recognize us as that. And that's why they talk to us—we know more what's going on with them a lot of times than the nurses, the doctors, or anyone else because they open up and they talk to us."

- PCS Worker



Care Team

Staff explained to us that the approach to care in the hospice is about working as a team, in which team members (including nurses, but also social workers, PCS workers, the chaplain, dieticians, and mental health providers) have autonomy to make decisions and contribute to care in their unique ways. Patients emphasized how attentive the care team was to requests, whether a serious concern or simply a basic need. Some members of the medical team emphasized the importance of team members working as a bridge with others. This was particularly true of social workers and PCS workers—positions that are not core to medical care in a prison setting, but which are integral to the patient-centered care model that the hospice provides. The role of the chaplain in the CMF hospice is uniformly recognized as a cornerstone that bridges all facets.

"I think the single biggest thing for me is just the way the team is looking at what their purpose is here. It's much more nurturing, it's much more focused on the individual holistically, and thinking about all the aspects of [the patient] and how they're doing as opposed to how are they medically doing today. It's a very different entity. I think there is far less of the hierarchical sense that I'm coordinating care from on high. Whereas in hospice, it's very much how can I [the physician] help facilitate what the team is doing as a whole. The buck always stops with the physician, but it becomes much more how can I work and move the team forward. You end up much more conducting a piece as opposed to playing all the instruments."

- *Physician*



PCS Worker Empathy Valued

PCS workers expressed that they value how the hospice creates an environment in which they can openly care strongly and emotionally for their patients. PCS workers are allowed to form strong bonds with patients, and those relationships are respected by the medical staff. They are also accommodated when grieving the loss of patients, and are given time, space, and resources to support in that process.



Power Sharing

We observed many examples of ways in which staff in the hospice (e.g., nursing, PCS, doctors) value the expertise and opinions of others. One example is when a new patient went on vigil, the PCS workers were primarily in charge of rearranging the living space to accommodate this. They sought approval from nursing, which demonstrated respect; and nursing and custody valued the expertise of the PCS workers and quickly moved to accommodate and supply approval. We observed staff working in harmony. There was almost no conflict observed in daily practices in the hospice.



Tokens of Hope

We observed that staff and PCS workers kept photographs and other tokens from PCS workers or patients who had been released from prison. The released people often sent back photographs of them in their “free” life that are highly valuable to the staff and PCS workers. We observed that many such photos were placed on walls and kept in albums to be observed and remembered. These tokens of hope hold a special place in the hearts of members of the hospice team and it is important for this remembrance process to be valued and supported. It is recommended that this practice of honoring incarcerated people’s successes and releases be implemented at other institutions as it appears to have an effect on staff morale to see positive outcomes of their efforts.



Patient Comfort Accommodations

We observed PCS workers and other members of the care team go above and beyond in their attempts to make patients feel more at ease in their transition to the hospice and help them feel comfortable and settled. For example, they went out of their way to discover a patient’s favorite music, provide them alternative food options, listen to fears and concerns, and get them amenities like socks and blankets in anticipation of their needs. They continually did their best to help the patients feel valued and content. In turn, this helped patients be more understanding with the medical staff, which results in better care experiences for the entire care team and the patient. Having the resources and permissions to better accommodate patients appears to increase staff satisfaction and sense of accomplishment.



Diet Accommodations

Patient access to alternative food options was reported as an important aspect of patient care that was heavily valued by the patients. Patients placed high value in comfort foods and foods they could easily identify. Patients valued access to fruits, condiments, drinks, cereals, and ice creams in the hospice area, and appreciated that they could at times make special requests from hospice staff or the kitchen. Diet accommodations, such as an open-access cereal bar, which could be used as a complement to a meal or simply as a snack, also provided patients with some sense of choice of what and when they eat.



Family Accommodations

The hospice allows visiting by family members with far fewer restrictions than the prison at large. Family members can visit for longer hours and for days on end. Hospice staff reported that they are conscientious and intentional about making the visiting experience comfortable for the family. We witnessed, for example, two generations of family visit a new hospice patient. The family had travelled a long distance to get to the hospice and were visibly pleased by the environment of the hospice and the attentiveness of the care team. PCS workers reported that they make an effort to be aware of the experience family members are having when visiting a patient, such as ensuring they have food to eat and lending an ear for family members coming to terms with how to grieve. The “family” visiting the hospice allows also includes peers from the prison. Some PCS workers first learned of the hospice by visiting friends who were patients in hospice and then became interested in being a caretaker.



Respecting Identity and Spirituality

We observed that the staff and PCS workers made a sincere effort to respect identity of patients to grant them dignity and make them more content at the end of life. Some of these efforts involved special accommodations around religious or spiritual desires and practices. Some of the accommodations are simple but important gestures of using preferred names and preferred pronouns when applicable.



Family Contact

An extensive and committed search is made to contact family members of hospice patients. These efforts often go above and beyond what might be expected, such as calls to embassies. The efforts have resulted in an extremely high success rate of reunification, and this service is highly valued by the patients. It is an example of a truly holistic approach to patient care that considers the patient's social and spiritual needs. It offers an invaluable service to the families of patients, who are often extremely grateful for the opportunity to connect with their loved one in the end. Playing a role in successful reunifications also brings a great deal of satisfaction and joy to the staff.



Care Team Huddle Inclusion

The inclusion of non-medical staff (i.e., custody, social workers, chaplain, and PCS workers) appeared to add great value to weekly team meetings. Non-medical personnel shared aspects of the patient's history, concerns, likes and dislikes, and their successes and failures in responding to the patient's holistic care needs, as well as release efforts. Some of this information resulted in meaningful plans or course corrections for medical care. The huddles also offered opportunities for the care team to bond and offer sympathy and support around the challenges inherent in operating a hospice (e.g., deaths, patient fears). This activity appears to help produce a stronger and more aligned team.



Compassionate Release Applications

Medical staff, other members of the care team, and patients all credited the efforts by the hospice leadership to efficiently seek compassionate release and find community placement on behalf of the patients. We were told of multiple cases in which compassionate release was achieved, and we saw on the walls of the hospice the many pictures sent in by patients who had been released, documenting these fortunate outcomes. Even in cases where the compassionate release doesn't come to pass, the possibility of a compassionate release and the care team's demonstrative effort to seek it and achieve it on the patient's behalf are a source of hope, giving patients some tangible path by which they could see themselves released from prison.

Areas For Improvement

This section discusses aspects of the hospice that study participants highlighted as areas that could benefit from increased attention, redesign, or other forms of improvement.



New Custody Staff Training

Some staff suggested that custody staff who are new to the hospice area or cover shifts in the hospice receive specialized training, as the PCS workers and some of the medical staff undergo. They suggested that working in the hospice requires a different approach and mindset than the rest of the facilities, and that certain accommodations and other differences in patient care need to be explicitly explained.

“Something that would be helpful is for there to be some way for a broader understanding between custody and medical. You’re coming into this job as a [correctional officer], but part of being a [correctional officer] in this environment is that people are sick and they’re going to be dying. You’re going to have a small part of what you do that holds some compassion for that. You’re entering this field, there is an aging population you’re going to have to deal with. They’re going to have dementia. They’re going to have lots of medical issues. Maybe your institution isn’t going to be able to address those. Please keep a pair of glasses in your pocket that you can put on and look through and see ‘this is one of those guys they talked about, how can I help this person.’ You’re still a service person. You’re a correctional officer in a facility, but that’s a human service job. But I think that ‘human’ part gets left off for some people. If somehow, they could be introduced, like, hey, you’re going into this environment and you’re going to see not just criminals. They’re also humans and they’re also aging and they’re going to have things that you should be aware of and maybe you can help flag them to the right person. We all have an aging someone in our lives, and maybe it’s part of the training. You all got a grandpa; you all got a grandma. There are gonna be grandmas and grandpas in there. Not yours—and doesn’t really matter if their someone else’s—but there are issues that are going to be the same, and you still find a place of advocacy in your heart within the scope of your job.”

- Care Team Member



Staff Transitions

When senior medical staff or other senior staff transition out of the hospice, it appears that there could be more time spent helping new staff in those roles to adapt to the unique practices of the hospice. We witnessed staff express frustrations that former best practices were no longer being replicated or supported, and that experienced lower-level staff were not being heard when trying to communicate long-standing best practices.



Medical Staff and PCS Culture Training

It was reported as common for new medical staff members in the hospice to need time to adjust to working side by side with PCS workers. Some staff reported that they were not used to working with incarcerated people so closely and felt that the incarcerated people expressed their opinions about patient care strongly, which initially was jarring. Because the hospice work experience is very different from other areas of prison assignments, there could be more support for new staff as they adjust to the hospice work environment.



Pain Medication Allocation

Doctors reported that some nurses might be overly cautious in providing the authorized amount of pain medication and not compliant with a doctor's orders. This was reported to be especially true of new or temporary nurses in the hospice. Some nurses reported that they felt they needed to still be highly cautious about pain medication distribution in the hospice. Nurses expressed concern over addictive behaviors in patients they have witnessed. Their concerns should be better addressed by the greater care team. It was expressed that more training on hospice pain management practices could be valuable.

