THE PENNSYLVANIA STATE UNIVERSITY
SCHREYER HONORS COLLEGE

DEPARTMENT OF BIOETHICS AND MEDICAL HUMANITIES

Returning Dignity Only at Death's Door: Can Incarcerated Individuals Acting as Hospice Caregivers Achieve Rehabilitative Goals Without Sacrificing Autonomy?

SNEHA ANMALSETTY
SUMMER 2021

A thesis
submitted in partial fulfillment
of the requirements
for a baccalaureate degree
in Biochemistry and Molecular Biology
with honors in Bioethics and Medical Humanities

Reviewed and approved* by the following:

Michele Mekel
Assistant Teaching Professor of Bioethics and Medical Humanities
Interim Director, Bioethics Program
Thesis Supervisor
Honors Advisor

Lorraine Santy
Associate Professor of Biochemistry and Molecular Biology
Honors Advisor
Faculty Reader

* Electronic approvals are on file.

ABSTRACT

As the number of individuals who are incarcerated increases in the United States, correctional institutions face a growing burden to provide adequate healthcare. End-of-life care, or hospice care, has become especially important for incarcerated individuals who are aging or have been diagnosed with terminal illnesses so that they are able to die with dignity. To address this need, prison infirmaries across the United States are implementing in-house hospice programs. Inspired by the program at the Louisiana State Penitentiary at Angola, many institutions are also involving incarcerated individuals in the care of prisoner-patients as volunteer hospice caregivers. Not only do these prisoner-caregivers improve the delivery of hospice and provide comfort for dying prisoner-patients, but they themselves experience positive emotional growth and gain important transferrable skills. However, their volunteerism must be considered in the context of the current state of corrections. Specifically, volunteer prisoner-caregivers lack protections for their physical and emotional labor, lack autonomy and are vulnerable to coercion, exemplify concerns with assignments of social worth, and highlight the need for a shift away from retributive justice practices in the criminal justice system. This work examines the impact of volunteer prisoner-caregiver programs on the caregiver, the patient, the correctional institution, healthcare institutions, and the overall criminal justice system.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

First and foremost, I must thank Professor Michele Mekel for her kindness, patience, and excellent mentorship. I have found a true passion and interest in bioethics as a result of her guidance. In addition, I would like to thank Dr. Susan Loeb, Professor Maria Dawson, Joe Venditti, Ryan Bach, Mercer Gary, Alannah King, Dr. John Kramer, Dr. Ben Jones, Dr. Howie Smith, and Jenna Spinelli. These individuals provided their time, their support, and incredible insight into the intersections of criminal justice, healthcare, and ethics.

My advisers and professors in Biochemistry and Molecular Biology as well as Bioethics and Medical Humanities, especially Dr. Lorraine Santy and Dr. Jonathan Marks, truly made my Penn State experience a positive one and gave valuable counsel throughout my studies. I cannot thank them enough.

Next, I would like to acknowledge my grandfather, who passed away as a result of the COVID-19 pandemic. I hope that even though I did not get to share my achievements with him, he will rest in peace knowing that his love and dreams for me brought me to where I am and will continue to drive me. Thank you to my parents who have always let me focus solely on my studies; that kind of support is rare and appreciated. Finally, I would like to thank my friends at Penn State who have made me laugh, encouraged me, and shaped me: Nebraska Hernandez, Leah Motimaya, Lydia Jordache, Adriana Romano, Sam Landmesser, Nakoa Guzman, Journey Matos, and so many more.

Chapter 1

Introduction

A. An Overview of the Modern Criminal Justice System

No institution in the United States of America is as wrought with complexity and contradiction as the criminal justice system, which is comprised of law enforcement, the courts, and corrections. As a result of the mass incarceration phenomenon, the latter component of the system has faced—and continues to experience—significant scrutiny, especially as it relates to the treatment of incarcerated individuals. The corrections system is responsible for an ever-growing number of people for increasing durations of time as a result of uniquely American political and legislative measures, such as determinate sentencing and "three strikes" rules.[22]

As of 2015, nearly 2.2 million people resided in jails or prisons, making the United States the country with the largest imprisoned population and highest per-capita incarceration rate.[1] Over the course of the last 40 years, there has been a 500% increase in the number of incarcerated individuals.[1] This population, however, is in no way representative of the general populace, with Black and Hispanic Americans accounting for 56% of those imprisoned even though they make up only 32% of the U.S. population.[12] Nearly half (i.e., 46%) of those incarcerated in state prisons in 2015 committed nonviolent drug, property, or public order crimes.[1] In addition, approximately one in nine are serving life sentences, with the largest population of these "lifers" residing in Alabama, Nevada, and New Jersey.[1] The number of people serving life sentences with or without parole has continued to rise even though the

number of serious, violent crimes has been on the decline.[1] Moreover, there is little to no correlation between length of sentence and public safety benefit.[1]

These are not the only notable statistics that describe this era of mass incarceration. As the prison population increases, so do the number of elderly persons behind prison walls. The number of prisoners aged 55 or older sentenced to more than a year in state prisons increased 400% from 26,300 (i.e., 3% of the total state prison population) in 1993 to 131,500 (i.e., 10% of the total state prison population) in 2013.[54] Moreover, the imprisonment rate for those aged 55 or older sentenced to more than a year in state prison increased from 49 per 100,000 U.S. residents of the same age in 1993 to 154 per 100,000 in 2013.[54]

Finally, those who are incarcerated tend to come from backgrounds of low socioeconomic status (SES).[2] This factor is also correlated with poorer health outcomes, with nearly 2,500 incarcerated individuals dying from acquired immune deficiency syndrome (AIDS), cancer, heart disease, and other ailments according to the Guiding Responsive Action in Corrections at End of Life (GRACE) Project.‡ [17, 25, 27] A long history of lack of medical care, substance abuse, and poor diet can add 10+ years to chronological age, thereby increasing risk for chronic conditions.[69]

These statistics serve to emphasize the distinct, layered, and intersecting circumstances experienced by those incarcerated. Even before a diagnosis of terminal illness, these individuals are far more vulnerable and disadvantaged compared to those who are not locked behind bars.

‡ The GRACE Project, a large and collaborative initiative, is designed to achieve community hospice standards for end-of-life (EOL) care in correctional settings through practice standards and program interventions, including inmate hospice volunteerism.[63] The project's work has been instrumental in the current policies of National Commission on Correctional Health Care and American Correctional Association, which have considerable influence in the correctional system.[63]

Thus, it is necessary to consider the many ways the positionality and intersectionalities of those who are imprisoned differs from those who are not.

B. Defining the Intersections Between Corrections and Healthcare

As those who are incarcerated are generally at greater risk for developing health issues while being imprisoned into advanced age, they often require greater access to care. Yet, many inmates with chronic physical or mental illness fail to receive adequate care during incarceration.[11] In fact, the health of elderly, male, incarcerated individuals is empirically worse than that of the general population and that of younger incarcerated individuals.[26, 29] This demand for care increasingly extends to EOL, palliative, and hospice care.[23, 24, 25, 26] Although people in prison are guaranteed healthcare under the Eighth Amendment and the prohibition against cruel and unusual punishment, their loss of liberty, due to imprisonment, means that they are not able to choose their healthcare providers and are entirely dependent on the penal institution for care.[3]

While incarceration serves as punishment, rehabilitation, and deterrence for the convicted, such purposes do not include deprivation of access to healthcare, as the courts have found such denial to constitute cruel and unusual publishment, which exceeds the bounds of the penal system.[5, 52] Thus, incarcerated individuals possess an affirmative, actionable right to healthcare, as well as a correlative right to self-determination regarding what treatments they receive and refuse.[52] Moreover, incarcerated individuals are entitled to the same standard of care that is provided to the wider community under the "principle of equivalence," a human rights concept enshrined in the United Nations' Basic Principles for Treatment of Prisoners.[52]

