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Since, 1992 the number of inmates over the age of fifty in the United States has almost tripled. This rapidly growing population of elderly inmates is due to a national “tough on crime” attitude, which has put 1 in 100 Americans behind bars, many of whom will age and die in a correctional setting.¹ The National Center on Institutions and Alternatives estimates that housing and caring for American inmates over fifty-five, costs state and federal governments an annual sum of \$2.1 billion – almost three times the amount it costs to accommodate a younger prisoner .² To successfully provide mental and physical care for a geriatric patient is not only expensive, but also costly in the sense that elderly patients require a more sophisticated level of care. Coupled with longer sentencing, and the War on Drugs law-enforcement initiative, there is a greater need for long-term and eventually end-of-life medical care in prisons. Ironically, prison inmates in the United States are the only citizens who have an inalienable right to health care. Yet, with an increasing emphasis on life sentencing and prison privatization, dying inmates are not receiving the level of care they deserve, which poses the question: who has access to a humane death?

This project examines both who, in fact, has access to a meaningful death, and also what constitutes a “good death” behind bars. Correctional hospice programs exemplify a new and modern initiative to make hospice and a “good death” accessible to inmates – some of America’s most underrepresented citizens. Prison Hospice represents a shift from an inhumane death in prison towards a compassionate consideration for a dying inmate.

Although the hospice movement in prisons is growing, many wonder if hospice behind bars will ever measure up to traditional, community hospice programs. There is the very real possibility that, with the current infrastructure of correctional facilities coupled with strict security procedures, a successful prison hospice program will never be achieved. Still, prison hospice could become a catalyst for improving America’s prison system. Perhaps a successful hospice program is the catalyst the United States needs to implement better care for its inmates. No prison hospice program will ever be successful without two essential elements: the autonomous voice of the prisoner and sympathetic support.

I present the majority of my argument in the context of the prisoner’s voice and the manner in which the inmate’s autonomous choices dictate the success of a prison hospice program, in giving dying inmates what they deserve: access to a good and meaningful death.

¹ Jenifer Warren and others, *One in 100: Behind Bars in America 2008*. (Washington, DC: The Pew Center on the States; The Public Safety Performance Project, 2008), 5.

² Mike Mitka, "Aging Prisoners Stressing Health Care System," *JAMA: The Journal of the American Medical Association* 292, no. 4 (2004): 424.

“The degree of civilization in a society can be judged by entering its prisons.”

-Fyodor Dostoevsky

ACCESS TO DEATH:
PRISONS, HOSPICE AND VOICES

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INTRODUCTION: THE INVISIBLE MAN

I am an invisible man. No, I am not a spook like those who haunted Edgar Alan Poe; nor am I one of your Hollywood-movie ectoplasms. I am a man of substance, of flesh and bone, fiber and liquids – and I might even be said to possess a mind. I am invisible, understand simply because people refuse to see me...When they approach me they see only my surroundings, themselves, or figments of their imagination – indeed, everything and anything except me.

-Ralph Ellison Invisible Man³

As academics, it is our tendency to seek truth in numbers. When I began my research for this essay in early September, I found myself surrounded by statistics – quantitative data which attempted to define impossible problems and answer difficult questions. In academia, data is proof. It gives us the confidence that we as researchers, scholars and even ordinary citizens need to make effective arguments, and to win one another's approval. When my study began, this was my intention: to discover the facts and figures which surround the history, application and need for prison hospice programs in the United States. I learned, however, that no matter how much I tried to define and convey my arguments with numbers and fact, I was not discovering the truth about hospice in the correctional setting. Instead, I was learning that, in the case of prison hospice programs, statistical data perpetuates objectification of the prisoner. In other words, the tendency to turn a rapidly increasing population of dying inmates into statistics deprives this population of human identity, rendering them invisible.

³ Ralph Ellison, *Invisible Man* (New York: Vintage, 1972), quoted in Kimberly Jacob Arriola, Ronald L. Braithwaite, and Cassandra F. Newkirk, "An Overview of Incarcerated Women's Health," *Health Issues among Incarcerated Women*, ed. Ronald L. Braithwaite, Kimberly Jacob Arriola, and Cassandra Newkirk. (New Brunswick, NJ: Rutgers UP, 2006), 3.