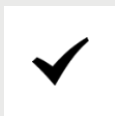


Alternative Menu Options

The CMF hospice offers patients an alternative menu option, such as sandwiches, in addition to the meal trays. Some patients reported that they were not aware of alternative menu options. It also could be difficult for some patients to retain the knowledge of these alternative meal options. A suggestion is the creation of an easy-to-read menu with pictures of the alternative meal options offering patients the option to mix and match some meal items. All of the meal items should be basic classic meal items, such as hamburgers or coleslaw. Some staff emphasized the importance of having choice in diet for its emotional benefits to patients.

"Here we try to give them a sense of more choices. We have a cold cereal dispenser here. They can take the cold cereal themselves. If they want something, they can ask the nurse, and if we have it, we can give it to them, which is different from the main line. The most challenging thing [in this job] is the limited food choices because we cannot give them everything. If you ask me, I would say give them two maybe three options for entrée every single day that they can choose from. But now we can only give them one entrée every day. If they have more choices, it will make people happier. If we go to a restaurant, we can look at the menu, we can choose whatever we like. At least we [could offer] two or three options to choose for them. Different choices provide you better emotions. It is a dilemma here because this is a prison, we cannot give them everything."

- *Dietician*



Transportation Practices

We observed an instance of a hospice patient returning after being transported to outside medical care in shackles. The shackles ripped open his skin, which was delicate from age and chemotherapy treatments. He reported that in the transportation vehicle he was thrown around the vehicle and was unable to brace himself, resulting in further injury. The results of this were visible physical harm and mental anguish. Acts and events like this can erode hard-earned trust and acclimation efforts.



Volunteer Access

It was reported that at times gaining clearance to provide volunteer services can be an obstacle to volunteers. Given the huge value provided, it is recommended that, in general, volunteers be given increased support and that recruitment and retainment of volunteers is heavily valued in the hospice.



Grief Group

Staff and PCS workers expressed their desire for a “grief group” in which any hospice team member would be able to voluntarily join. The group would meet regularly to discuss their challenges around grief and their strategies for working through their grief. The group could be led by staff members with training in this area. While many in the hospice have their own ways of dealing with grief and share that grief within their own community (e.g., nurses with nurses), some see the value in having a venue to share their grief across lines communally.



Weekly Check In

It was reported that early on at the hospice PCS workers, volunteers, and medical staff coordinated a weekly meeting group. Those weekly meetings served both as opportunities for continued trainings and also as opportunities to share and discuss aspects of the job. Some hospice staff and PCS workers identified these meetings as essential elements that had contributed to building the culture and the community of the hospice. It was suggested that weekly meetings where people could check in, obtain additional trainings, get support, and share challenges and successes would still be productive today.



Better Dissemination of Information about Hospice

PCS workers and patients reported on the lack of information that many incarcerated people have about the hospice, even in CMF. Some potential patients may not know the hospice exists. Patients and PCS workers also reported that misinformation about the hospice circulates in the prison and in other prisons. Potential patients may envision the hospice as akin to a CTC area in other medical prison units, where they would be housed in a locked room. Potential patients may be told that the hospice is a place where people simply go to die. At CMF, misinformation about the hospice is counteracted by tours of the facility that include introductions to medical staff, PCS workers, and the chaplain, and also include visiting the outdoor garden space. Tours are not possible, however, for patients considering a transfer to hospice from other institutions. PCS workers reported that when new patients arrive at the hospice, they are often surprised by the freedom of movement that is possible and the choices they have.

“There are people that have come here, and they’ve been told by other people that, ‘yeah, that’s where you’re going to go to—that’s a place where you’re going to get locked in a room and you’re going to die.’ This is a place where you get anything but locked in a room. This is a place to live, not to die. This is a place to come to try to live the last part of your life at its fullest possible for the situation in which you’re finding yourself in. That’s what this is—a place to live your life to the fullest.”

- PCS Worker

Replicating the Hospice: Aspects to Consider

This section discusses aspects of the hospice that study participants noted as important to take into consideration if the hospice is to be replicated at another institution.



Social Life

PCS workers and patients reported that the social aspects of the hospice experience were very important to them, including group activities like bingo and music therapy. We observed people in high spirits during group activities, which contributed to their overall well-being and contentment. Incarcerated interviewees emphasized that for future care planning for older adults, the facilities need to include social spaces. Given strong fears of dying in an isolated environment, even if medical care at a facility is top quality, incarcerated people would strongly avoid going to a facility that did not have basic access to social spaces and activities.



Larger Living Quarters

Some of the medical staff recommended that if the hospice were to be replicated in another facility an important consideration is having larger living areas for patients and making sure that these living areas have the room to be wheelchair accessible. Patients also reported wanting larger living areas so that they could experience more privacy and have more space for their personal possessions.



Number of Beds

One member of the medical staff recommended that if the hospice were to be replicated in another facility an important consideration would be to have more than a few beds (the CMF hospice, for example, has 17 beds)—enough beds so that the facility would be able to house enough patients to make a community. Community being an essential element of the hospice.



Beautified Outdoor Space

Medical staff, PCS workers, and patients consistently emphasized the importance of an outdoor space, such as the hospice garden at CMF. Given our experience witnessing the daily activities and interactions that took place in the hospice garden, it is hard to overstate the importance of the garden to the medical and social environment and to the patient-centered care the hospice provides. Patients regularly visit the garden to walk, sit, or socialize with other patients or members of the care team. It provides a healing place to visit with family. The outdoor space is a site for creative and artistic collaborations between volunteers and patients, such as the mural on the long wall of the garden space on which we witnessed patients and volunteers drawing and painting. The garden also serves as a space for activities such as music therapy. The garden is a place for memorials of patients who recently passed away. PCS workers and patients contribute to tending to the garden. A former patient who recovered at the hospice described the garden as a space that allowed him to thrive.

"To me, the garden in the hospice is very important, very important, because some of the folks are not going to live—a lot of them they push them out to the garden in their beds. And I know that even though a lot of them couldn't talk that they felt something good inside their heart for being outside of the walls, even if it's for ten or fifteen minutes outside. Looking at the birds flying by or looking at the flowers or talking to the guys out there, just being outdoors brings happiness to you inside. When you're locked in a place where it's all closed in it's a little depressing, especially if there's not lights. The light brings happiness and good feeling out of you, where a dark room makes you sad. When you're closed in and not being able to go outside, it's tormenting. For you to be able to look outside and see the sun and even the dirt out there, it does something to you. It does something to you. And in hospice, it did something for me just going outside."

- *Former Patient*



A Distinctly Separate Space

Medical staff, PCS workers, and patients emphasized the importance of situating the hospice in a space that was physically separate from the rest of the prison. The physical separateness of the hospice space was seen as an important element contributing to the feeling of a distinct community, providing not only medical but also social and psychosocial care. It also helps to have a distinctly separate space in which all patients are aligned in their end-of-life care philosophy because it allows the staff to plan and deliver a unified vision of care, which can in turn increase staff cohesion.

“Making the space distinctly separate, both in terms of logistically and kinds of things like the garden, as simple as it is. The layout of the unit, while it’s not ideal, is nice in that it’s a large communal space that’s there that ends up being—it feels emotionally and physically distinct from the correctional facility around it. I think it wouldn’t serve well to be just a new block somewhere that’s designated ‘hospice’. It really wouldn’t have that same feel to it.”

- Physician



Open Door Policy and Freedom of Movement

The option to move freely in the hospice space was emphasized as an essential ingredient to the culture and experience for patients in the hospice. An open-door policy for patient rooms in the hospice was recognized as a core part of this. Freedom of movement allows quick medical responses, but also inclusion and spontaneity of social interaction that is integral to the hospice culture.

“Some of it is the physical space. Taking into account whatever safety and security constraints there are in a particular place, I think having an open unit where there’s freedom of movement within the unit ... open doors. I would like to see a more open and dynamic environment for people regardless of what age they are.... Having more gradations of openness, where, if society decides that people need to be incarcerated at that age that we have more openness and basically create a more humane environment for the people who are still here.”

- Physician



Support at All Levels

Medical staff, members of the care team, and patients all recognized the importance of multiple levels of support for the hospice facility. Support of people up and down the chain—a cultural anchor, such as the current chaplain at the CMF hospice, as well as people at higher levels of leadership and administration who understand the culture of the hospice facility and are vigilant about protecting it. In addition, the importance of having seasoned people (veteran nurses and custody staff, PCS workers who have been incarcerated for a long period of time) working in the hospice who respect the culture was also emphasized. As one person put it, it takes everybody’s full buy-in to allow this to happen. Some medical staff and PCS workers also noted that the culture of CMF as a medical institution is unique to begin with, which may make it easier to find hospice-ready staff at the institution. When asked if they could imagine this institution being replicated in the South, one patient responded: “Yeah, sure, if the right people are involved. It all depends on that.”

Indirect Benefits of a Hospice Unit

This section discusses aspects of the hospice that study participants designated as having an impact beyond the immediate care of patients and outside the walls of the hospice.