C. Barriers to Accessing Healthcare While Incarcerated

Nevertheless, prison healthcare systems vary from state to state, and, as a result, consistency of care cannot be guaranteed.[3] Moreover, most, if not all, penal institutions operate under severely limited resources.[77] Thus, the strain on correctional health systems is not only due to a lack of resources but also hinges upon the increasing number of inmates and their health needs. While incarcerated people have lower mortality rates than the general population due to, in many cases, newfound access to healthcare, the absolute number of deaths among inmates is climbing alongside the aging of the inmate population since 1995.[27, 35, 36, 37, 38, 39]

As of 2001, the cost of care per inmate was $7.41 per day, with a total cost of $3.3 billion annually.[32, 40, 41] As of 2015, the total cost was $8.1 billion annually, an almost 200% increase, accounting for inflation.[65] Estimates for the care of an elderly inmate range from $60,000 to $69,000 per year, in contrast to about $20,000 per year for a non-elderly, non-AIDS-infected, male inmate.[30] In addition, the cost per inmate varied dramatically by state in 2015, with Louisiana spending $2,173 and California spending $19,770 per year.[§ 65]

Cost of providing care is not the only reason that care may vary among institutions. Due to bias against incarcerated individuals, access to and appropriate attention from the healthcare staff might also be lacking. One 1997 study of nurses found that, even though they owed a

[§] The annual amount covers medical, dental, mental health, and substance use treatment. Some factors that might contribute to this drastic difference in spending include pre-incarceration access to adequate community care, regional medical prices, staffing and compensation levels, facility capacity and related economies of scale, and incidences of high-risk behaviors and associated disease burdens.[65] Some smaller contributors included "staffing levels, whether and how state corrections departments and the Federal Bureau of Prisons engaged with contractors to deliver care, the provision of certain screening procedures on a routine basis, the prevalence of particular high-cost populations (for instance, inmates age 55 and over), and certain cost-containment strategies (such as requiring copayments to discourage potentially unnecessary doctor visits)."[65]

professional responsibility to their patients irrespective of patient background and status, they maintained negative attitudes toward incarcerated patients.[3]

Another barrier to accessing adequate healthcare while imprisoned is that incarcerated individuals are more likely to have lower health literacy, meaning the ability to read, understand, and use healthcare information to make appropriate decisions for oneself, than the general population because they tend to be of lower SES.[42, 43] This can lead to feelings of frustration or increased mistrust between incarcerated individuals and healthcare providers, resulting in even poorer health outcomes.[44]

Finally, healthcare provision in prisons is inherently different from a regular patient-physician relationship as patient-prisoners lack both liberty and other significant rights. As a result of their loss of autonomy during incarceration, there is an element of paternalism and coercion inherent in such patient-physician relationships.[75] This, in turn, can be cause for concern regarding the validity of a patient's acceptance or refusal of treatment, for example. And such paternalism can be linked directly back to a prisoner-patient's lack of health literacy, as well. While the right to refuse treatment has been constitutionally upheld as extending to prisoners under *White v. Napoleon*,[51] this right is rendered useless if prisoner-patients cannot make informed decisions about their care due to lack of necessary skills. Moreover, this right has not been regarded as absolute (see, e.g., *Commission of Corrections v. Myers*),[51] as it can be overridden if there is a strong public health reason, such as mandatory vaccination against highly communicable and dangerous diseases or if the prison system believes that the patient is incompetent to make personal medical decisions.[51]

Although many in "free" society may assign a low priority to allocating further tax dollars to providing prisoners with healthcare and increasing prisoner access to care, it is an

imperative of the justice system and of American society to provide appropriate care to those society incarcerates. Incarceration, itself, and not substandard healthcare, is the punishment for committing a crime, and the denial of care or the provision of inferior care infringes upon the Constitutional bar against cruel and unusual punishment, as well as inalienable human rights. Cloyes et al. describes it succinctly:

> Arguing from an interconnected set of moral, ethical, and clinical premises, these [patterns] establish that the poor health and aging outcomes of incarcerated people creates an increased risk for dying while incarcerated, which itself is associated with a risk of undue physical and psychological suffering and a risk of receiving inadequate care—or no care at all—at the end-of-life.[6]

Still, whether the minimum standard of care has been met for most inmates is debatable.[11] There is a well-documented need for better healthcare in prison, specifically EOL care, but questions arise as to how that goal is best achieved.[11]

D. Current Models of Delivering End-of-Life Care to Incarcerated Individuals

As described, prisoners face a myriad of issues related to access to care in prison. Prison healthcare systems are also bearing the weight of these ever-increasing burdens. While there are medical prisons and greater use of telemedicine, traditional prisons are not designed as places to care for terminal illnesses; nonetheless, they have become such.[24, 29] EOL care refers to healthcare for a person with a terminal illness that has become advanced, untreatable, or for

which additional treatment is deemed medically futile.[59] The goal of this type of care, which can also be described as palliative or hospice care, is to alleviate pain and support the highest quality of life possible for the remaining duration of the patient's life. In the prison environment, there are limited options available to achieve these goals while also adequately meeting patient autonomy and balancing the unique security-related issues that exist within prisons.[8]

In addition, there are significant questions regarding how EOL care should be delivered to prisoner-patients, who should deliver such care, and who should provide the resources to do so.[6] In order to support prisoners at the end of their life while incarcerated, many different interventions have been examined and enacted. These involve revamping existing correctional healthcare systems (as California is currently doing), including creating inmate-staffed hospice programs.[28, 76]

One such option is *compassionate release*, otherwise referred to as medical parole.[4] It is called for when terminal illness, or other significant medical circumstances, outweigh continued imprisonment.[4] A physician might make recommendations to prison administrators who may then grant permission for an inmate to leave the facility and be with their loved ones before death.[4, 32] There are current projects in Michigan and Georgia that enable physicians to determine whether incarcerated individuals meet good, fair, or poor levels of wellness for a number of conditions, including hypertension, asthma, and diabetes, and whether, given the wellness score, should be considered as a basis for medical parole.[25] Of 49 correctional agencies surveyed in 2001, 43 offered some form of compassionate release.[32] The average number of annual requests was 18 per correctional agency, and the average granted was 8.[32] These options exist in states like New York, but they face many complications.[4] For one, most prison systems do not have the funds or institutional power to provide adequate discharge planning for incarcerated individuals.[4]

Thus, under-resourced families are handed the burden of caring for a loved one close to death and for whom there is no health coverage (as access to such care ends with discharge).[4] And, in other instances, there is no family to which to discharge the ailing inmate.[4] In addition, as compassionate release ultimately depends on a correctional facility's determination of the prisoner's inability to commit another crime while released, such discharges are rare.[4] Hence, prisoner-patients are resigned to spending their final days while incarcerated.

Another option is to establish prison hospice care systems, and such effort typically includes using other incarcerated individuals as part of the staff. This option has become popularized by a model program established at the Louisiana State Penitentiary at Angola.[**50] By involving fellow incarcerated individuals as volunteer caregivers, prisons are more capable of providing therapeutic, palliative, and more humane care to EOL patient-prisoners.[50] While promising on the surface, there are several, deeply rooted ideological objections to the involvement of incarcerated individuals in providing aspects of EOL care.

E. Methods to Improve Delivery of End-of-Life Care for Incarcerated Individuals

The Louisiana State Penitentiary at Angola is the largest maximum-security prison in the United States.[17] Its inmate population is nearly static because of the sheer number of incarcerated individuals serving life sentences or extremely long sentences.[17] Approximately 85% of the men imprisoned at Angola will die in the facility as a result of these sentences.[17] As a result, in 1996, the prison entered into a collaboration with the local university hospital to create a prison hospice

[**] Maryland, Iowa, and Pennsylvania are trying to adopt similar programs.[10,62,68]

program.[‡‡17] They recognized the need to "provide for their own" because there was limited support for this vulnerable population.[6]

Of course, implementation faced challenges. In addition to the expected financial and logistical burdens of instituting a hospice system in the existing prison infirmity, there was significant concern from prisoners who did not understand the goals of hospice and believed that prison physicians had given up on them.[50] There was also the preexisting mistrust between Black Americans and healthcare systems—something that was only amplified in a prison setting, such as at Angola, where there was and is a disproportionate representation of Black Americans.[§§ 50]

Yet, the program proceeded and has been heralded as a success. At Angola, inmates can volunteer to support their peers through terminal illness as hospice caregivers—medical assistants whose responsibilities vary from maintaining the prisoner-patient's personal hygiene to sitting at the bedside to provide companionship or to hold vigil.[17] These prisoner-caregivers are not responsible for the tasks of licensed medical professionals, although they may aid with such tasks under direction.[50] As a side bonus, these programs are viewed as addressing the criminal justice system's goal of reform and rehabilitation by allowing prisoner-caregivers to develop strong task-based skills and empathetic responses.