This is not to say that numbers are not an important part of the research process. Statistical data is used extensively throughout this essay to describe the crisis that is happening in American corrections. Like voice, quantitative data can demonstrate why prison hospice is crucial to creating a humane future for our nation's offenders. I would like to stress, however, that although quantitative data is valuable, it is nothing compared to the voices, stories and testimonies of America's dying inmates. My propensity to embrace the voice of the prisoner, to give the dying inmate an individual identity, has changed the purpose of my research from discovery into advocacy. For this reason, instead of beginning this introduction with statistical data, I would like to begin with a story which proves the importance of the individual voice, and what happens when it is ignored or non-existent.

In his book, *Dying Inside*, Benjamin Fleury-Steiner describes many of the horrific realities of dying behind bars in America. One of the most disturbing accounts comes from Heather Michael Samuels, an AIDS activist and prison hospice volunteer who described the death of an anonymous prisoner. Samuels recounts:

I had another patient who had very advanced AIDS and was slowly losing his mental faculties as well as his ability to walk or move his arms in any way. And they insisted that he had to be shackled to the bed; he was totally confused . . . We thought the jail would say, 'we can't manage somebody this sick' and release him . . . But he was basically dumped there in jail. And they kept him for about three weeks; when he came

back to the hospital he died. . . He died in custody still shackled to the bed.^{4,5}

This story of a nameless prisoner dying chained to a bed, nameless and alone, not exemplifies the great need for prison hospice programs but also the crucial component of the inmate's autonomous voice and identity in end-of-life care.

Even prisoners who retain an identity are sometimes left without a voice, rendering them completely powerless. In 1998, Glen Herbert died in the infirmary of Angola State Prison in Angola, Louisiana. Nicknamed the “Alcatraz of the South,” Angola State Prison is the nation’s largest maximum-security correctional facility; approximately 2,600 men, fifty percent of the prison’s population, are serving life sentences. These men, like Glen Herbert, will grow old and eventually die in prison. Since Glen Herbert’s family lives half way across the state of Louisiana, they will not make it to his bedside before he passes away. Instead, he must rely on his fellow inmates for comfort, most of whom are only allowed restricted access to the medical ward. Sadly, like many of the individuals at Angola, Glen Herbert will most likely die alone, without friends or family. When asked about men like Glen Herbert, warden Burl Cain explains that in Louisiana:

Once you break the law, you don't get another chance. If it were up to me I'd say let's not keep dying old men in prison. They're too old to pull an

⁴ Benjamin Fleury-Steiner, *Dying Inside : The HIV/AIDS Ward at Limestone Prison* (Ann Arbor: University of Michigan Press, 2008), 91.

⁵ Heather Michelle Samuels’ remarks reflect, as Benjamin Fleury-Steiner states in his book *Dying Inside*, “a [national] prison system that is largely indifferent to sick prisoners” (Fleury-Steiner 91). Samuels states, “[Inmates] are shackled to their beds no matter how sick they are.” These horrifying conditions bring into question the issue of inmate personhood and whether a tough-on-crime attitude has destroyed prisoner access to a good death.

armed robbery or be a ski-mask rapist. They ought to do about twenty years on most any serious crime and when they turn about fifty years old when those two come together on a graph they pretty well should have a good shot at going free.⁶

The story of Glen Herbert and the anonymous inmate raise important questions about punishment and dying in America's jails and prisons. Should prisoners have access to proper palliative care and, if so, how can a good death be achieved behind bars?

In a normal hospice program, care is completely patient-centered. All of my research on regular hospice programs stressed the importance of patient choices, family involvement and comfort. Hospice patients in normal society enjoy what is considered a *good death* by American standards in the sense that these individuals can make autonomous decisions about their dying process. In her book, . . . *And A Time to Die*, Sharon Kaufman describes hospice as: “A contemporary symbol of the Anglo-American, middle-class idea of “the good death” – a patient and family centered process in which the foci of attention are personal comfort for the patient and material and emotional support for family and friends, while the patient knowingly and reflexively declines towards death.”⁷ After researching regular hospice programs and discovering more about prison hospice programs, I began to wonder if this level of comfort care can even be achieved in a correctional setting.

⁶ Anne M. Seidlitz, “‘Fixin’ to Die’: Hospice program opens at LSP-Angola.” *NPHA News* 5, no. 1 (1998): 3.

⁷ Sharon R. Kaufman, . . . *And a Time to Die: How American Hospitals Shape the End of Life* (New York: Scribner, 2005), 7.