Virtuous Lifestyle

Incarcerated people reported that people housed in the dorms with PCS workers regularly observe or join in conversations with them about the hospice. In the housing unit, non-hospice affiliated incarcerated people reported that they felt inspired by the PCS workers. The people in the housing units listen to stories that demonstrate virtue and selflessness on the part of the PCS workers. PCS workers consistently reported that work and interaction in the hospice allows them to give back, make living amends, be the person they want to be. Both PCS workers and their greater community of incarcerated peers benefit from the examples of virtue set by the PCS workers.



Community and Home

The combination of best practices and environmental factors noted above contribute to a social sense of community, to a comfortable material environment, and to a space that some patients come to feel is home. Patients and PCS workers consistently identified dying inside prison as an end that no incarcerated person wants. Yet some patients who had applied for compassionate release, and who expected to be granted release to outside nursing homes, expressed that they were nevertheless considering whether to stay and spend their last days at the CMF hospice because there were people who made them feel cared for and comfortable.



Culture of Optimism

Medical staff, PCS workers, other care team members, and patients reported finding hope and inspiration in the hospice environment that they might not find in other places. They find hope in the patients who leave prison through compassionate release. They find joy when family reunifications can take place thanks to the monumental efforts of the staff. In the face of prolonged exposure to death, the team has managed to build a culture that maintains and uplifts moments of hope and optimism whenever possible. This culture appears to be an important aspect of supporting the mental health of the team and the ability for team members to sustain their position for long periods of time. In facilities where there might not be much optimism overall, the hospice offers a different approach.



Medical Staff/ Incarcerated Person Interaction

Both medical staff and incarcerated people (PCS workers and patients) reported that they built better relationships with each other while in hospice. Medical staff reported that they felt their collegial relationship with PCS workers inspired them to think more about the possibilities of change and amends with incarcerated people, and that the PCS workers also helped them better understand the needs and motivations of their patients. PCS workers and patients reported that they greatly valued the high levels of compassion, care, and support shown by the medical staff in the hospice unit. We observed many instances of trust and mutual aid between medical staff and PCS worker that produces a culture seemingly unique to the hospice.



Medical/Custody Interaction

Some medical staff reported that having the hospice onsite contributed to a stronger and more communicative relationship between medical and custody at the institution. Significantly, the investment in the hospice at all levels of administration historically has helped to generate and maintain communication with medical, and this has led to more flexible and productive decision-making over time.

"I would say that having the hospice makes the relationship at this institution—makes the relationship between custody and medical stronger and more flexible when it can be. The leadership is all the same people whether you're talking about hospice or outside of hospice, but the fact that we have a mission to have this hospice here, and all the other different levels of care, you know, we have the different levels of mental health care here, not all institutions have that; we have all the different levels of medical care, nursing care, so the idea that we have all those things under one roof creates a history over decades of the custody leadership collaborating with the medical leadership. So, I don't think that we [medical] necessarily have more clout in hospice, but the fact that we have the hospice here allows those relationships to develop over time and then, when there is an issue, we can talk to each other and actually find better solutions."

- Physician



Note: Limits to Indirect Benefits

Some incarcerated people and staff reported that there are areas in the CMF facility that lack a respectful and holistic care environment, in which patients are cared for in non-optimal ways. Some incarcerated people and staff reported that they saw the hospice as an isolated space within the larger prison and found that the care practices of the hospice did not extend beyond its walls. In particular, in-patient psychiatric, administrative segregation, and areas that house patients with low levels of mental competence were mentioned as areas that often lack humanistic care practices. It was reported that the environments of these places made it very difficult to provide adequate care and implement holistic care practices because patients could not get to a baseline level of mental health stability.



Group Interviews

Groups of five to twelve patients who were 50 years old and older and living with a chronic illness were interviewed at ten CDCR institutions. This is a summary of what participants reported in the group interviews.

Group Interviews

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Positive Experiences with Medical System

This section discusses the most common positive experiences participants reported about their experiences with the medical system in CDCR.

● Individual Doctors

At most facilities, patients reported having made a good connection with at least one doctor. Participants were very quick to praise the doctors they have had positive experiences with. What often made those doctors stand out to participants was the doctor's willingness to listen to their concerns, their effort to make the patient feel comfortable and cared for, and their thoroughness in conducting a full review of the patient's file and involving the patient in any updates or amendments to it. Participants desired to continue care with these doctors as long as possible and would try to stay housed in the same yards and facilities to maintain care.

● Treatments

Participants reported that they were appreciative of the medical treatments they receive for their conditions. Some participants reported receiving a relatively quick diagnosis and course of treatment for pressing conditions. A few participants expressed that they felt they received faster care or better treatments than they would be able to acquire outside of prison.

● Medical Team

Beyond individual doctors, some participants discussed being satisfied with care they received from their medical team, including mental health and nursing. When the team as a whole treated the participant as a regular patient (i.e., akin to someone outside of prison) and not as a "prisoner," they were much more satisfied with their overall medical care. In particular, patients were very happy when they found nurses who were responsive to their needs and had a caring and respectful attitude.

● Outside Specialists

Participants were often satisfied with the care they received from outside specialists. They expressed that outside specialists would often listen to their concerns and recommend thorough courses of treatment that participants supported. However, some participants, particularly those housed in rural areas, were concerned about the overall quality of care in outside hospitals.

"Dr. [X] is doing whatever he can to make me comfortable. And I appreciate that. I've told him, if I ever get out, I would love to have him as a doctor on the outside."

"I'm one of the guys who wants to stay here because I love my specialist, who treats me well. I'm getting the treatment I need. I'm without pain."

Negative Experiences with Medical System

This section discusses some of the most common negative experiences participants reported about their experiences with the medical system in CDCR.

● Unresponsive Staff

Many participants reported instances of poor medical care due to what they perceived as the fault of undertrained staff or staff that were unwilling to provide necessary care. They reported tests and medical care—for example, catheter placement—being done incorrectly and resulting in negative health outcomes. A large part of these concerns focused on nursing staff. Participants felt that some nurses failed to adequately communicate with doctors and/or correctly follow instructions from doctors. As well, some participants expressed that nurses were not prepared to handle the needs of older adults and those at the end-of-life, such as understanding and accommodating dementia patients.

● Communication

Participants regularly reported that their care team failed to communicate essential information to them about their health and care. They reported that, at times, basic information such as what type of cancer they had, was not shared with them. Participants felt that medical staff often did not believe their conditions and therefore did not respond with necessary testing and treatment. Participants also reported that when treatments had adverse effects on them, their reports of adverse effects were often not believed or minimized. As seen in quotes throughout this section, patient conditions and treatment options/plans may not be communicated clearly to patients, which leads to high dissatisfaction with their medical care.

● Inadequate Care

A common issue reported in the group interviews was that participants experienced long delays in having their conditions tested, diagnosed, and treated, including long delays between each of these steps. Participants often reported that their initial symptoms were dismissed and, therefore, their condition was caught too late to have a good possibility of a successful outcome with curative treatment. Participants routinely discussed how requested tests were denied or so long delayed that treatment was provided only when their condition reached an emergency hospitalization level of care. Some participants, even when in high levels of pain and with visible maladies, reported that they were not receiving adequate care to treat their symptoms or manage their pain. Other participants reported receiving the wrong treatments for their care, such as incorrect medications or injections, which caused adverse medical conditions.

● Post-Op

Participants often reported that they felt their post-operation care was severely inadequate. They were concerned that the post-care instructions given by the operating physician were not followed. They reported that they did not receive the medication prescribed by the operating physician, including medication to prevent infection. In general, it was frequently reported that patients had a difficult time recovering from procedures due to conditions they felt were preventable. In turn, they felt their poor recoveries often produced further health complications which required increased medical care and perhaps further medical procedures.

"I had a brain tumor removed from here. It caused me to have seizures. And it is supposed to get checked every six months. And they're not doing it. It's hard for me. I can't even look behind my neck, behind my back. I cannot do that. Because it hurts. And they still have not took me out to get another test run to see if I have another tumor growing. And the doctor in [outside hospital] told me they supposed to check every six months. And they ain't doing it yet. And I have fluid in my legs. And it's hard for me to walk. The bottom of my feet hurts when I walk. Then they tell me it's not fluid. And I know that is because it runs in my family. And they not even draining it."

"When I went to the window, I said, 'Hey. I have something with my eye.' They said, 'Oh, okay. Go to the nurse. The nurse is going to give you something.' When I go inside with the paper, the nurse gave me a drop. She said, 'Put two drops in both eyes.' I said, 'No. It's only the one eye.' The nurse gave me the wrong eye drops. I put it in my eyes, and my eyes, they stung. In maybe 20 minutes I opened my eyes. I went and looked in the mirror and it was white. White. The pain was hard. When I go to CTC, the doctor told me, 'Oh, no. You're going to go to the hospital.' In the hospital, it was two days to check my eyes. Two days in the emergency rooms. I lost my vision because the nurse gave me something. She ain't a doctor. I don't see nothing with this eye. I don't. It melted out. It melted out."

Diet

This section discusses the common concerns and desires incarcerated participants reported about their diet in the general population and in-patient medical areas.

● Serving Size

Participants in general population reported that the serving sizes of their meals were often inadequate to satiate their appetites. In response to this, participants reported feeling the need to supplement the meals provided with food purchased from the canteen. While this helps to supplement food intake for those who can afford it, the food options at the canteen are limited and often lack nutritional value.