Nevertheless, qualms with this model primarily revolve around the prisoners providing care to their fellow inmates. Convicted prisoners lose many of their rights as punishment for the crimes they committed. Among these rights are the abilities to work and earn wages in the free market. While there are limited opportunities to work in the prison setting, prison labor is done

---

[‡‡] Initiation and develop of the program were led by Angola's then-Warden Burl Cain.[17] Collaboration with the nearby non-profit, university hospice program allowed for staff who could offer education, training, and counseling to inmates and prison personnel to develop and run such a program.[50]

[§§] The Louisiana State Penitentiary is built on land that was once a slave-holding planation.[74]

for little to no pay, as exemplified by the recent use of prisoners as firefighters in the California wildfires and as workers to move the bodies of deceased COVID-19 patients to mobile morgues in Texas.[56, 57] Unlike many prison-labor assignments, prisoners who volunteer as caretakers in prison hospice programs receive training to perform this role. Those who are ultimately released may desire to continue using this skillset professionally; however, that is most likely not possible due to background checks. In addition, the question of whether prisoners should be rewarded for their labor-intensive role as hospice volunteers remains. There are also several intersectional questions regarding identity, include race, age, and gender, and how that might affect prisoners receiving and providing palliative care (e.g., the number of individuals choosing to enroll in hospice).[50]

Moreover, it can be argued that the current prison hospice system requires extensive improvement in terms of providing quality EOL care to its patient-prisoners to make it on par with hospice care in non-carceral environments. Part of this requires that prisoners who volunteer as caretakers for fellow inmates in hospice be provided compensation and workplace protections because they have experienced an indicative and positive change, which means that prisons have fulfilled their rehabilitation function.[50]

Chapter 2

Caregiving

A. What Is Caregiving?

At Angola, prisoner-caretakers have three broad responsibilities: (1) complete administrative duties for organization purposes and peer education; (2) act as a patient assistant giving support, companionship, and practical help; and (3) sit vigil with prisoner-patients who are actively dying.[28, 50] In 2001, 26 of 49 correctional agencies indicated that inmate volunteers are used to assist chronically ill inmates, and 3 used volunteers only in their hospice programs.[32] Another report from 2011 showed an increase, with 69 prison hospices operating in the United States.[7] However, much of this data is self-reported rather than observational, and all programs operate in accordance with different policies and practices.[7]

In general, however, the training for prisoner-hospice caregivers requires one week, and the curriculum emphasizes eight features of hospice: (1) the philosophy of hospice, (2) volunteer responsibilities, (3) patient rights and responsibilities, (4) patient confidentiality, (5) basic communication, (6) how to sit with an prisoner-patient and maintain a nonjudgmental attitude, (7) near-death experiences, and (8) physical and emotional changes to expect from a patient at EOL.[17] In addition, prisons with inhouse hospice programs strive to achieve five essential elements in order to provide effective prison hospice: (1) patient-centered care, (2) an inmate volunteer model, (3) safety and security, (4) shared values, and (5) teamwork.[7]

B. Impact of Caregiver on the Corrections System and the Incarcerated Patient

As noted earlier, for EOL prisoner-patients, there are few options available for a comfortable, peaceful, and dignified death. Yet the demand for such continues to rise considering the number of elderly incarcerated individuals.[23, 24] With the introduction of volunteer-based prison hospice programs, staffed in part by fellow incarcerated individuals as volunteer hospice caretakers, several significant impacts arise for the patient-prisoner, the corrections system, and the prisoner-caregivers.

Just as with physical ailments, incarcerated individuals are more likely to have or be at greater risk of developing mental health illnesses, ranging from depression to schizophrenia.[55] Studies report that 40% of individuals with serious mental illnesses have been in jail or prison at some time in their lives.[55] Prisoners already experience low levels of wellbeing and psychiatric health compared to non-detained individuals.[18] Mental illness might result in poorer medical prognoses as a result of social isolation and minimal social contacts and support.[16] This is especially salient as wellbeing has been found to relate of suicide rates among those imprisoned, as well as other negative outcomes during incarceration.[***19]

It is possible that prisoner-patients may experience decreased isolation and, perhaps, more confidence in their ability to advocate for themselves when a prisoner-caregiver is involved in their care. Emotion-focused coping, receiving visits, engaging in structured activities, and experiencing less fear of victimization all contributed to better adjustment among healthy male prisoners.[21] This is likely also experienced by the EOL prisoner-patients, who may be able to better process grief and depression associated with a terminal diagnosis.

[***] Evidence demonstrates that personal wellbeing is inversely correlated with reoffending, meaning improving individual wellbeing may reduce recidivism.[20]

Additionally increasing their mental wellbeing may enable incarcerated individuals to feel more social connected and engaged in fulfilling social interactions while in prison.[16] This social aspect is beneficial in many aspects. First, as explained by Koudenburg et al., social groups can provide their members with a sense of autonomy, as members have a stronger self-definition that strengthens the experience of their decisions as autonomous.[15] In addition, having caregivers, including prisoner-caregivers, interact with prisoner-patients provides a platform interaction with fellow group members, making each aware of the ways in which they can uniquely contribute to the group; this, in turn, leads to the self-perception of being an autonomous actor, even in compromised conditions.[15]

This is immensely powerful for prisoner-patients who may experience fear and uncertainty about being transferred to hospice care, while grappling with an EOL diagnosis, and it may improve their relationship with prison physicians.[15, 16] Patients who are elderly, of color, former drug users, or infected with HIV are especially—and rightfully—suspicious of the systems from which they receive care. For example, they tend to decline to execute advance directives because they see them as methods of the systemic denial and deprivation of care.[30] However, having a peer be a part of their care strategy as caregivers may make these prisoner-patient's feel more empowered to make or enforce personal medical decisions. This would diminish the risk of losing the right to make personal medical decisions or help them be more willing to use advance directives to declare their preferences and designate individuals to make decisions on their behalf.[52]

While there is limited academic literature regarding the implementation and utilization of advance directives in prison, it is well-known that lack of trusting health practitioners is a barrier to advance-care planning.[58] In addition, despite concerted efforts to encourage the use of advance

directives, it is rare to find any patient population where more than 25% actually sign such a document.[30] Reversal of this trend would substantially increase autonomy for prisoners. This is key as a lack of autonomy has a marked negative impact on an incarcerated individual's wellbeing, as described in Skyes' ethnographic account of the "pains of imprisonment."[14] People who lack independence are denied self-determination, have very few choices, are constantly being controlled by others, and, as a result, develop helplessness and frustration; this, in turn, leads to increased stress and aggression—and even gang involvement, which is especially prevalent in a prison population.[13, 14]

Another benefit of having prisoner-caregivers is that EOL patient-prisoners may have greater access to emergency medical services. In general, it is challenging to provide incarcerated individuals with the emergency medical care because it requires convincing prison staff, who may not be medically trained, that the situation is sufficiently urgent.[52] Caregivers, including prisoner-caregivers, who are trained to notice particular symptoms or be a source of support may be valuable in advocating for patients, and if they are handpicked by the prison institution, they may be seen as more trustworthy to prison officials, allowing the prisoner-patient to access needed care more rapidly. This may improve patient outcomes or help prison hospices to satisfy the goals of hospice such that patients should die in a pain-free manner, surrounded and comforted by trusted individuals.[59] In spite of this progress, however, many studies show that, even in the most advanced medical centers, many patients still die in pain.[30] As philosophers Nancy Dubler and Budd Heyman put it:

> Punishment and care are generally incompatible. Even if retribution is justifiable, dying alone, in pain, without comfort, exceeds the boundaries of the permissible for the vast majority of inmates.[3]

Thus, it is true that prisoner-caregivers fill a void that otherwise would be left unmet. They are increasing the autonomy of the dying patient-prisoners, providing company and care in a beneficent manner, and they are acting as advocates for their fellow inmates.