This is how I arrived at what became the main question about advocacy in my research: Do inmates like Glen Herbert have access to a good death behind bars? And, if not, what needs to be done to improve prison hospice care? I believe the real strength in tackling this issue comes from our ability to recognize the humanity of the prisoner – to give him an identity and a voice. Dying behind bars should not be a punishment – people like Glen Herbert deserve to reach the end of their lives feeling like a true person, “a man of substance, of flesh and bone, fiber and liquids” (Arriola, Braithwaite and Newkirk 3). This essay serves the purpose of advocating for the prisoner and searching for a way to convince the American people that prison hospice may be the starting point for change in the infrastructure of our nation’s prisons. Regulated hospice programs could become the catalyst we need to change our growing prison crisis. Furthermore, advocacy for prison hospice programs creates a larger discussion about punishment and suffering in our nation’s correctional system. I have realized, in my research, that empathy and compassion for our imprisoned is something our country has and continues to struggle with. Due to a growing and aging incarceration population, the clash between punishment and compassion is something the United States and the national department of corrections can no longer ignore. To care for a prisoner with formal hospice care is not to excuse his or her crime.

The United States has the largest and fastest growing incarceration rate in the world. According to the United States Bureau of Justice Statistics, the total population of state and federal prisons in the United States in 2008 was just over

2.3 million people, which is roughly one out of every one hundred adult citizens.⁸ To put America's prison population in a global context, nearly one quarter of the world's prisoners are behind bars in United States correctional facilities. Explosive incarceration rates are the result of a myriad of political, social, cultural and economic elements. The origins of these factors are numerous, and one could fill many pages theorizing how America's prison system has roiled out of control. The genesis and culmination of these elements can be seen in real life examples including The War on Drugs and "tough on crime" legislation. For example, since Nixon declared the War on Drugs in 1971, the United States prison population has multiplied over five times, making America's correctional system a national subject of scrutiny and criticism. Unfortunately, as the prison population grows so does the age of the general United States population. By the year 2002, 420 million Americans were over the age of sixty-five.⁹ This combination of a graying United States population and a rising prison population means that many of our nation's inmates are also aging and eventually dying in prison. An aging prison population also imposes a large financial burden on the United States. In 2007, according to the National Association of State Budget Officers, states spent \$44 billion in tax dollars on corrections.¹⁰ Additionally, housing and caring for an inmate over the age of fifty-five costs state and federal

⁸Jenifer Warren and others, "One in 100: Behind Bars in America 2008," (Washington, DC: The Pew Center on the States; The Public Safety Performance Project, 2008), 5.

⁹ Ronald H. Aday, *Aging Prisoners: Crisis in American Corrections* (Westport: Praeger, 2003), 2.

¹⁰Dan Rodricks "Given Failed War on Drugs, Lewis Charges No Surprise," *The Baltimore Sun*, March 4, 2004, sec. Op/Ed.

governments an annual sum of \$2.1 billion, almost three times the amount it costs to accommodate a normal prisoner.¹¹ But an aging prison population is not only a fiduciary issue; it is also an issue of social hierarchy. How will prison employees justify their obligation to treat geriatric and terminally ill prisoners differently from healthy inmates? What will this “special status” do to the organization of the total institution? But most importantly how are prisons going to prepare inmates for life and death in prison?

This essay is not only a study of prison hospice, but also the overview of a larger issue in America’s criminal justice system. In order understand how the treatment of American inmates has changed, it is important to note how correctional systems and prison populations have changed in the United States.

As Anne Marie Cusac, author of *Cruel and Unusual*, explains:

But for all these transformations, and for all the popularity of “tough on crime” talk in the past decade, American punishment is still almost invisible, conducted by our government’s private spaces rather than, as once was true, in the public square. That near-invisibility of our criminals and their treatment can make it easy for the rest of us to disregard prisons, . . . American convicts, and the methods of punishment currently employed.¹²

Punishment in America has not only become invisible and private, it has become as mass-produced as the correctional system’s population. Punishment in America no longer serves the purpose of rehabilitation – it is no longer corrective. Instead, inmates are made non-existent, hidden and isolated from society.

¹¹ Felicia Cohn, "The Ethics of End-of-Life Care for Prison Inmates," *Journal of Law, Medicine and Ethics* 27, (1999): 253.

¹² Anne-Marie Cusac, *Cruel and Unusual: The Culture of Punishment in America* (New Haven: Yale University Press, 2009), 2.

Punishment serves no constructive purpose; simply put, it America's criminal justice system is punitive for the sake of being punitive. If hospice programs are going to thrive or even exist in a correctional setting, American politicians, policy makers and citizens need to alter their attitudes about punishment, and fast.