● Special Needs Diets

Participants in general population and medical units reported that they did not receive medically necessary changes to their diets, even after major medical events like surgery. Participants reported that they would like to be able to monitor and control health issues, like high blood pressure and diabetes, with medically necessary changes in their diets, but were unable to do so. They would like the ability to request diets low in carbohydrates, sugar, and other factors important to the management of health conditions.

● Nutritional Value

Participants in general population reported that their provided meals and canteen food options are often highly processed and high in carbohydrates and sugar. Participants want healthier meal options that would allow them to better manage their long-term health. They reported that their diet exacerbates negative health conditions.

● Food in Medical Units

In medical units visited during the group interview phase of the project, the quality of food was a very common and strong concern. Many participants found the separate food provided in these units to be inedible because of its contents or the manner in which it was cooked. Some participants nearing the end-of-life strongly desired access to general population food because it was seen as a significant improvement to what they were receiving in medical areas, which was a distinctly different meal. Some participants discussed forgoing meals because of the poor quality of the food, which could have consequences to their health and morale when they are medically vulnerable. Others expressed that meals in the medical units were not tailored to their conditions and therefore often not an improvement health-wise over what they would have received in general population. Participants requested hot meals in the medical area and meals that do not have packaging that is difficult for sick and weak patients to remove.

"Take the dinner. I don't want the dinner. I'm not supposed to get a fruit cup. A fruit cup is made of all corn syrup – sugar. Pound cake, all sugar. Graham crackers, sugar. Wafer thins, sugar. The doctor has told them do not give me anything with sugar. I'm still getting that. Food's cold. Food is burnt. I've gotten food that was for dinner that the pasta was burnt. I'm supposed to be on a low-carbohydrate diet. Is pasta low carbohydrate? No. Rice, no. Corn – not supposed to have high in sugar. Okay? Potatoes – carbohydrates. Everything they give you here is carbohydrates. You're supposed to be on a diabetic diet."

Medication

This section discusses concerns participants expressed about their ability to access and properly regulate their medications.

● Pain Medication

In most facilities, participants reported that they had a lot of difficulty acquiring the appropriate level of pain medication for chronic pain and post-op care. Patients reported receiving nothing more than “over the counter” medication. We could visibly observe some patients in high levels of pain during the interviews. Participants reported that doctors were unwilling to prescribe them the appropriate level of pain medication due to concerns about substance abuse.

● Access to Medication

Participants reported that they routinely were in situations where they were on a medication that was helping them but then were taken off that medication for non-medical reasons. They said that when they transferred, or acquired a new doctor in the same facility, that medications would be missed or new doctors would not believe that medicine to be necessary and would stop prescribing it. Participants discussed that after a medication was working and symptoms abated due to the medication, doctors or nurses would take this as a sign that the medication was no longer necessary, instead of it being effective. Participants also frequently reported being denied medication recommended by outside doctors and given no comparable alternative.

● Overmedication

Specifically in relation to psychiatric medication, there was a strong concern among some participants that they were being routinely overmedicated to the point where they became unable to carry on a conversation or participate in regular daily activities. We observed some participants who were very sedentary and had difficulty communicating, who were able to communicate better later in the interview when they said their medication had begun to wear off.

● Drug Interactions

A common worry among participants across facilities concerned interactions between medications and that their physician would not recognize possible negative interactions. Multiple participants shared personal experiences of having bad drug interactions and later learning that those medications have warnings to not be prescribed together. Some patients expressed that they regularly did not take new medications prescribed to them because they did not trust that a thorough review of their medical file had been done before a new medication was prescribed.

“So, I had to spend a couple extra days in the hospital. I’d go for chemotherapy, like I said, every two weeks. [A CDCR institution] ‘OD’ed me on my insulin, and my metformin, and most of my other drugs. I’ve been trying to get that lowered since I got [new CDCR institution]. The doctors look at me and they say, ‘No, we can’t do it.’ They can’t lower my medications. But they’re ‘OD’ing me. I take them and they knock me out. I go unconscious for almost half the day.”



"I'm telling them my pain is up to like about nine. My body feels like a toothache all day, every day. And I'm telling them. And I'm taking NSAIDs. But I have been taking them for a long time. And it was bursting the little veins, capillaries. So that says you should be not taking that anymore. And I had been on injectable. And then, it gave me psoriatic arthritis. So, I had to get off of it. I didn't have psoriatic arthritis before. We never addressed that. And I still have it after five years, on my feet and on my legs, where it's just peeling, peeling, peeling all the time. And so, they keep dismissing these things. And I say the same about the inflammation, that I know that's where the aching is coming from. And they keep saying it's normal. But I'm saying, 'How is it normal if I ache like this?' And then, when I went yesterday, the nurse tells me, 'Well, you know, the weather has gotten cold.' I hate that excuse. But my rheumatoid arthritis is an autoimmune problem. It's not osteo. I know the difference. And now my joints are changing. Like my knuckles and everything and my ankles are changing, where now my hands are beginning to ache really bad because it's progressing. And the medication's not working like it's supposed to. And now I was almost in tears yesterday. I almost never sleep anymore. I maybe sleep maybe an hour. And I said I feel like a rotisserie chicken. All I do is turn all night long. That's all I do."

Housing

This section discusses housing concerns only as they relate to patients' health. The focus is not on their preferences, but on how they report some housing accommodations to be essential for health.

● **Single Cell Health Accommodation**

Many participants expressed the need for a single cell medical accommodation. It was the top housing concern across facilities. Many patients were sincerely afraid of being stabbed or killed by their cellmate due to their cellmate's anger over a medical issue they couldn't control, such as incontinence or a colostomy bag. They expressed that being housed with others while having certain medical conditions put their life in danger. Some also reported that they feared they would need to stab cellmates as the only way to transfer away from these dangerous housing arrangements. Overall, even if it did not get to the point of bodily injury or violence, participants expressed that having a single cell medical accommodation when living with chronic conditions or undergoing treatment would greatly reduce their stress and give them better opportunities to heal or manage symptoms. Additionally, older patients noted that, as they weaken, they are often the target of theft, stolen medication, and stolen property, commonly food. This poses health concerns because patients are not able to take necessary medications or get their diet supplemented with food from the canteen, which can contribute to an already weakened state. Finally, participants were concerned that, when receiving medical treatments that weakened their immune system, pods and larger dorm settings were unsafe environments, and felt it would be safer to be housed in a single cell for at least the duration of the treatment.

● **Accessibility**

Participants reported that accessibility accommodations within a cell or housing unit would significantly improve their ability to manage their health conditions and prevent falls or other injuries to which older adults are more susceptible. They would like lower bunk accommodations more readily, and many individuals across facilities with mobility issues reported that they did not have this accommodation after repeated requests. Similarly, participants reported the need for shower or bath access for people with mobility issues as well as extended time in washing areas. Especially for those in medical units or facilities, participants reported the need for an emergency call button because in some facilities it was difficult or impossible for them to get the attention of a guard or nurse during night hours.

● **Geriatric Unit**

In response to the safety concerns related to declining health that people experience as they age on the mainline, participants across facilities proposed a geriatric yard or prison as a solution. In a geriatric unit, participants anticipate that they would be able to better focus on managing their health conditions and recovery from procedures, in part because fear of violence would be largely removed from the equation. In this area, there could be medical staff with geriatric training and groups/programming to better support populations with similar medical conditions, such as cancer support groups. During interviews, however, it was sometimes stressed that entry into a geriatric unit should be voluntary because some participants enjoyed mentoring youth or living among a diverse group of ages.

● Hospice Units

During the interview process at most institutions, we were asked to describe a prison hospice—participants were not aware of the CMF hospice and did not know what a prison hospice would provide. Upon learning about the CMF hospice, many people liked this option for potential end-of-life care. However, it was also common for participants in Southern California or Central California facilities to express reluctance to move away from family. And many participants, regardless of location, expressed concerns about transferring for reasons including liking their doctor and having people who cared for them at the current institution. Participants in multiple interviews proposed the need for additional hospice units in the CDCR system, especially a unit in Southern California.

"I was asleep, and the gentleman, who was younger, was on an upper bunk. And because of the incontinence and issues like that, he attacked me while I was asleep. And I have a broken nose and broken eye sockets and a concussion. And I also have damaged vertebrae in my neck. I've had to deal with that ever since. And they ignored it. Medical completely ignored it. I can't breathe. If I lay down at nighttime."

"Sometimes they try to put young cats in the cells... and their mindset is completely different. Usually when you're over a certain age, you mature and your thoughts on how you do things. If you get some young person in here, you're not going to get along. It's going to be a complicated situation. It's unnecessary stress in that situation.... Because as you age, some people get vulnerable. When you get vulnerable, you have some people that aren't scared of us, and they'll try to take advantage of, or exploit somebody."

Environmental Conditions

This section describes aspects of the patient's environment that affects their health.

● Temperature Regulation

In Southern and Central California institutions, especially desert institutions, participants expressed high levels of concern about heat and their health conditions as they aged. They suggested that older adults and people with high levels of comorbidities should not be housed in desert facilities where the temperatures regularly remain above 100 for extended periods of time. During hot periods, older adults have high difficulty accessing outdoor spaces and transporting themselves to medical appointments. Participants also reported that they were on medications that caused heat intolerance and yet were housed in desert facilities. Participants in facilities, especially in the north, reported that they lacked warm clothing and blankets in medical units to protect themselves from the cold. We observed patients who were shivering in medical units.