The true impact of caregiver-prisoners on the corrections system, however, has more to do with cost containment and effectiveness of care delivery. Firstly, it is more cost-effective to establish a medical unit within a prison as opposed to relocating patients to a nearby hospital with guards in tow,[4] as extra expenses are incurred to pay the security staff.[4] This is especially true when medical staff are augmented by unpaid volunteers who are onsite, such as prisoner-caregivers. For example, in the Angola inhouse hospice system, there are no additional expenses except for the upfront cost of establishing a hospice center and providing ongoing investment in prisoner-caregiver selection, training and support. These types of programs must grapple, on an ongoing basis, with volunteer selection, training, defining the volunteers' scope of practice, ensuring security, guaranteeing patient confidentiality, and attending to volunteers' emotional needs.[28] For example, volunteers must overcome any biases they may have regarding race or committal offense. They must also be able to deal with death and loss. Additionally, these volunteers often participate in healthcare delivery processes, not just on the periphery. Providing quality care requires an interdisciplinary group of management staff, correctional officers, spiritual advisers, medical and mental health professionals, and volunteers.[17]

However, running these programs on a large-scale are not without difficulties or controversy.[49] Per the passage of the Prison Rape Elimination Act in 2003, it is problematic for two incarcerated individuals to be in close personal contact without the supervision of a correctional officer charged with maintaining safety and reducing risk of victimization of vulnerable and sick incarcerated individuals.[6] In addition, there is concern of "de-skilling" the correctional nursing staff and handing certain responsibilities over to unpaid staff, the volunteers charged with caregiving duties.[6]

As seen, the overall impact of volunteer prisoner-caregivers on EOL patient-prisoners and the corrections facility is generally positive. However, it is questionable whether these benefits translate to the caregiver-prisoners themselves.

Chapter 3

Impact of Caregiving on the Caregiver

A. Achieving the Rehabilitative Goals of Corrections

Training individuals to work in a prison hospice is relatively simple given that their roles involve administrative tasks, some physical labor, and a compatible personality. And, indeed, there are some benefits that inure to the prisoner-caregiver. One of the main arguments for such programs is that they provide redemptive opportunities for incarcerated persons. After their training, these caregivers become one of the first people a dying prisoner-patient communicates with because the responsibilities of these prisoner-caregivers include supporting the emotional needs of the EOL patient.[3] As such, prisoner-caregivers have the opportunity to care about others in a very genuine way—something they may never have been able to do. These programs inspire the emotional rehabilitation and growth that incarcerated individuals may need to honestly consider the consequences of the actions that led to their incarceration.[6, 47, 48] Additionally, participation in programs, such as Angola's, are entirely voluntary, and such participation is not seen as inducement, as it has no impact on the possibility of parole.[17] Moreover, participation as a hospice volunteer exists outside the scope of regular prisoner tasks and jobs, so the time spent as a caregiver does not replace their other responsibilities.[17] Even with these constraints to participating, the anecdotal responses to these program have been positive.

One inmate remarked:[17]

> I'm 34. I've been at Angola for 17 years. I committed murder and will be here for the rest of my life. I hope to get out some day, but I know I won't. I deserve to be punished. Prison has changed me and I've learned so much while incarcerated. I've learned how to be patient and to obey authority. But because of hospice, I've learned the most important lesson: how to love.

Another stated:[17]

> Most of us were violent offenders. I committed murder. There isn't a damn thing in this for me. Nothing we do with hospice can be put in our record. We're strictly doing this from our heart.

It is powerful to witness such demonstrated personal growth and a willingness to confront the past wrongs. In their role, prisoner-caregivers contribute back to their penal community and hope that, one day, they may also receive this type of care and attention. And, from this perspective alone, it seems as through such programs should be incorporated in large state and federal prisons that have sizeable populations requiring hospice care. But, as alluded to earlier, these programs, while on the whole beneficial, are not without controversy.

B. Do Incarcerated Individuals Also Experience a Redemption Arc?

Certainly, a large proportion of the individuals who will likely die while in prison have violated their side of the social contract. Prisons are public—although increasingly privatized—institutions designed to punish these individuals through imprisonment and deprivation of liberties, including the right to vote. Secondary to incarceration, prisons cite rehabilitation, reform, and redemption as necessary for re-entry into society (should prisoners be released) as functioning and contributing members of the civic order. Unfortunately, once a person goes to prison, it is very difficult to remove the stain of being deemed a "prisoner" or "convict"—even after the debt to society has been paid. This reinforces the sociological notion of prisons as total institutions.

As Erving Goffman theorized, being a prisoner is one's "master status."[53] A total institution is "a place of residence and work where many like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life."[53] Such institutions have four main characteristics: (1) batch living, (2) binary management, (3) the inmate role, and (4) the institution perspective.[53] Batch living is essentially the antithesis of individual living, where each phase of a member's daily activity is carried out in the company of others without any personal choice.[53] Binary management describes diametrically opposed groups, such as dichotomy between prison officers and prisoners.[53] Individuals fill the inmate role through a deculturation and role stripping so powerful that a person may be rendered incapable of normal living upon return to the wider community.[53] Goffman argues that the admission procedures of a prison are a "series of abasements, degradations, humiliations, and profanations of self" for the purpose of a person's dispossession

from their original identity and becoming the identity that the institution has given them.[53] This process, in and of itself, is a punishment that is not uncommon in American prisons.

Thus, imprisonment, as a whole, puts prisoners in a situation where they must adopt this provided identity or be labeled as unrepentant or unfit to rejoin free society. It is here that the idea of redemption comes into play. Redemption is a concept often invoked to justify programs like Angola's caregiver program.[9] It is an essential concept in many major religions, and it means being saved from sin, error, or evil. Programs like Angola's hospice caregiver system can help "redeem" these individuals and return to them their status as humans first, prisoners second.[9]

The concept of redemption assumes that people who are incarcerated should be defined by the worst thing they did in their life until someone decides otherwise (e.g., the prison wardens and parole officers). As Kantian philosophy would argue, "people matter not in relation to their ability to benefit or harm society, but as ends in and of themselves."[67] If Kant's words stand, we can form a "kingdom of ends," a moral community that actively asks whether the intended maxim of their action could be functional as a universal rule.[67] Everyone would have an imperfect duty, or an obligation to increase other's capability to enact choices. Without Kant's original interpretation, we should take this to mean that, even those who are incarcerated should be given the autonomy to enter the kingdom of ends, to become more moral persons without the weight of their past wrongdoings.

However, calling upon Kant's work in this situation is inherently problematic because his interpretation did not extend to protect people who have violated the Universal Principle of Right (UPR).[66] In fact, his work is a paradigm for retributive justice arguments of punishment such that the government should and must punish a "criminal."[66] Meanwhile, I argue for restorative justice

practices that move away from the "eye-for-an-eye" approach and do consider context of the committal offense.

There are truly heinous crimes, and there are people who have no desire to become more emotionally intelligent or repent for their acts. However, this is not the population that is in question: the people in question are those who choose to volunteer as hospice caregivers even after being labeled "irredeemable." Redemption can also only be earned in a prison environment because there is a stark power differential, and redemption can only be bestowed by an authority vested as able to cleanse one of "sin." In this case, that authority rests in the people running the prison. Redemption becomes utterly meaningless in life outside prison because redemption gained in a controlled environment from authorities cannot be a status maintained beyond the bounds of that system in a broader, more dynamic environment. People generally commit crimes as a result of their environment, and there is nothing stopping a person from again becoming a victim of their circumstances without systemic and significant change.[70, 71]

So much, including autonomy, is stripped from incarcerated individuals that they will grab onto any opportunity to feel empowered and autonomous once more. This may be a major reason that caregiving inspires positive feelings in incarcerated individuals unlike other prison jobs, such as cooking or laundry. As mentioned earlier, prisons are places where negative traits, like anger, may be amplified, overshadowing pre-existing, more personable, and empathetic traits. This tough cultural environment, with all its labels, is a challenging place in which to experience compassion, which caregiving might provide.