In this essay, I explore the history of the hospice movement, and investigate the possibility of comprehensive palliative care in a correctional setting. Most importantly, I explore why the voice and autonomous choices of the inmate are so important to the future success of prison hospice. I conclude that prison hospice programs present an opportunity for correctional facilities and their personnel to work backwards from giving prisoners a good death, to changing the lives lived within prison walls and the correctional infrastructure of the United States.

Chapter One examines the history and origins of hospice in America as well as the slowly evolving opportunities for hospice in a correctional setting, and what a *good death* represents, especially in contemporary American society. Chapter One also explores the challenges facing prison hospice including the instability of prison hospice infrastructure and the variants of formality in each prison hospice facility. The conclusion of this chapter recommends the establishment of uniformed approaches and regulations across all regular prison hospice programs.

Chapter Two examines the growing prison population crisis in America, including the current state of health care in America's correctional facilities in the

context of two rapidly increasing prison groups: the elderly and drug offenders.

Chapter Two also investigates how prison privatization has erased the demand for public accountability and has perpetuated the prisoner's identity as a number rather than as a human being.

Chapter Three is perhaps the most crucial section of this essay in the sense that it emphasizes the importance of the prisoner's voice and autonomy in a correctional setting – especially in death. In this section, medical experimentation, both inside and outside the prison walls is used to demonstrate how people of authority use their power to dictate the choices and future of the individual – especially in a correctional setting.

Chapter Four looks at one of the most important players in the success of prison hospice: the volunteer. Although this section examines the prisoner's family (both outside and inside the prison walls), the volunteer is established as the greatest advocate for the patient. Having a fellow and trained inmate present at the end of life brings a great comfort to many dying inmates. Hospice volunteers are able to facilitate a relationship of comfort and trust in a hostile environment. This chapter demonstrates how the volunteer becomes an extension of the prisoner's voice, and in a very real way, remembers the inmate after they pass. Chapter Four also explores the fact that although the advanced directive has come to define the autonomous death in America, it creates an uncomfortable discourse where prisoners and their mistrust of the medical system are concerned. Chapter

Four exposes the larger issues of prison hospice: the hostile nature of America's correctional system.

Regulated prison hospice programs represent a catalyst for change in American correctional systems. The Russian novelist Dostoyevsky once said, "The degree of civilization in a society can be judged by entering its prisons."¹³ Anyone who understands the realities of America's prison crisis cannot help but feel a flush of shame and irony when measuring our correctional system against this statement. If America is a country founded on the principles of equality, why are its incarcerated citizens denied the end-of-life care they deserve? I ask those who read this paper not only to absorb the facts, but also to experience the stories, voices and testimonies of those who are trying to make correctional facilities a better place for the dying inmate, and, indeed, for every offender in the United States. My hope is that this essay serves as a call for action, a challenge to America's criminal justice system to fully recognize prisoners as human beings with a voice, a mind, and the right to a good death behind bars.

¹³ Fyodor Dostoyevsky, *The House of the Dead* (Harmondsworth, Middlesex, England: Penguin, 1985).

CHAPTER ONE: A HISTORY OF HOSPICE

The Modern Hospice Movement

The modern hospice movement began in 1967. Its founder was Dame Cicely Saunders who, with the establishment of St. Christopher's Hospice in London, sought to put end-of-life care into the hands of her dying patients. Dame Cicely Saunders not only wanted to provide comfort for individuals and their families, she was also committed to educating medical professionals about proper palliative care practices, especially in the context of pain management.¹⁴ She wanted to help the terminally ill while creating long-term initiatives that could alleviate the suffering and anxiety associated with terminal illness. Most importantly, Dame Cicely Saunders sought an alternative to the idea of death as a failure of the medical system; rather, she viewed death as a part of life and dedicated herself to helping people in a time of great uncertainty. Dame Cicely Saunders illustrated how St. Christopher's Hospice created an environment of safety and acceptance explaining, "We [at St. Christopher's] make it possible to face the unsafety of death" (Sachs and Brand 4). In this way, Saint Christopher's Hospice signified the establishment not only of the modern hospice movement, but also a solution to the anxiety associated with dying.