● Environmental Toxins

Participants in multiple facilities reported that they were exposed to environmental toxins at their facility. Some participants brought documents with them in an effort to support their claims. Some of the toxic conditions reported included: pesticides and other chemicals from land adjoining the prison, water with high levels of toxins, and contaminated food.

"We haven't been out in a month. My cell, when it rains, it shuts off the floor's power and the cell floods. So, this place ought to be condemned truthfully. You see, it smells like something died up in here. We haven't left there in a month. With no showers."

● Access to Outdoors

At some facilities we visited, participants reported limited access to the outdoors. This occurred in medical areas and general population areas. In one medical area, patients reported that they were only allowed out of their cell ten minutes a day. In one general population area, participants reported that they had not had yard time in over a month. Participants discussed that they were concerned about how the inability to have adequate movement and exercise was exacerbating some of their health conditions.

● Building Design and Upkeep

Participants expressed concerns about ventilation and how that affected their health, in relation to infectious disease and toxic contaminants. Another concern commonly expressed was the lack of sanitation in some facilities and the inability to acquire adequate cleaning supplies. Additionally, the design of some yards or facilities are not accessible to older adults. Participants reported difficulty with stairs, and long walks to access necessary resources, including medical areas.

"[T]hose buildings are real dirty. And in my block, it's just bad health, bad air, bad everything, and I'm breathing every day. You know what I mean? The majority of us have respiratory problems. And so this bad air, poor air quality and everything else, it just has a tendency to affect us. And I'm not just talking about people that's 50 and over. I see youngsters here getting sick a lot. So, the building needs to be cleaned up."

Medical Supplies

This section reports what participants had to say about medical supplies, including lack of access to medical supplies that are necessary or beneficial for their health.

● Quality of Supplies

Participants discussed receiving malfunctioning medical devices, as well as medical devices that failed to meet their needs, such as walkers and wheelchairs that were much too small and did not function as intended. Additionally, some participants discussed having to wait for extended periods of time to receive medically necessary supplies and devices, and many participants discussed having these supplies or devices taken away from them when they transferred facilities.

● Temperature Regulation

Participants reported that their health would be improved by medical supplies that could aid in temperature regulation, including curtains, warm clothes, blankets, fans, and other cooling or heating supplies. Older adults and patients with multiple comorbidities request special accommodations to prevent health crises.

"Because when I was at [CDCR institution] with the heart, they gave me the stretch bands and everything. But when I got here, they took my walker. They want to take my shoes. They want to take my stretch bands. They took all that and said, 'You don't need this'.' And that's why I still don't have a walker."

● Support for Aging

Participants reported that they desired an array of medical supplies to manage or reduce their chronic pain symptoms. They request access to arch supports, support pillows/wedge pillows, supportive mattresses, cleaning supplies (for incontinence), and basic pain relievers like cough medicine.

"When they put a port in me, they had to pull the port out because they put a defective port—one that the doctor said is no longer in use. So, the doctor that I went to actually had to pull the port out and put a brand-new port in. It's not working in the middle of chemo. And it's throwin' me back. I mean I got so sick, you know. While they're checkin' my heart, doin' all kinda things, and then they said, 'Ok, we gotta check the port.' And it's right through the main artery. Right in my vein. And so, blood is backin' up and they're not going through. And it's so painful 'cause it feels like your chest is keepin' it in."

Stress and Stress Reduction

This section reports on how participants discuss stress and anxiety affecting their overall health. It also includes recommendations on ways participants feel that their stress could be reduced.

● Stress and Health

Across facilities, participants discussed experiencing high levels of stress. They are concerned that prolonged somatic stress responses are negatively impacting their physical well-being. They report that they believe that stress affects their blood pressure, causing or maintaining high blood pressure. They are also concerned that stress negatively affects their ability to heal and recover after medical procedures or illness.

● Lack of Support

Participants reported that they believe medical staff, such as doctors and nurses, do not take their concerns about their high levels of stress and anxiety seriously. They feel that medical staff is dismissive of their concerns until a very obvious health situation occurs. Participants discussed that they would like support for stress reduction that doesn't require a mental health classification or the use of psychiatric medication.

● Anxieties

Participants reported feeling high levels of anxiety about aspects of the aging process in prison. They have high anxiety about current or future memory loss and how that will make them vulnerable to mistreatment in prison. They worry about being robbed and assaulted as they age and can no longer defend themselves as they used to. They worry about not receiving timely or proper medical attention as their conditions worsen. Participants also discussed that some of their peers turn to drug use to reduce their anxiety.

● Stress Reduction

Participants across facilities discussed various kinds of physical and mental stimulation they thought would help reduce stress. The most common forms of aid mentioned were yoga, art classes, music therapy, dog programs, support groups for older adults, and exercise programs designed for aging or disabled bodies. They also mentioned programs where they could help others and make amends, which would give their life meaning. Just as crucially, they emphasized that some of the aspects of stress reduction currently available, such as access to the yard and contact with family, should not be removed, and should be offered more frequently for older adults.

"Yeah, I suffer from anxiety all the time, you know, especially when they're putting you into a cell with a man that you don't even know. You don't know his history. You don't know what he's there for. You don't know if he might wake up and be in a bad mood and assault you while you're still asleep."

"They take away my wheelchair, right? I ended up having a nervous breakdown, locking myself in the cell for seven days. He took the wheelchair away from me. It was definitely retaliation. I'm supposed to be able to just shut my feelings off and deal with it. But it doesn't work like that. Your emotions and just the day-to-day activity of being in a wheelchair or behind a walker or just dealing with medical, period."

"I have anxiety. It causes more stress on the medical condition. It causes you to feel worse."

Isolation & Peer Support

This section covers participants' experiences of isolation reported during the group interviews and how isolation affects their health care. It also addresses the value participants place on peer support, which they argue is a very important factor in their overall physical and mental health.

● Isolation in Medical Units

Across facilities, participants reported that one of their strongest fears and concerns about entering a medical unit if their condition progressed was the isolation experienced by people in medical units such as CTCs and OHUs. Once in these units, participants noted they would no longer have access to their yard, their groups, and their peers. The common areas in most of the medical units we visited were underused because participants reported that they found them bare and uncomfortable, and that they rarely had access to them or had no access to them at all. Participants had a very strong fear of dying alone in a medical unit, separated from their peers. Participants reported that this fear of isolation caused them and others they know to delay going to medical units as long as possible. In one medical unit we visited, participants reported they were only allowed out of their cell for ten minutes a day. All participants in that group had never spoken to another patient in their medical unit and felt the effects of extreme isolation. They described a desperation to speak to any human, even it meant waking up at 4 am during cancer treatment to briefly speak to a cleaning person. They also described becoming more agitated and despondent at different times due to isolation.

● Isolation in GP

In some facilities, general population participants described having very limited to no yard time. As well, they described having very little time out of the cell for any activities, such as classes. At one facility, participants said they had not had yard time for a month. At another facility, they said they spent 22 hours a day in their cell. Participants at facilities with limited time outside the cell want increased yard time and programming time. They also stressed the importance of family visits that are not conducted with the incarcerated person in a cage.

● Peer Care in Medical Units

In medical units where peer care was present, participants highly valued the presence of peer care givers. Some participants felt that the only people in those units they could strongly trust were the peer care givers. They emphasized that peer care workers were far superior to ADA workers on general population yards because of the training peer care workers had completed. Participants also reported that it was very important to them to have a peer care giver with them in the event of their passing because they would know that they would not die alone and would be with someone who they trusted would be compassionate.

● Peer Care in GP

On most general population yards, participants described the value they found in peer support. Peer support could take many forms, including people that helped others with mobility issues, people who gave canteen to those who could not afford it, people who advocated for others, and many other actions small and large. Participants reported that they especially valued having others in their own age range to spend time with and found spending time with them less stressful than with younger incarcerated people.

"I've been having occasional episodes where I may have to go out to the hospital or go over to the clinic for one reason or another due to my health. And I'm up in age now – 67. So, my health is deteriorating. And I don't want to die alone. Nobody wants to die alone. But me, myself, I prefer to be around people that I can talk to and be around, we can discuss like my social activities, daily. I just can't see myself being somewhere isolated, waiting to die. That's not what I want. It may be okay for others, but not me at this point. Unless the doctor tells me, you got two days left. You know? Other than that, I just prefer to be somewhere around folks."

● Mentoring

While most participants wanted to spend more of their time with their older peers, there were some participants who found mentoring youths to be an invaluable part of their life. They found mentoring positive for their mental health and an important aspect of peer support inside prison. They also felt this was an important way to make amends and give back to the community (by helping prevent young people from recidivating). In particular, these participants were less likely to want to join a geriatric yard or prison if one was available and emphasized the importance of geriatric areas remaining optional and that they allow for the inclusion of younger people as visitors and peer care support.