Secondly, it is important to consider an incarcerated individual's legal status, and the coercion that it inherently entails, as well as how that makes healthcare in prisons different.[2] There is an inherent power differential in penal relationships in which incarcerated individuals

are accustomed to following orders and institutional rules, which, in turn, translates into an avoidance for taking initiative.[52] This extends to both the prisoner-patient and the prisoner-caregiver who are placed in a very intimate situation, perhaps for the first time in their prison experience. Given this, it is understandable why an incarcerated individual might choose to perform emotionally-taxing, affective labor without compensation. However, I would argue that it is unethical for the burden that an incarcerated individual already bears to be exacerbated by exploitation of their physical and emotional labor in order to make an unjust system easier to run—even if it provides benefit to others who are similarly situated.

C. Performing Labor as a Form of Punishment or Rehabilitation

The correctional health staff and corrections officers responsible for this program at Angola argue that the program is ethical, economical, beneficial, and administratively feasible.[1] They state that involving prisoner-caregivers has allowed the provision of hospice care to be more comprehensive and reduced the prevalence and severity of EOL symptoms in prisoner-patients, thus improving EOL care.[45, 46] While this may be true, the prisoner-caregivers who make this possible are not being compensated for the physical efforts or especially for the emotional tolls they take on in their role. This argument would not apply to purely physical labor, such as cooking or laundry, because that type of labor does not entail substantial emotional costs to self.

First, labeling the Angola caregiving program, a "program," does not change the fact that it calls for uncompensated prison labor. Prisoners are excluded from the legal protections provided to other workers because they are not allowed to unionize, they do not receive

minimum wage, their wages can be seized by the prison, they are not protected by workers' compensation if injured or killed on the job, and they cannot recover damages in court.[56] In addition, prison is an inherently coercive environment, and arguments that incarcerated individuals can volunteer to be caregivers is fraught. Incarcerated individuals are, quite literally, a captive workforce of 2.2 million people. In fact, in 2014, the California prison system argued against granting early release credits for minimum security prisoners because it would "severely impact fire camp participation."[56] The State wanted to keep inmates in prison to act as firefighters, performing dangerous labor for laughable pay. While the court eventually rejected the argument, this case clearly illustrates that governmental desires exist to maintain prisoners as a free or greatly reduced-fee labor source.

California's actions align with Kant's retributivists arguments which underpin much of the United States' existing criminal justice system. Once punishment is warranted, the quality and quantity of punishment can be determined by *lex talionis*, or the law of retribution.[66] While the general goal of punishment is deterrence and retribution, Steffen argues:

> Retribution … was not a goal or reason for punishment but rather a limitation on the state's right to inflict punishment… Thus one may threaten to punish citizens, with the goal of deterring crime, but 'after a criminal violation has occurred the focus shifts from instrumental priorities of general crime prevention to the just treatment of the individual.'[66]

Preeminent scholars have argued about whether *lex talionis* emboldens or places limitations on the state to use a person as a mere means, as it applies to prison labor as a form of

punishment for people who have violated the UPR, but the fact remains that uncompensated labor is being used in conjunction with and as punishment.[66] Disregarding Kant's position on those who violate the UPR, it is clear that incarcerated individuals are being used as mere means, especially if they are not being fairly compensated and extended protections in a way that protects their autonomy. While a convicted criminal has been deemed by society to have violated the social order in a significant way, and while the state has a responsibility to punish and deter such violations, there is no justification for the state to usurp people's bodies and minds as punishment.

It is true that for the prisoner-patient, there are tangible and powerful benefits, including increases in autonomy and wellbeing, and for the prisoner-caregiver, there is a feeling of emotional rehabilitation. The latter catharsis is explored thoroughly in documentaries like "Serving Life" and "Prison Terminal: The Last Days of Private Jack Hall," and the anecdotes are compelling and moving.[9, 10, 67, 68] However, those valuable benefits do not make the enterprise of prison hospice ethical. Incarcerated individuals may have chosen to participate in a caregiving program with laudable intentions. They likely desired to experience positive emotional growth and build a more caring prison environment. Outside of their existing responsibilities, like cooking and laundry, they may desire to become an engaged member of their community. All these motivations are, no doubt, true, yet their "volunteer" efforts in hospice caregiving programs are mission critical and essential for the effective functioning of such programs. They are essential workers. Thus, their volunteerism is no longer simply voluntary.

In addition, there is limited applied research that empirically proves emotional rehabilitation or growth has occurred for these prisoner-caregivers. Anecdotal evidence is unreliable, and individuals who are forced to accept the master status of "prisoner" are unlikely

to have contradictory opinions, especially when given the opportunity for positive experiences like caregiving.[14,53] Not only is there a psychological deterrent to dissent for prisoner-caregivers, which ultimately decreases their autonomy as a result of acting under coercion,[19] but there is also the matter of labor ethics to consider.

Third, prisoners are recognized as a vulnerable and marginalized population.[†††] And a incarcerated individuals lacks many rights, are undercompensated or uncompensated for labor, and unprotected by labor laws, coerced work, even under the label of volunteerism, constitutes a form of enslavement.[5] To describe the labor of prisoner-caregivers as volunteerism is a gross mischaracterization because of the environment in which they live and work—even if prisoner-caregivers, themselves, fail to express such sentiments.

Finally, not only are incarcerated individuals vulnerable, but they are also predominantly Black and Brown individuals, who already bear the burdens of systemic social injustice. Such labor simply further entrenches such injustice. And it does so in a particularly deceptive and egregious manner by making it appear, on its face, that prisoner-caregivers are exercising autonomy in making the affirmative, uncoerced decision to take on this volunteer role.

Keeping in mind these objections to volunteer prisoner-caregiver programs, in-house prison hospice programs should absolutely continue to exist and expand, but they should not do so on the backs of prisoner-caregivers—who are often minorities—who are uncompensated and unprotected. Compensation or early release for this type of work is far more justifiable than for other types of prison labor because such efforts demonstrate a commitment to rehabilitation and

[†††] Prisoners are a protected group according to the Belmont Report, and require protection from research and labor abuses as a result of a lack of autonomy.[76]

upholding of the social contract.‡‡‡ In undertaking the role of prisoner-caregiver, these inmates are participating in a program whose foundational goals derive from feminist ethics: the ethics of care.[72] This desire to build, exist, and act within the context of relationships underpins prison hospice systems staffed by prisoner-caregivers.[72] The moral agent, the incarcerated individual acting as a caregiver, leans into the traditionally feminine values of care and compassion and empowers even more vulnerable individuals, like the prisoner-patients.[72] This type of programming also call upon restorative justice, such that harms caused by the individual's crime can—and must—be recognized and corrected by the perpetrator.[73] In the case of prison hospice programs, prisoner-caregivers likely already recognize their wrongs against their victims and society, and are undertaking their role as a way of "giving back" to society and others. In such instances, the use of early release would not be an incentive for productive and positive behavior, but rather would act as a recognition of restorative action by the offender.

Moreover, caregiving programs that lack protections or compensation for incarcerated individuals who assume the role of prisoner-caregiver assign diminished human value to incarcerated individuals who must earn back their human dignity through labor. As Cohn stated: "Are we to love the sinner and hate the sin or equate the sin with the sinner. To impose suffering on an individual, when that suffering can be prevented, is to devalue that person as a human being. It begins to set up criteria of social worth."[3]

‡‡‡ Compensation or early release happens in a number of contexts with varying ethicality. For example, in Tennessee, a judge offered reduced sentences to incarcerated individuals in exchange for getting vasectomies or Nexplanon, a birth control implant for females.[61] Other programs, like those in Davidson County, TN, allow for incarcerated individuals to receive credit for work to reduce jail or prison time, such that they earn two days off a sentence for one day worked.[60]

Chapter 4

Conclusions

Imprisoned individuals do not receive adequate care in many instances, and disparities in access persist.[3] Efforts to change this reality are not looked upon favorably by most members of free society. But, as prison populations age, the needs for care, including EOL care, only increase. Yet, establishing funding for EOL care for elderly and terminally ill prisoners does not tend to soften hearts or loosen the purse strings. Thus, prisons rely on models that allow for transformation within prison walls using resources available to them: namely, uncompensated prison labor under the guise of volunteerism.