Dame Cicely Saunders and her vision of a world with comprehensive end-of-life care are reflected in the story of St. Christopher himself, the patron saint of

¹⁴ Andrea Sachs and David Brand, "Cicely Saunders: Dying with Dignity," *Time Magazine*, September 5, 1988, 1.

journeys and travelers. The most popular story associated with St. Christopher describes an occasion on which he unknowingly assisted the Christ child across a dangerous river. The story goes that Christ, disguised as a small child, pleaded with Christopher to make the perilous journey across powerful currents. Christopher agreed but as he traversed the raging rapids, he found that the child's body was growing heavier as the water was becoming deeper. The Saint struggled to stay afloat and barely reached the other side with the burdensome child. When he finally reached the shore, Christopher said to the child, "You have put me in the greatest danger. I do not think the whole world could have been as heavy on my shoulders as you were." Christ informed Christopher that he not only carried a child on his back, but also the sins and troubles of the world. This story, and the choice of Saint Christopher as a symbol for the first modern hospice program, however apocryphal, represents the fact that many patients need someone to help carry them to the other side. Dame Cicely Saunders saw death as a transition, a time when individuals carry the heavy load of fear and doubt upon their backs. With hospice, however, they are able to make it across of the river peacefully unharmed.

Although the contemporary palliative care movement did not emerge until the twentieth century, the origin of the word *hospice* is deeply rooted in the medieval history of Western Europe. In the Middle Ages, hospice was a post or house where people could stop and rest during long pilgrimages across the continent. Whole communities and villages dedicated their time and money to

these hospice posts, thus infusing the term hospice with an element of community. Edward Dobihal, one of the founders of Hospice, Incorporated, the first hospice organization in the United States, underscores the point, “Hospice means a community of people with a common goal – to care for travelers on their way . . .”¹⁵ The fact that the modern hospice movement was founded upon the ideas of journey and community allows comfort to become a reality for individuals as they approach death. Dying in hospice includes a myriad of doctors, nurses, volunteers, and, most importantly, families and friends. Hospice and its history demonstrate the cultivation of a human approach that cannot exist in a hospital’s bureaucratic and medically-oriented setting. In emergency rooms and hospital wings, death is treated like a disease – an illness that must be remedied with God-like medical interventions and advanced procedures. In hospice, however, life is not prolonged, nor is death accelerated. In programs like those at Saint Christopher’s Hospice, patients are able to traverse even the strongest currents comfortably, crossing the river with minimal hindrance.

The modern hospice movement came to the United States just as American citizens were becoming increasingly concerned with their lack of autonomy in the health care system. People wanted complete decision-making control over their medical care, especially end-of-life medical care. More than anything, modern hospice in the United States represents an intense obsession with controlling death. In her book, . . . *And a Time to Die*, Sharon K. Kaufmann

¹⁵Paul M. DuBois, *The Hospice Way of Death* (New York: Human Sciences Press, 1980), 13.

explains, “People today want things from death, and their desires are both contradictory and unprecedented . . . Many want to control the way death happens for themselves and their loved ones by planning ahead for it, yet few are actually prepared for the moments when decisions must be made or for the kinds of questions that will emerge when death is near.”¹⁶ It is crucial to realize that although patient autonomy is important in hospice, it has also raised expectations of how death should occur. Death has become increasingly centered around the ideas of “peaceful” and “good.” People want a natural end to their life journey. In a country where death is stigmatized or seen in a negative light, hospice has become the answer to the “problem of death.” It has also become intertwined with our concept of decision-making, as Kaufman states, “Dying and personhood have become such entangled concepts in America society” (Kaufman 84). Even with lingering questions, hospice has come to represent the closest thing to an autonomous, natural end.

Death is like any other unknown in the sense that our perception of it has evolved over time. Our understanding of death in western society has developed from a religiously-centered journey of the body to the modern view of death as a failure of biomedicine. In his book *Revival of Death*, Tony Walter identifies how the approach to death has changed over time. According to Walter, death used to be uniform – it happened to everyone for unknown reasons. However, as the concept of biomedical science and the theory of disease have been transformed

¹⁶Kaufman, Sharon R. . . . *And a Time to Die: How American Hospitals Shape the End of Life* (New York: Scribner, 2005), 3-4.

into concrete truths, Americans have become more and more obsessed with the concept of a *good death*. As Walter states it, the definition of a modern, good death is: “An opportunity to say farewell to one’s family and a preparation to meet one’s Maker. In the modern era, death should be quick, unconscious or at least painless.”¹⁷ Therefore, in a modern sense, death is the summation of a life in which we were not alone. With family and friends surrounding us, we expect to die quickly and unknowingly. Death becomes a process where we move towards a point of acceptance and away from a point of grief.