"These guys [at the interview] are like the first, other than the workers, that I've really seen since I been back here. We're kept away from everybody. We're locked down pretty much 24/7. You only come out for like a 10-minute shower. I've been here three months. It feels like a year. It's just so slow, everything's so slow. Look forward to going out and getting chemotherapy, that's how bad it is in here. Just so boring. The hard part is don't let your mind run away. You know, I got a TV and a radio. I feel bad for those that don't got nothing, just staring at the walls. But you got to just hold onto your mind. If you start thinking, I could see a person get depressed real quick. I'll be being in the room and then like I would get frustrated, because I asked the nurse or doctor something, and I didn't get a response like within a day, two days, a week will pass sometimes. That is frustrating, because you're just in here. That's it."

Patient-Medical Staff Relationship

This section discusses issues that participants commonly raised concerning their communications, interactions, and relationships with medical staff. Issues include trust, respect, clarity, and the importance of in-person care.

● Trust

A lack of trust between a medical staff member and patient was commonly reported in the group interviews. Participants frequently reported instances in which medical staff assumed they were attempting to manipulate them and therefore did not believe their symptoms or offer treatment. Participants also commonly reported their own lack of trust of the medical staff due to a history of medical errors and lack of respect on behalf of the medical staff. Participants explained that when they did not trust their doctor or nurses then they became reluctant or refused necessary treatments and medication.

● Information

Participants across facilities frequently reported that they lacked proper information about their condition, their care plan, and the reasoning behind treatment decisions. For example, due to the lack of information about some common testing for older adults, patients would often refuse those tests because they did not understand the importance of them. Participants also requested more information from their doctors about the reasons behind them not following the treatment recommendations of outside specialists they had seen or received a procedure from.

● Respect

Some participants reported being directly insulted by medical staff, mainly nursing staff were reported in this aspect. Overall, participants often felt that they were treated as a prisoner and not a patient. They reported that they felt their medical needs and concerns were not being given the proper weight and that they were frequently not believed because of their status as a prisoner. Some patients stated that this feeling of being ignored or dismissed would cause them to “act out” with negative behavior just to get the attention of medical staff.

● In-Person Care

Some facilities we visited offered their patients access to doctors primarily through tele-med services. The only medical staff regularly on the yards were nursing staff. Participants did not object to tele-med care wholesale but wanted it to be in conjunction with access to routine in-person care with doctors.

● Long-term Relationships

Participants regularly expressed concern about their inability to build sustained relationships with doctors. They expressed that moving from doctor to doctor caused a higher number of errors and missed critical information about their conditions and care to occur. It also caused their care to be uneven and disjointed, as they would be given medical supplies or medication by one doctor to only be denied by another, and then given the same or different items by further doctors. This caused their conditions to by turns improve or worsen with each change of provider. Patients stressed that as they got older and had increased comorbidities their continuity of care mattered more and more.

"So, I was taking metformin when I first came in. And, at some point, they stopped giving it to me. This doctor, the other day, asked me why they quit giving me metformin. And I said, 'I have no idea. They never told me.' You know? Because, if they don't want me to have that vest [for mobility-challenged incarcerated people], then let me know why. I'm okay with that. I can struggle getting up and down if I have to. It's like a lack of information. They're not telling me why they're making the decisions they're making. I've had X-rays done and never gotten any kind of reply on from what it showed. You know, I just wish that they would tell me."

"When a doctor orders the test, it can take six weeks, two months. And even then, they may not approve it. That's part of the problem. I just recently found out I have a spot on my lung. And this test was done last year. And they're just telling me about it a couple weeks ago that they saw a spot on my lung. And I'm going, 'Well, how come I was never told?' 'Well, we don't know why you were never told.' But I've got four tests right now pending with the doctor now that he hasn't given me the results on yet. When you go to the CTC here, if it's not for that reason – the subject like, say, my kidneys and I have another illness going on – they won't tell me about the other illness. They only want to talk about my kidneys. They don't want to hear about anything else other than that one problem."

Medical & Custody Roles

This section discusses concerns participants expressed about custody staff negatively interfering with their medical care, and about how close relationships between custody and medical staff can negatively affect their care.

● Custody Staff Interference with Care

Across facilities it was commonly reported that custody staff routinely interfered in the medical care of participants. Participants recounted incidents in which custody staff would not allow them to go their appointment, would intimidate incarcerated people not to report medical issues in 602s, would have access to their confidential medical files, would act in retribution when patients complained about poor medical care, would override the medical decisions of medical staff and deny aspects of care, would move patients against medical orders and remove medical holds, and would make it very difficult to see doctors without going “man-down.”

“It’s not like you can just walk into medical when you want to. There’s two doors. What’s sitting right here are two officers, okay? Everything going in that medical has to go through them first, everything. They’re even monitoring diabetics in the morning. They tried to refuse me to go get my shot in the morning. ‘You’re not a diabetic. Get out of here.’ I’ve had to tell them on more than on occasion, ‘Listen, unless you want to be in a HIPAA court, get out of my medicine.’ And then when we get to the doctors, they’ve already been in there. They’ve already been in there talking to the doctor. ‘Well, this guy’s faking, and this guy’s faking.’ They’ve tried to get me out of this wheelchair three times now. They just called me again today at 9:50 to try to take this chair away from me because custody complained about me being in a chair because I’m on the second tier. The chair was for me to go long distances because I can’t walk long distances. If I walked from here to medical to get meds, it would take me almost an hour because I have to sit down. And custody doesn’t care.”

● Medical Staff & Custody Staff Closeness

Some participants expressed concern that the close relationships that sometimes develop between medical staff and custody staff unduly influence how medical staff perceives patients. Patients reported that the scales are unfairly balanced toward custody’s view of patients because custody and medical staff are allowed to socialize, while for patients and medical staff to socialize is considered overfamiliarity. Participants discussed that closeness of these two staff positions can cause retribution to occur by either medical or custody staff if one side dislikes a patient. It produces an “us against them” mentality that creates poor health outcomes and unnecessary tensions between medical staff and their patients. Participants discussed that at times romantic relationships between medical and custody staff are also discussed in front of the patients, which adds to patients’ distrust.

“When you get out of the hospital and you get put in these situations where it’s custody and medical clashing, they don’t go together. So, for example, there might be an officer or somebody who gets into your medical. Like you’ll be standing there, and then the officer, he’s lying, he’s bullshitting, you know, he’s not in the room for that. That’s medical. They interject themselves in places they’re not supposed to and the nurses actually then listen to them. Well, because the nurses have to. That’s their comrades. Like, you know, they wear uniforms.... So, when an officer starts to interject their personal feelings about a patient, it can be a real problem for that patient.”

Medical System Management

This section includes participant discussions about common concerns and perceptions with how the medical system is managed in CDCR at a local and global level.

● Consistency

A common concern for participants across facilities was the inaccuracy or lack of attention to their medical records by medical staff. They often encountered a situation where a new doctor could find no evidence of long-existing conditions in their medical record and, therefore, they would be denied care or have to restart the process for care. Participants are concerned that too many staff are handling their records or have edited their records which has led to numerous and repeated errors. When patients go to new doctors or facilities, they often have numerous issues in continuity of care in regard to medication, treatments, and medical accommodations. They feel that if their medical files were handled or organized better this would be less of a problem.

● Oversight

Participants often reported numerous problems with the administrative appeal process for remedying medical errors or oversights. They expressed feelings that the system was designed to wear them out and not solve their concerns. Even if they were able to acquire the resolution they desired, it was often severely delayed, so that their medical condition had continued to worsen.

● Staffing

Some participants discussed problems with medical staffing shortages at their facility which led to delays in care and lack of access to in-person providers. They also reported that the high turnover in some areas greatly affected the quality of their care due to the lack of consistency.

● Transportation of Older Adults

A common concern among participants was that they are not receiving accommodation for age and health conditions when they are transferred to outside medical facilities or other CDCR facilities. The cuffs, chains, and backboxes at times cause severe injury to their fragile skin, which bleeds and bruises easily. The process can cause large wounds which take a long time to heal and can be susceptible to infection. They also reported that guards handled them roughly in the transfer process which led to injury. At one facility, we witnessed guards shoving and pushing older adults in a very aggressive manner into a van to the point where one person fell and yelled in pain.

“He [doctor] says, ‘Well, we treat the symptoms.’ Long story short, I still have it. I still get the pain.”



● Decision Making

Participants reported being told by their doctors at certain points that the doctors were not allowed to do more complete, preventive, and holistic care. Participants also reported being told they cannot receive medications that doctors would normally recommend because custody will not allow the use of the medication. Participants desire for their doctors to have more autonomy in how they care for patients to increase the care of the patients when warranted. In general, many patients reported that they strongly desired more preventive and holistic care, which they felt would save them and CDCR from more prolonged and expensive future treatments.

“They had me on medication, blood thinners. But he says, ‘This is the policy. We don’t treat. We don’t treat you. If you have a heart attack, we will treat the heart attack. That’s it. We’ll give you medication.’ And I said, ‘But hold it. The surgeon who’s been doing this his entire human life, in charge of the department at one of the most prestigious hospitals on the planet Earth, said I have to have these stents replaced in about five years. It’s been ten. We’re on 20, and I exhibit some of the conditions.’ He said, ‘We only treat the symptoms. We will not send you out to have stents replaced.’ So, that is consistently what’s going on.”