Nevertheless, the ability for incarcerated individuals to volunteer as caregivers for EOL prisoner-patients signals a shift in the way we perceive incarceration. It provides death with dignity for EOL prisoner-patients and contributes to positive emotional growth in prisoner-caregivers—thereby adopting notions of ethics of care and restorative justice. Of course, there is also a tremendous benefit that enures to the corrections system: better care at less cost, This, however, all comes at the cost of unethical free prisoner labor.

While prison hospice programs benefit the criminal justice system by providing more humane care, the current prison hospice model requires extensive revision. Not only does it fail the equivalency test in terms of providing prisoner-patients with the same quality of hospice care and EOL life as hospice in non-carceral environments, but volunteer prisoner-caregivers lack compensation and protections for their physical and affective labor—even when such work indicates that prisons have fulfilled their rehabilitation function for these inmates.[50]

This use of uncompensated prison labor, under the guise of volunteerism in a highly coercive environment populated by a protected class of individuals who are mainly comprised of

Black and Brown bodies who have and continue to bear the burden of systemic injustice, is unethical. For true racial justice and criminal justice reform to occur, attention must be paid to such programs. Prison hospice programs that rely on prisoner-caregivers have it only partially right. But where they have it wrong points to injustice writ large and entrenches racial and social wrongs. Prisons, filled with Black Americans serving longer sentences, cannot continue to be viewed as a warehouse for the extortion of free labor that is the equivalent of enslavement. Prison hospice programs continue to perpetrate this historic harm in a particularly damaging way by justifying it under the umbrellas of volunteerism and rehabilitation.

BIBLIOGRAPHY

1. Sentencing Project, The (2020). Criminal Justice Facts. Retrieved 30 November 2020, from https://www.sentencingproject.org/criminal-justice-facts/.
2. Mahon, N.B. (1999). Introduction: Death and Dying Behind Bars—Cross-Cutting Themes and Policy Imperatives. Journal of Law, Medicine & Ethics, 27(3), 213–215. https://doi.org/10.1111/j.1748-720X.1999.tb01454.x.
3. Cohn, F. (1999, Fall). The Ethics of End-of-Life Care for Prison Inmates. Journal of Law, Medicine & Ethics, 27(3), 252. https://link.gale.com/apps/doc/A58669726/LT?u=carl39591&sid=LT&xid=fb2dd319.
4. Beck, J.A. (1999). Compassionate Release from New York State Prisons: Why Are so Few Getting Out? The Journal of Law, Medicine & Ethics, 27(3), 216. https://doi.org/10.1111/j.1748-720X.1999.tb01455.x.
5. Parker, Jr., FR., & Paine, C.J. (1999). Informed Consent and the Refusal of Medical Treatment in the Correctional Setting. The Journal of Law, Medicine & Ethics, 27(3), 240. https://doi.org/10.1111/j.1748-720X.1999.tb01458.x.
6. Cloyes, K., Rosenkranz, S., Supiano, K., Berry, P., Routt, M., Llanque, S., & Shannon-Dorcy, K., 2017. Caring to Learn and Learning to Care. Journal of Correctional Health Care, 23(1), 43–55.
7. Cloyes, K., Rosenkranz, S., Berry, P., Supiano, K., Routt, M., Shannon-Dorcy, K., & Llanque, S. (2015). Essential Elements of an Effective Prison Hospice Program. American Journal of Hospice & Palliative Medicine, 33(4), 390–402. https://doi.org/10.1177/1049909115574491.

8. Loeb, S., Penrod, J., Hollenbeak, C., & Smith, C. (2011). End-of-Life Care and Barriers for Female Inmates. Journal of Obstetric, Gynecologic & Neonatal Nursing, 40(4), 477–485. https://doi.org/10.1111/j.1552-6909.2011.01260.x.
9. NPR. (2011). 'Serving Life': Facing Death, Inmates Find Humanity. Tell Me More [Podcast]. Retrieved 14 September 2020, from https://www.npr.org/2011/10/19/141505983/serving-life-prisoners-find-humanity-in-face-of-death.
10. Walters, J. (2014). HBO Documentary 'Prison Terminal' Shows the Human Side of Dying in Prison. Newsweek. Retrieved 14 September 2020, from https://www.newsweek.com/hbo-documentary-prison-terminal-shows-human-side-dying-prison-238972.
11. Wilper, A., Woolhandler, S., Boyd, J., Lasser, K., McCormick, D., Bor, D., & Himmelstein, D. (2009). The Health and Health Care of US Prisoners: Results of a Nationwide Survey. American Journal of Public Health, 99(4), 666–672. https://doi.org/10.2105/ajph.2008.144279.
12. Criminal Justice Fact Sheet. (2020). Retrieved 19 January 2021, from https://www.naacp.org/criminal-justice-fact-sheet/
13. Setty, E., Sturrock, R., & Simes, E. (2014). Gangs in Prison: The Nature and Impact of Gang Involvement Among Prisoners. London: The Dawes Unit, Catch 22.
14. Sykes, G.M. (1958 [2007]). The Pains of Imprisonment. In G.M. Sykes, The Society of Captives: A Study of a Maximum-security Prison (679–701). Princeton, NJ: Princeton University Press.

15. Koudenburg, N., Jetten, J., & Dingle, G. (2017). Personal Autonomy in Group-Based Interventions. European Journal of Social Psychology, 47(5), 653–660. https://doi.org/10.1002/ejsp.2230.

16. Kyprianides, A., & Easterbrook, M. (2019). Social Factors Boost Well-Being Behind Bars: The Importance of Individual and Group Ties for Prisoner Well-B eing. Applied Psychology: Health & Well-Being, 12(1), 7–29. doi: 10.1111/aphw.12171.

17. Osofsky, M., Zimbardo, P., & Cain, B. (2004). Revolutionizing Prison Hospice: The Interdisciplinary Approach of the Louisiana State Penitentiary at Angola. Corrections Compendium. Retrieved from https://www.thefreelibrary.com/Revolutionizing+prison+hospice%3a+the+interdisciplinary+approach+of+the...-a0121643812.

18. van der Kaap-Deeder, J., Audenaert, E., Vandevelde, S., & Soenens, B. (2017). Choosing When Choices Are Limited: The Role of Perceived Afforded Choice and Autonomy in Prisoners' Well-Being. Law & Human Behavior, 41(6), 567–578. doi: http://dx.doi.org/10.1037/lhb0000259.

19. Liebling, A., & Ludlow, A. (2016). Suicide, Distress and the Quality of Prison Life. In Y. Jewkes, B. Crewe, & J. Bennett (eds.), Handbook on Prisons (2nd ed., 224–245). London, UK: Routledge.

20. Bouman, Y. H. A., Schene, A. H., & de Ruiter, C. (2009). Subjective Well-Being and Recidivism in Forensic Psychiatric Outpatients. International Journal of Forensic Mental Health, 8, 225–234. http://dx.doi.org/10.1080/14999011003635647.

21. Picken, J. (2012). The Coping Strategies, Adjustment, and Well-Being of Male Inmates in the Prison Environment. Internet Journal of Criminology, 1–29.

22. Hospice and Palliative Care in Prisons: Special Issues in Corrections. Longmont, CO: US Dept. of Justice, National Institute of Corrections Information Center; September 1998.

23. Mitka, M. Aging Prisoners Stressing Health Care System. JAMA. 2004;292(4):423–424.

24. Yorston, G.A, & Taylor, P.J. Older Offenders: No Place to Go? Journal of American Academic Psychiatry & Law. 2006;34(3):333–337.

25. Voelker, R. New Initiatives Target Inmates' Health. JAMA. 2004;291(13):1549–1551.

26. Fazel, S., Hope, T., O'Donnell, I., et al. Health of Elderly Male Prisoners: Worse than the General Population, Worse than Younger Prisoners. Ageing. 2001;30 (5):403–407.

27. Mumola, C.J. Medical Causes of Death in State Prisons, 2001–2004. Washington, DC: US Dept. of Justice; 2007:12. http://www.ojp.gov/bjs/pub/pdf/mcdsp04.pdf. Accessed 25 July 2007.