In spite of its idealistic goals, exploring the origins and evolution of hospice in the United States and in Great Britain causes me to wonder if hospice is just another opportunity for inequity. Hospice programs can be expensive, and the amount of family involvement required demands the kind of flexibility that some people cannot afford. The possibility of dying with dignity seems more and more like an exclusive club, a system of privilege where the rich, white members of society are given comprehensive choices that will spare them from suffering a painful death. Even Dame Cicely Saunders stated, “Not everyone is meant to die in hospice,” after reporters demanded to know why she would not allow AIDS patients in St. Christopher’s Hospice programs (Sachs and Brand 4). Just in terms of origin alone, at least in Dame Cicely Saunders’ view, hospice was not created as a solution to the suffering of the poor, dying minorities; it was created with the intention of giving autonomy and comfort at the end of life to

¹⁷ Tony Walter, *The Revival of Death* (New York: Routledge, 1994), 59.

those who were able to pay for it. This is not to say that low-income patients do not now have access to hospice services. In recent years, surprisingly the bureaucratization of medicine has allowed Medicare to cover end-of-life care. However, in order to use Medicare money to pay for hospice, it must be strictly determined that the patient only has six months to live, thus sharply limiting the kinds of illness and diseases that can be considered for low-income patients within a palliative care facility. All these contradictions bring us to the million-dollar question: Who has access to a good death?

The lack of strong hospice programs for the poor and neglected citizen raises the question of whether hospice is a luxury or an inalienable right. Prison hospice programs challenge the idea that end of life care is an extravagance. Prison hospice represents a new and modern initiative to make hospice and death accessible to America's most under represented citizens: inmates. With an aging prison population and a growing number of inmates who will die in prison before the end of their sentences, there is a great need for long-term palliative care. Still, there are a number of difficult ethical questions that plague correctional systems and how exactly they will cater to inmates who seek end-of-life care. Nancy Neveloff Dubler, author of "The Collision of Confinement and Care: End-of-Life Care in Prisons and Jails," states, "The antagonism, suspicion and fear that have governed the relationship between inmate and authorities prior to the last stages of illness continue to define and constrain that relationship during the inmate's

dying.”¹⁸ This mistrust can negatively affect the inmate’s final wishes, and it further raises the question of whether or not an inmate can enjoy the same autonomous choice as regular citizens in hospice programs. In the case of both Do Not Resuscitate orders (DNRs) and certain aggressive life-saving interventions, for example, there is a real concern for inmates and the dangers they face in being manipulated by prison staff to make difficult end-of-life decisions. Still, the prison hospice movement is gaining volunteers and supporters. In their book, *Health and Health Care in the Nation’s Prisons*, Melvin Delgado and Denise Humm-Delgado explain, “In many prisons, there has been a slow but no less dramatic shift in culture regarding the establishment of prison-based hospice programs provides staff and inmates with an opportunity to refocus from concerns about safety and punishment to humanistic concerns for the dying.”¹⁹ It is true that the movement is gaining momentum, but will prison hospice programs ever compare favorably to traditional, community hospice programs? There is a very real likelihood that the current infrastructure of correctional facilities, along with strict security procedures and the growing privatization of prisons, will make a successful prison hospice program impossible.

In his book *A Time to Die*, Charles McKhann’s describes the ideal situation for end-of-life care stating that, “Comfort care is better given in less

¹⁸ Nancy Neveloff Dubler, "The Collision of Confinement and Care: End-of-Life Care in Prisons and Jails," *Journal of Law, Medicine and Ethics* 26, (1998): 152.

¹⁹ Melvin Delgado and Denise Humm-Delgado, *Health and Health Care in the Nation's Prisons: Issues, Challenges, and Policies* (Lanham, Md.: Rowman & Littlefield Publishers, 2009), 148.

pressured environments: homes, nursing homes or residential hospice institutions.” McKhann also insists upon a patient-initiated directive, making sure that the dying individual’s needs are met.²⁰ Based on McKhann’s recommendations, it is easy to become skeptical that jails and prisons will ever be able to offer efficient hospice or palliative care programs. There is, however, still the hope that prison hospice will offer prisoners the opportunity to take a long hard look at what the correctional system in America has become. The prison hospice program not only evidences a willingness to treat dying convicts with compassion, it also gives the individual prisoner an autonomous voice in an otherwise total uniform, institutional environment. Palliative care in a correctional system forces American prison officials, policy makers, politicians and citizens to consider the humanity of the prisoner, forcing the United States to reconsider our traditions of liberty, democracy and compassion. In reality, prison hospice could be the issue that saves the correctional system in America, becoming the push that the criminal justice system needs to create real, humane change.