Hospice Decision Making

This section covers some of the considerations that participants reported about their decision-making process as to whether they would want to receive hospice care if they got to that point and qualified for it.

● Lack of Information

When we asked participants about their knowledge and opinions on hospice care in CDCR, by far the most common response was that the patient was unaware that there is hospice care in CDCR. It was also common for them to have confusions or misinformation about hospice care in prison. The participants often asked us a series of questions about hospice care. They wanted to know what the criteria were, how hospice care was different than care in regular medical units, and if there was the possibility to receive this kind of care closer to their current location. Participants were often far more aware of the possibility of end-of-life care at CHCF than at CMF. Participants were very eager for information about hospice care and often wondered why their doctor had never discussed this possibility with them. They would very much like to be more informed about their eventual end-of-life options. We found that even in medical units with patients that were likely to be close to end-of-life, it was still common for them to not have been informed about hospice care as an option.

● Substance Use Disorder

Across institutions, a common concern about all medical units or facilities was that they would be full of “drug addicts” who would take up most of the resources and make dangerous companions. Participants wanted to be assured that the hospice would not be mixed with other kinds of patients, especially young “drug addicts.”

● Family/Peer Considerations

A common concern people had about moving to hospice care was leaving behind their relatives who lived within comfortable driving distance or leaving behind a supportive community of peers who had been helping them manage their conditions. Participants strongly advocated for either small hospice units on prisons throughout the system or the creation of another larger centralized hospice in Southern California, where many participants and their families are from.

● Lack of Trust

Due to negative experiences with individual doctors, medical staff members, or the medical care system, it was common for participants to not be open to believing that the conditions of the hospice as described were accurate. They expressed worry that it is just a place where people are sent to die alone and abandoned to not be a burden to their current facility anymore. They worry at that weakened state that they could be abused. They worry that they still won't receive proper pain management and that they will sit alone in dirty beds and be ignored. In some focus groups there were one or more participants who had been at CMF before and seen or heard of the hospice. Participants were much more likely to believe the benefits of the hospice if reported by a peer. The participants also wanted to be assured that the decision to go into hospice was truly voluntary.

● Transfer Risks

In relation to transfer to CMF, participants had multiple concerns. They are worried about the physical conditions of transfer when they are in a vulnerable state, especially considering most participants currently experience very rough and painful transfers. They fear leaving their current doctor if they have a doctor they trust. They fear leaving a place they know for an unknown place that is potentially worse. They fear that their current treatments that help manage or reduce pain will not continue in a new institution. They are also anxious about the possibility of a long hospice admission process and not learning the results of their admittance.

● Timeline

Participants often expressed concern about the six-month or less to live medical qualification to enter hospice. They expressed concern that by the time they were diagnosed with six months and began the bureaucratic process to transfer to hospice, they would be dead before they were approved for transfer. If hospice was as good as it was presented to be, then participants wanted to spend more time in a place in which they would not be in pain and have their needs met. They thought a year or more qualification would be necessary for them to have a realistic chance to get to the hospice with six months left to live. Due to past experiences with bureaucratic delays in their health care, they have skepticism that the hospice transfer procedure will occur as quickly as promised.

● Benefits

After we or a knowledgeable participant described the hospice at CMF to the group, the top benefits they were most enthusiastic about were as follows. They very much wanted to be in a caring environment with nursing staff and doctors that were knowledgeable about their stage in life and treated them respectfully as patients. That was the largest motivating factor. The second most important factor was the presence of peer care givers and the assurance that they would not die alone. The final top factor was the unlimited time with family during their final days.

"I don't want to die. I want to live forever, but, unfortunately, I'm going to die whether I like it or not. All I'm asking for is that when I get ready to die, which I'm not ready yet, but I'm getting damn close. You know, I can't walk anymore. I can't breathe. I can't remember what the hell I'm doing. I don't know where I'm at. I fall down at least once a week, but I'm scared to death to go tell them. The doctor told me, 'If you go down there, we'll give you a little vest. If you go down there and tell them that you fall down a lot and you're crippled and you're a mess, you know what they're going to do to you? They're going to send you out to Vacaville.' My family lives in Valencia. I can't see them in Vacaville. 'And you know what they're going to do with you? They're going to put you in a hospice unit.' Everything I've heard from my fellow inmates is hospice sucks. You are a vegetable waiting to die. I don't want to die like that. I don't want to be treated like an animal. So, I don't want to go to a hospice unit. I'm afraid to tell the doctor I can't walk up the stairs to go to chow. I can't. It's just too painful. So, I don't go unless I have to. But if I go tell the doctor that, you know what they're going to do to me? They're going to send me to Vacaville, someplace with a ward with 200 guys. Everybody is dying. And I don't want to be there. So, I suck it up, I keep my mouth shut, and I live with it. So, all I'm saying is: Can you make hospice human? Can I go to a place where I can be treated like a homosapien. I'm not asking for Cedars-Sinai. I'm just asking for Martin Luther King Hospital."

End-of-Life Desires

At the end of each focus group, we asked the participants to tell us about what they would ideally want for end-of-life care if it were to have to occur in prison. Almost all participants expressed freedom as the most important end-of-life desire, but within the limitations of still being incarcerated there were a wide range of responses.

1

Peer Care

Participants saw peer care workers as trustworthy and believed they would treat them like humans. They wanted the peer care workers to be present when they passed. And they wanted the peer care workers to have rigorous training.

2

Respectful Care

Participants want to be treated like a patient first. They would like medical staff who are friendly and polite. They would like to have regular, long-term staffing as much as possible, and for staff to remember their care needs and medical histories.

3

Quality Food

Participants want individualized diets tailored to medical needs, access to basic foods throughout the day, and special foods like ice cream, milkshakes, and other comfort foods. Participants were not concerned with healthy diets at the end-of-life and instead wanted familiar comfort foods.

4

Open Unit

Participants would like the freedom of movement of being in an open unit where they could go to different areas of the unit of their own accord.

5

Safety

Participants would like to be housed in a single cell for their safety. Most participants would also like to be housed separately from young people and substance users, for their safety.



6

Access to Family

Participants would like to be as close to their family as possible and have unlimited visiting hours with their family.

7

Access to Peers

Participants would like to be able to visit with peers from the general population yards. They would like, if capable, to still attend groups or programming, or have their own groups or programming inside the unit. They would like ways to still be engaged with each other and the larger world, find meaning, and see their peers.

8

24/7 Access to Medical Staff

Participants would like to have access to medical staff even in the late hours of the night. Participants sometimes expressed this desire as having call buttons and others wanted nurses that worked overnight shifts in the unit.

9

Access to Nature

Participants would like access to outdoor environments during the day and evenings. They would like to be around gardens and plants and be able to touch grass.

10

Disability Accommodations

Participants would like to have disability accommodations in the form of emergency call buttons, accessible showers, and mobility aids.

11

Mental and Physical Stimulation

Participants would like cognitive games, puzzles, and group activities to keep their minds stimulated. Participants would like yard time, group exercise, and exercise equipment with a focus on older adults to keep their bodies moving.



12

Holistic Care

Participants would like access to items and experiences that improve their overall wellbeing, such as music therapy and radios in their rooms. They would like ways to make amends and feel valued. They would like to discuss natural care options and other personal or religious preferences.

13

Individualized Care

Participants would like individualized accommodations that align with their symptoms and treatment plans. They would like individualized diets and individualized support items, such as pillows and bedding.

14

Environmental Regulation

Participants would like to have ways to stay warm or cold in different weather conditions (e.g., heavy sweater), curtains to block out light, and be able to control the interior lights to some extent.

15

Clean Facility

Participants would like the facility to have good ventilation and for their bedding to be changed regularly, and to have access to showers or be bathed by staff regularly.

16

Posthumous Care

Participants would like to be aware of their options related to what happens to their body after they die and be able to work with a staff member to set up a plan for how their desires can be accomplished.

17

Access to Spiritual Support

Participants desire readily available access to spiritual and religious support in the form. This can be in the form of religious leaders, prayer practices, and access to religious materials.

Policy Recommendations

In this section, the study team has compiled our main policy recommendations reported to us in interviews with patients and medical staff, and in our interviews and observations at the CMF hospice facility.

● **CDCR Hospice in Southern California**

This is recommended for safety and ease of patient transport, continued access to family, and support for increased need for end-of-life care.

● **Cross-disciplinary Care Teams**

It is recommended that medical units develop cross-disciplinary care teams to better communicate about care for high-risk patients.

● **Geriatricians**

It is recommended that CDCR increase the hiring of geriatricians and nursing staff with experience in elder and hospice care.

● **Geriatric Yard/Facility**

It is recommended that patients 50 years or older with chronic medical condition(s) who wish to be housed separately for their safety and wellbeing be given this option. This has the potential to greatly reduce stress and allow for superior access to quality care.

● **More Palliative Care Units**

It is recommended that more facilities across CDCR offer palliative care in supportive housing areas for patients that are independent but closer to end-of-life.

● **Medical Staff Geriatric Training**

It is recommended that all medical staff undergo training on best practices to working with older adults, including the areas of memory care and respectful communication practices.