28. Linder, J., & Meyers, F. (2007). Palliative Care for Prison Inmates. JAMA, 298(8), 894–901. doi: 10.1001/jama.298.8.894.

29. Watson, R., Stimpson, A., & Hostick, T. Prison Health Care: A Review of the Literature. International Journal of Nursing Studies 2004;41(2):119–128.

30. Dubler, N.N. The Collision of Confinement and Care: End-of-Life Care in Prisons and Jails. Journal of Law, Medicine & Ethics. 1998;26(2):149–156.

31. Byock, I. Dying Well. In Corrections: Why Should We Care? Correct Care. 2002;16(4):18.

32. Anno, B.J., Graham, C., Lawrence, J.E., & Shansky, R. Addressing the Needs of Elderly, Chronically Ill, and Terminally Ill Inmates. Middletown, CT: Criminal Justice Institute; 2004:162.

33. Barnard, J. Convicted Murderers Relearn Compassion in Prison Hospice Oregon: With the Spread of Tough Sentencing Laws and HIV, More Inmates Are Dying Behind Bars. Associated Press. August 1, 1999. http://www.aegis.com/news/ap/1999/ap990801.html.

34. Head, B. The Transforming Power of Prison Hospice. Journal of Hospice & Palliative Nursing 2005;7(6):354–359.

35. Harrison, P., & Beck, A. Prisoners in 2005. Washington, DC: US Dept. of Justice, Bureau of Justice Statistics; 2006:13.

36. Mumola, C., & Beck, A. Prisoners in 1996. Washington, DC: US Dept. of Justice, Bureau of Justice Statistics; 1997:15.

37. Beck, A., & Harrison, P. Prisoners in 2000. Washington, DC: US Dept. of Justice, Bureau of Justice Statistics; 2001:16.

38. Beck, A., & Gilliard, D. Prisoners in 1994. Washington, DC: US Dept. of Justice, Bureau of Justice Statistics; 1995:15.

39. Cummings, C. Older Inmates: The Impact of an Aging Inmate Population on the Correctional System. Sacramento: California Dept. of Corrections; 1999:87.

40. Stephan, J., ed. State Prison Expenditures, 2001: Bureau of Justice Statistics Special Report. Washington, DC: US Dept. of Justice; 2004:9.

41. Kinsella, C. Corrections Health Care Costs: Critical Information for State Decision-Makers. Lexington, KY: Council of State Governments; 2004:38.

42. Partnership for Clear Health Communication Steering Committee. Eradicating Low Health Literacy: The First Public Health Movement of the 21st Century Overview. http://www.aameda.org/MemberServices/Exec/Articles/sum03/EradicatingLowHealthcareLiteracy.pdf. Published March 2003. Accessed 26 July 2007.

43. Bennett, I.M., Kripalani, S., Weiss, B.D., & Coyne, C.A. Combining Cancer Control Information with Adult Literacy Education: Opportunities to Reach Adults with Limited Literacy Skills. Cancer Control. 2003;10(5)(suppl):81–83.

44. Haigler, K., Harlow, C., & O'Connor, P. Literacy Behind Prison Walls. Washington, DC: US Dept. of Education, Office of Educational Research and Improvement, National Center for Educational Statistics; 1994:187.

45. Cloyes, K.G., Berry, P.H., Supiano, K., & Martz, K. Characteristics of Prison Hospice Patients and Symptom Prevalence on Admission and 72 Hours Before Death. Journal of Correctional Health Care. 2015; 21:298–308. [PubMed: 26084951]

46. Cloyes, K.G., & Burns, K. Considerations in the Care of Geriatric Patients in Prisons and Jails. In Appelbaum, K.L., Metzner, J.L., & Trestman, R.L. (eds). The Oxford Textbook of Correctional Psychiatry. New York, NY: Oxford University Press; 2015. p. 326–330.

47. Cloyes, K.G., Rosenkranz, S.,, Wold, D, Berry P., and Supiano K. To Be Truly Alive: Motivation for Providing End-of-Life Peer-Care and Service Among Prison Inmate Hospice Volunteers. American Journal of Hospice & Palliative Medicine. 2014; 31:735–748. [PubMed: 24071627]

48. Loeb, S.J., Hollenbeak, C.S., Penrod, J., Smith C.A., Kitt-Lewis, E., & Crouse, S.B. Care and Companionship in Isolating Environments: Inmates Attending to Dying Peers. Journal of Forensic Nursing. 2013; 9(1):35–44. [PubMed: 24158099]

49. Craig, E., & Ratcliff, M. Controversies in Correctional End-of-Life Care. Journal of Correctional Health Care. 2002; 9:149–157.

50. Evans, C., Herzog, R., & Tillman, T. The Louisiana State Penitentiary Angola Prison Hospice. Journal of Palliative Medicine. 2002; 5(4):553–558. [PubMed: 12243680]

51. Institute of Medicine (US) Committee on Ethical Considerations for Revisions to DHHS Regulations for Protection of Prisoners Involved in Research; Gostin. L.O., Vanchieri, C., & Pope, A. (eds.). Ethical Considerations for Research Involving Prisoners. Washington (DC): National Academies Press (US); 2007. 2, Today's Prisoners: Changing Demographics, Health Issues, and the Current Research Environment. Available from: https://www.ncbi.nlm.nih.gov/books/NBK19877/.

52. Andorno, R., Shaw, D., & Elger, B. (2014). Protecting Prisoners' Autonomy with Advance Directives: Ethical Dilemmas and Policy Issues. Medicine, Health Care and Philosophy, 18(1), 33–39. doi: 10.1007/s11019-014-9571-z.

53. Jones, K., & Fowles, A. (2008). Understanding Health and Social Care: An Introductory Reader - Chapter 13: Total Institutions (pp. 103–106). Sage.

54. Bureau of Justice Statistics. (2020). Aging of the State Prison Population, 1993–2013. US Dept. of Justice.

55. Torrey, E.F., Kennard, A.D., Eslinger, D., Lamb, R., & Pavle, J. (2010). More Mentally Ill Persons Are in Jails and Prisons Than Hospitals: A Survey of the States. Treatment Advocacy Center and National Sheriffs Association.

56. Fathi, D. (2018). Prisoners Are Getting Paid $1.45 a Day to Fight the California Wildfires. From https://www.aclu.org/blog/prisoners-rights/prisoners-are-getting-paid-145-day-fight-california-wildfires.

57. Rocha, A. (2020). Incarcerated Texans Enlisted to Work in County Morgue as COVID-19 Deaths Overwhelm El Paso. From https://www.texastribune.org/2020/11/15/coronavirus-texas-el-paso-inmates-morgue-deaths/.

58. Macleod, A., Nair, D., Ilbahar, E., Sellars, M., & Nolte, L. (2020). Identifying Barriers and Facilitators to Implementing Advance Care Planning in Prisons: A Rapid Literature Review. Health & Justice, 8(1). doi: 10.1186/s40352-020-00123-5.

59. Meier, E.A., Gallegos, J.V., Thomas, L.P., Depp, C.A., Irwin, S.A., & Jeste, D.V. (2016). Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue. American Journal of Geriatric Psychiatry, 24(4), 261–271. https://doi.org/10.1016/j.jagp.2016.01.135.

60. Sawyer, A. (2016). Big Changes to Davidson Jail Work Credit Policy Raise Concerns. From https://www.tennessean.com/story/news/crime/2016/07/26/big-changes-davidson-jail-work-credit-policy-raise-concerns/87545314/.

61. Rosenblatt, K. (2017). Judge Offers Tennessee Inmates Shorter Sentences If They Have a Vasectomy. From https://www.nbcnews.com/news/us-news/judge-offers-inmates-reduced-sentences-exchange-vasectomy-n785256.

62. Bratt, L. (2013). Why Maryland Needs Hospice Behind Bars. From https://www.washingtonpost.com/opinions/why-maryland-needs-hospice-behind-bars/2013/03/15/db5139e8-762e-11e2-95e4-6148e45d7adb_story.html?tid=a_inl_manual.