Uncertain Statistics:
How Prison Hospice Differs from Hospice in Normal Society

*Nothing is easier than to denounce the evildoer;
Nothing more difficult than understanding him
—Fyodor Dostoevsky²¹*

²⁰ Charles F. McKhann, *A Time to Die: The Place for Physician Assistance* (New Haven: Yale University Press, 1999), 76.

²¹ Russian Novelist Fyodor Dostoevsky (1821-1881). Quoted in Philip Zimbardo, "How People Become Monsters...Or Heroes," TED: Ideas Worth Spreading. TED Talks, Feb. 2008. Web. Jan. 2011. <http://www.ted.com/talks/lang/eng/philip_zimbardo_on_the_psychology_

The vague statistics, numbers, and regulations which surround prison hospice programs, represent the ambiguous future of hospice care in a correctional setting. Over the course of this research, much of the misleading information that I discovered resided in the qualitative data. While there are many structural differences between hospice programs in normal society and end-of-life care in a correctional setting, the inability to determine federal hospice guidelines was a critical contributor to the uncertain future of hospice programs behind bars. For example, in their article, “Characteristics of Prison Hospice Programs in the United States,” Heath C. Hoffman and George E. Dickinson tried to contact sixty-nine known prison hospice programs in the United States. Only sixty-two percent of hospice programs responded to the survey, which sought to determine, “How prison hospice programs were similar or dissimilar to hospices in the free society.”²² Hoffman and Dickinson’s article was intended to describe how our country’s hospice programs differ from palliative care programs behind bars. Unfortunately, their study was hampered by a lack of consensus among scholars and national organizations as to what constitutes a “formal” prison hospice program.

In 1998, the National Institute of Corrections (NIC) conducted the very first survey of prison hospice and palliative care in the United States. The GRACE project, which stands for Guiding Responsive Action in Corrections at

of_evil.html>.

²² Heath C. Hoffman and George E. Dickinson, "Characteristics of Prison Hospice Programs in the United States," *American Journal of Hospice and Palliative Medicine*, (2010): 1.

End of Life, was established the same year as the NIC prison hospice survey. In a report titled “Incarceration of the Terminally Ill: Current Practices in the United States,” the GRACE project described the NIC’s findings. The GRACE project and the NIC observed that in 1998, “Eleven states and the U.S. Bureau of Prisons operated “formal” prison hospice programs at one or more sites within their correctional systems.”²³ But the question remains, what is *formal*, and whether defining this word be the first step in regulating hospice care behind bars.

Although Hoffman and Dickinson state that, “Prison hospice programs tend to follow both the National Prison Hospice Association and the GRACE Project guidelines,” Federal and State correctional departments have resisted the call for developing a national set of “formal prison hospice” guidelines. A wide range of researchers, scholars and organizations have been unable to agree as to what a formal prison hospice is to define what formal truly means.

In 2009, the National Hospice and Palliative Care Organization worked with the National Department of Corrections to publish *Quality Guidelines for Hospice and End-of-Life Care in Correctional Settings*.²⁴ This report includes a checklist for all hospice volunteers, and dictates a stringent set of regulations that every prison hospice program should follow. Still, nowhere in the report does it state that these regulations have been implemented in a single correctional

²³ Margaret Ratcliff and Elizabeth Craig, "The GRACE Project: Guiding End-of-Life Care in Corrections 1998-2001," *Journal of Palliative Medicine*, 7 (2004): 6.

²⁴ National Hospice and Palliative Care Organization, *Quality Guidelines for Hospice and End of Life Care in Correctional Settings*, Publication no. 821495 (Alexandria: National Hospice and Palliative Care Organization, 2009).

facility. Moreover, there is no consensus around a single set of guidelines: The National Prison Hospice Association and the GRACE project have a diverse set of guidelines that differ both from the NHPCO and the United States DOC, and also from each other.