● **Custody Staff Training**

It is recommended that custody staff receive additional training on best practices for supervising older adults in custody, including the areas of transportation, access to care, and respecting medical privacy.

● **Peer Care Aids**

It is recommended that all medical facilities employ the use of palliative Peer Care Support workers or volunteers to build better support and trust with patients.

● **Diet Accommodations**

It is recommended that patients have more access to individualized meal plans to support their health needs, including comfort food near end-of-life.

● **Access to Peers**

It is recommended that patients in medical units be required to have access for two or more hours a day to peers in their units or outside yards.

● **Mental & Physical Stimulation**

It is recommended that older incarcerated people have access to activities and programming that support their cognitive and physical upkeep.

● **Medical Records Overhaul**

It is recommended for CDCR to update its medical record system to better provide consistency of care and track medications. Medical staff and patients reported that important notes and information could often get buried or “lost” in the system.

● **Safety Considerations**

It is recommended that older adults receive special housing considerations for their increased vulnerability, including single cells, elderly housing, and lower bunks.

● **Family Connections**

It is recommended that all medical units increase access to family visits and virtual forms of communication.

● **End-Of-Life Information**

It is recommended that CDCR develop better educational material to inform older adults of their end-of-life options. These materials should be distributed directly to the patients.

● **Access to Durable Medical Equipment**

It is recommended for CDCR to increase access to items that commonly support older patients, such as comfort and safety devices, and to provide these items in prime working condition.

Conclusion



With the increase in the number of older individuals in prison, medical services for older adults and those approaching the end-of-life—geriatric, palliative, as well as hospice care—have become a central issue for prison administration and management. In California, where life sentences generate more than thirty percent of the prison population, the hospice that formally began at the California Medical Facility in the 1990s has been a national leader, indeed a model for in-prison medical and hospice care. But the CMF hospice's seventeen beds (even when buttressed with an additional thirty palliative-care and sixty memory-care beds throughout the state) only just begins to respond to the current need for prison end-of-life care in the California Department of Corrections and Rehabilitation. Further, the CMF hospice, which is situated in Vacaville in Northern California, remains far from many California prisons and therefore a trek for patients who are medically unfit for a long transport. More, the criteria for hospice eligibility require a prognosis of less than six months to live, which excludes some people who are nevertheless chronically ill and ready for palliative care. A more expansive approach to end-of-life care throughout the CDCR, therefore, is needed.

This project has relied on interviews with medical staff, groups of incarcerated patients (men and women), and patients and members of the multidisciplinary care team at the CMF hospice (including physicians, nurses and, among others, peer care workers, a chaplain, and social workers) to better understand how end-of-life care is provided across institutions in the CDCR and the needs, concerns, and perspectives of patients and medical providers. As the CDCR/CCHCS considers and makes decisions about expanding and improving medical services for older patients and patients living with chronic and terminal illnesses, the perspectives, concerns, and suggestions provided here are offered as a source of information drawing from the people who are most directly involved: the patients, the medical staff, and the care teams. On the yards and at the institutions we visited, outside the CMF hospice, we heard of instances of positive care and reports of support and gratitude for individual staff, but we also heard reports of very concerning conditions and of delayed, partial, or even harmful treatment. We witnessed anxiety caused by doubts about medical care and by lack of trust in the medical system and staff, experienced by patients navigating the prison environment with debilitating illness. Overall, we found that on many fronts the concerns of staff and patients aligned: medical staff want more training and more specialized care units to support their aging patients; incarcerated patients want respectful, compassionate care as they age and approach the end of life.

One of the strongest messages that came out of our interviews with medical staff across institutions was the importance of the medical care team as a unit. A unit comprised of staff with different specialties and complementary roles. This was exemplified at the hospice, where the care team model is an integral part of the palliative care philosophy—a holistic philosophy that prioritizes a patient’s personhood, their needs and wishes, and their relationships with family and peers. But the importance of care teams was emphasized as well by practitioners at other institutions; at those institutions, however, the multidisciplinary care team was often presented as an ideal to be achieved, one yet to be realized. The CMF hospice is, without question, a unique and remarkable facility. One that has grown from particular historical developments, and with the particular support of key decisionmakers up and down the chain and the day-to-day vigilance of the care team and staff. But the CMF hospice and the end-of-life care provided there is not so unique that it cannot be replicated. Doing so simply requires dedication and determination to generate a physical environment with particular attributes that is properly staffed and supported by administration.¹

One benefit of the care team model, according to participants in the interviews and as we observed at the hospice, is that it is imbued with practices of holistic, patient-centered care that make patients more content but also make physicians, nurses, and other staff more satisfied with their work. We observed related connections between the care team model and staff satisfaction in other ways. At the hospice, it was impossible to miss the presence of pictures, letters, and other objects (like weavings or pieces of art) that served as memorials of people who had been in the hospice, many of whom had been granted compassionate release to die outside. These tokens, we noted, are sources of hope for the PCS workers and patients. But the objects also serve an important purpose for all people working in the hospice, helping the staff sustain joy from positive outcomes and receive positive reinforcement about the quality of their work. In that sense, the tokens contribute to what we observed to be one of the great strengths of the care provided in the hospice and the ability of the team to work together: taking pride in medical care well done leads staff to feel better in their jobs and more engaged, which in turn raises the quality of medical care provided overall.

¹ As we witnessed from our observations at the hospice and learned from interviews with patients and the care team, in order to realize in practice the patient-centered approach that defines end-of-life care at the hospice, certain elements are crucial: materially, a physical space that allows free movement and an open-door policy and ideally a beautified natural space; socially, group activities as well as opportunities for casual social interaction; and medically, personnel who are empowered and confident that they have clear institutional guidelines to support their patient-centered decisions and a care team that is trained in palliative practice and comfortable carrying it out (the importance of peer care support workers cannot be overstated). Administratively, too, decisionmakers are needed who understand the distinction between palliative care and standard medical care and take it into account.

Another theme that connected many of the interview responses—from medical staff, members of the care team, and incarcerated patients—is communication. We heard regularly about lack of trust and effective communication between patients and medical staff, which in turn impacted the care provided as well as patients’ decisions about their health. While communication and trust are essential in any medical-patient relationship, given the framework of the prison and the negative experiences that many patients have had while incarcerated, effective communication with medical providers presents a challenge. Failed communication affects patient perceptions and contributes to patient distrust in the system, to patient confusion and uncertainty about their health and care, and hence to anxiety and stress, which in turn can negatively impact mental as well as physical health. Some medical staff emphasized, therefore, the importance of approaching interactions with patients from an inquiry stance and with good faith—taking care to prioritize clear communication and build trust in each interaction. Communication will not solve all problems, of course, but it will minimize the amount of unnecessary stress and anxiety that people experience and is more likely ensure that patients do what the doctor recommends. Incomplete or failed communication can be seen underlying many of the comments from medical staff and patients presented above.

A related topic on which medical staff and patients align is consistency or longevity of care. We heard about lots of turnover of medical personnel, of yards on which medical services were provided principally by tele-med, and of transfers of incarcerated people that disrupted health care. It was evident from the interview responses that longer-term care relations would make doctors and patients happier. Less movement, and longer patient retention would allow doctors to build established relationships as a care-giver, gain more familiarity with patient health, and offer better quality of care. Consistency of care is also beneficial because it works toward reducing the communication and trust issues that hinder and frustrate medical-patient relationships, as noted above. The better a doctor or nurse knows a patient, the better they may interpret the patient’s description of their problems and assess their concerns; the better the patient knows the medical staff, the more likely they will be to trust the medical team rather than feel anxious and unsure. More regular and sustained contact with medical providers can, as a general matter, breed trust and understanding.

The points made above about the multidisciplinary care team, communication, and consistency of care converge in a topic that came up often in interviews: having specialized yards, facilities, and even prisons for older incarcerated people. Designated geriatric housing could centralize resources and medical expertise in caring for older adults, while also providing greater safety for patients and consistency of care. We urge consideration of specific spaces—yards, facilities, prisons—for older incarcerated people that are staffed by a regular medical team trained in geriatric and palliative medicine as well as a custody team that has been trained to be aware of and respect the differences in approach to medical care at the end of life.

In closing, it bears emphasis that many of the conditions and issues raised here are a consequence of the exceptionally large number of people incarcerated in the State of California and the long sentences that many people in California prisons serve. The unavailability of resources such as lower bunk assignments and single cells, the reduced time that doctors are able spend with patients, the frequent moves between prisons that disrupt physician-patient relationships: so many issues of concern to incarcerated patients and medical staff derive in significant part from the burdens placed on a prison system by having so many people incarcerated—many of who are older, chronically ill, and pose effectively no safety risk. People who, if found suitable, could be released to die outside prison in the presence of family and loved ones. A comprehensive response to the needs and dignity of those reaching the end-of-life in CDCR therefore involves connecting medical care with second-chance legislation and other reforms that work to address excessive use of the prison. Compassionate release, medical parole, and elder parole, as mechanisms for reducing the prison population and providing opportunities for people who are older and chronically ill to be released from prison, are essential components of the enterprise this report refers to as “care in the end.”

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Care in the End

Thank You

Thank you for your time and consideration reading this report.

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