63. Ratcliff, M., & Craig, E. (2004). The GRACE Project: Guiding End-of-Life Care in Corrections 1998–2001. Journal of Palliative Medicine, 7(2), 373–379. doi: 10.1089/109662104773709549.

64. Huh, K., Boucher, A., McGaffey, F., McKillop, M., & Schiff, M. (2017). Prison Health Care: Costs and Quality. Philadelphia: Pew Charitable Trusts.

65. National Research Council. (2014). Growth of Incarceration in the United States: Exploring Causes and Consequences. Washington, D.C.: National Academies Press.

66. Steffen, J.R. (2020). Moral Cognition in Criminal Punishment, British Journal of American Legal Studies, 9(1), 143–179. doi: https://doi.org/10.2478/bjals-2020-0002.

67. Cohen, L. (2011). Serving Life [Film]. Angola, Louisiana: Virgil Films.

68. Barens, E. (2014). Prison Terminal: The Last Days of Private Jack Hall [Film]. Fort Madison, Iowa: Cinema Guild.

69. Smyer, T., & Burbank, P. (2009). The U.S. Correctional System and the Older Prisoner. Journal of Gerontological Nursing, 35(12), 32–37. doi: 10.3928/00989134-20091103-02.

70. Walters, G.D. (2018). Positive and Negative Social Influences and Crime Acceleration During the Transition from Childhood to Adolescence: The Interplay of Risk and Protective Factors. Criminal Behaviour and Mental Health, 28(5), 414–423. https://doi.org/10.1002/cbm.2088.

71. Garnier, S., Caplan, J., & Kennedy, L. (2018). Predicting Dynamical Crime Distribution from Environmental and Social Influences. Frontiers in Applied Mathematics & Statistics, 4. doi: 10.3389/fams.2018.00013.

72. Pettersen, T. (2011). The Ethics of Care: Normative Structures and Empirical Implications. Health Care Analysis, 19(1), 51–64. https://doi.org/10.1007/s10728-010-0163-7.

73. Lloyd, A., & Borrill, J. (2019). Examining the Effectiveness of Restorative Justice in Reducing Victims' Post-Traumatic Stress. Psychological Injury & Law, 13(1), 77–89. doi: 10.1007/s12207-019-09363-9.

74. Thompson, K. (2016). From a Slave House to a Prison Cell: The History of Angola Plantation. Retrieved 20 January 2021, from https://www.washingtonpost.com/entertainment/museums/from-a-slave-house-to-a-prison-

cell-the-history-of-angola-plantation/2016/09/21/7712eeac-63ee-11e6-96c0-37533479f3f5_story.html.

75. Peteet, T., & Tobey, M. (2017). How Should a Health Care Professional Respond to an Incarcerated Patient's Request for a Particular Treatment? AMA Journal Of Ethics, 19(9), 894-902. doi: 10.1001/journalofethics.2017.19.9.ecas3-1709
76. Linder, J. F., Knauf, K., Enders, S. R., & Meyers, F. J. (2002). Prison hospice and pastoral care services in California. Journal of palliative medicine, 5(6), 903–908. https://doi.org/10.1089/10966210260499096
77. Solomon S. R. (2013). Protecting and respecting the vulnerable: existing regulations or further protections? Theoretical medicine and bioethics, 34(1), 17–28. https://doi.org/10.1007/s11017-013-9242-8

Sneha Anmalsetty

EMAIL
(XXX) XXX-XXXX
ADDRESS

|| EDUCATION ||

The Pennsylvania State University (PSU), Schreyer Honors College Graduation: **Aug 2021**

B.S. Biochemistry and Molecular Biology GPA: X.XX/4.00

Minor: Bioethics and Medical Humanities

Relevant Coursework: Biochemistry, Microbiology, Molecular Genetics, Cancer Biology, Quantitative Genetics, Cell Development, Health Disparities and Ethics

|| WORK EXPERIENCE ||

Centre LifeLink - Emergency Medical Technician (EMT) **Sep 2020 - Apr 2021**

- Volunteer as a basic life support provider at local emergency medical service.
- Certified since May 2019.

Corteva Agriscience - Regulatory Toxicology and Risk Intern **Jun 2020 - Aug 2020**

Project: Applying Predictive Human Health Risk Assessment Strategies to Inform EU Registrability Assessments Using RISK21

Supervisor: Edward Chikwana, Ph.D., MPH, Regulatory Toxicology and Risk at Corteva

- Modeled plant protection product risk to human health using tools from the European Food and Safety Authority and Health and Environmental Sciences Institute for 8 products.
- Streamlined risk assessment procedures to help the company reach imminent deadlines.
- Collated decades of dislodgeable foliar residue data to operationalize future risk assessments.

Student Technology Services, PSU - Student Supervisor **May 2018 - May 2021**

- Provide technical support to students and faculty for software and hardware issues.

|| RESEARCH AND ACADEMIC PROJECTS ||

Using an *in vitro* Tumorigenesis Model Based on Live-Cell-Generated Oxygen and Nutrient Gradients to Map EMT and Inflammatory Factors in 4T1 Cells **May 2021- present**

National Cancer Institute (NCI)

PI: William Heinz, Ph.D., Staff Scientist at National Institutes of Health (NIH)

- Plan to quantify relationship between EMT markers like vimentin and inflammatory signals like COX2, as well as role of hypoxia-induced cell-cell organization in a tumor microenvironment.
- Goal to publish an article within the next year in preeminent cell biology journal.

Returning Dignity Only at Death's Door: Can Incarcerated Individuals Acting as Hospice Caregivers Achieve Rehabilitative Goals Without Sacrificing Autonomy? **Aug 2020 - Aug 2021**

Penn State University, Department of Bioethics

PI: Michele Mekel, J.D., MBA, Interim Director of Bioethics Program

- Examined ethicality of volunteer caregiving by incarcerated individuals within prison hospice systems.

|| AWARDS ||

Cancer Research Training Award for Post-Baccalaureate Fellowship at the National Institutes of Health **May 2021 - present**

- Chosen to be a full-time research fellow at the NIH with the goal of scientific advancement and professional growth.

American Society for Bioethics and Humanities Student Paper Award, 2020 Winner **Jan 2020 - Aug 2020**

Project: The Plight of Intravenous Drug Users: Is It Unethical to Provide Addiction Patients Multiple Heart Valve Transplants for Infective Endocarditis on the Basis of Medical Futility?
Mentor: Michele Mekel, J.D., MBA, Bioethics Program at Penn State

- Currently working on publishing this article in cardiovascular medicine journals.

|| LEADERSHIP AND EXTRACURRICULARS ||

PSU Eberly College of Sciences Learning Assistant **Jun 2019 - May 2021**

- Tutored peers in biology, biochemistry, and genetics coursework.

Remote Area Medical **Feb 2018 - May 2021**

- Volunteered as triage assistant at free medical clinics in underserved regions of WV and OH.
- Lobbied state government of PA to change legislation restricting out-of-state physicians from volunteering in PA.

International Affairs and Debate Association - Chief of Staff, Integrity Chair **Sep 2017 - Jan 2021**

- Appointed unanimously as Integrity Chair to establish good ethical conduct.
- Coordinate conferences for high schoolers to facilitate policy-oriented debate.
- Managed 15,000$+ in funds to organize conferences.

Pennsylvania Governor's School for the Sciences, Carnegie Mellon University, PA **Jul 2016**

Project: Comparative Analysis of Mineral Concentrations in Potable Water Sources
PI: Barry Luokkala, Ph.D., Dept. of Physics at Carnegie Mellon

- Published in the 2016 Pennsylvania Governor's School for the Sciences, pg 107: https://tinyurl.com/ydeqzadd
- Received a grant from the Pennsylvania Dept. of Education

|| SKILLS ||

languages: English, Telugu (advanced), French (advanced), Korean (basic)

lab techniques: biomolecule extraction and purification, PCR design and gel electrophoresis, PAGE, blotting, eukaryotic and prokaryotic cell culture, spectrometry (NMR, IR, etc.), fluorescent microscopy, flow cytometry, SEM, genetic engineering techniques

bioinformatics techniques: MATLAB, SnapGene, BLAST, R, FlowJo, ImageJ