Both the GRACE project and the NIC claim that they are the authorities on what is and is not considered a formal prison hospice program. Like the research conducted by Hoffman and Dickinson, both of these organizations tried to determine the accreditation of prison hospice programs by polling each correctional facility via a mailed survey. However, the GRACE project and the NIC surveys were not identical, and the two organizations did not use the same correctional department contact list. These discrepancies and variations in data could be the reason why many prison hospice programs are either unaccounted for or do not receive *formal* accreditation. Without some form of official support, these programs cannot receive adequate resources, create uniform protocol or, most importantly, receive state or federal support. In his article, “The Prison Hospice Movement,” Fleet Maull believes that without the support and involvement of national organizations or state and federal governments, prison hospice will never become a reality:

Without the continual advocacy and involvement of organizations like the National Prison Hospice Association and the National Hospice and Palliative Care Association as well as state hospice organizations, community hospice professionals, and concerned corrections professionals, many prison hospice programs will be “hospice” in name only and, in some cases, may simply become an

empty care vehicle for reducing medical costs in an environment of increasing budget pressures.²⁵

Without adequate state and federal public policy advocating for a national prison hospice system, many formal correctional palliative care programs are overlooked and thus do not receive the support of resources their patients deserve.

The debate surrounding the accreditation of prison hospice programs begs the question: what can be done about creating formal prison hospice programs? More importantly, can it be done at all? In a normal hospice program, care is completely patient-centered. Regular hospice programs stress the importance of patient choice, family involvement and comfort. In their article, “What Impact do Setting and Transition Have in Quality of Life at the End of Life and the Quality of the Dying Process?,” Mathy Mezey explains that, in a correctional hospice system, helping someone obtain a good death is not the prison’s only motivation: “The goal of [prison hospice] care is quite often not aligned with what the prisoner wishes but what is best for the smooth prison administration . . . No prison has achieved the goal of “patient-centered care,” as this is inimical to corrections philosophies and systems.”²⁶ The fact that many prison hospice programs prioritize security over their patient’s pain management is one of the most troubling discrepancies between prison hospice and palliative care programs in normal society. By emphasizing the institutional nature of surveillance, prison hospice programs not only compromise proper pain management but also family

²⁵Fleet Maull, "The Prison Hospice Movement," *Explore*, 1.6 (2005): 479

²⁶ Mathy Mezey et al., "What Impact do Setting and Transitions have on the Quality of Life at the End of Life and the Quality of the Dying Process," *The Gerontologist* 42, no. 3 (Oct. 2002): 63.

involvement, volunteer participation and most importantly, patient trust and comfort. These obstacles deserve further exploration.

Prison Hospice versus Punishment: The Prisoner as Convict and Human

How can a prison hospice program work correctly in a setting that aims to punish the prisoner rather than alleviate the prisoner's suffering? This question of punishment versus care is important when considering the approaches to pain management in a correctional setting. Many state and federal prisons even stigmatize patients for past narcotic addiction by regulating, and even restricting, much-needed pain medication. Prisons are designed to punish and perhaps, eventually, rehabilitate. Yet, how does a prison rehabilitate someone who will not live long enough to leave prison? Do dying prisoners deserve equal punishment to those that will be released back into society? Dostoevsky once said that, "Nothing is easier than to denounce the evil-doer; Nothing more difficult than understanding him" (Zimbardo). The correctional system's tendency to continue to punish those who have reached the end of their lives is indicative not only of the common practice of correctional facilities but also of the American public's view the life and death of the prisoner.

Prison hospice programs raise a larger discussion about punishment and suffering. To care for a prisoner with formal hospice care is not to excuse the crime. I have found in my research that empathy and compassion for the imprisoned is something our country continues to struggle with. American

citizens do not want to understand the evil-doer because they perceive that gesture as weak, as condoning the crime. Even before giving thought to the idea of formalizing prison hospice programs or to the importance of proper pain management, the federal department of corrections needs to address how Americans perceive and respond to the punishment of their prisoners.

CHAPTER TWO: THE PRISONER

No man is an island entire of itself; every man is a piece of the continent, a part of the main; if a clod be washed away by the sea, Europe is the less, as well as if a promontory were, as well as any manner of thy friends or of thine own were; any man's death diminishes me, because I am involved in mankind.

--John Donne, *MEDITATION XVII*²⁷

I had another patient who had very advanced AIDS and was slowly losing his mental faculties as well as his ability to walk or move his arms in any way. And they insisted that he had to be shackled to the bed; he was totally confused...We thought the jail would say, we can't manage somebody this sick' and release him...But he was basically dumped there in jail. And they kept him for about three weeks; when he came back to the hospital he died...He died in custody still shackled to the bed.

– Heather Michelle Samuels, *AIDS Activist and Prison Hospice Volunteer*^{28,29}

America's Growing Prison Crisis

To understand America's growing prison catastrophe, it is imperative to unravel the stories of those who are most susceptible to the shortcomings of adequate end-of-life care in a correctional setting; therefore, this chapter will focus on the life and death struggles of the dying inmate, or the true victim of the prison health care system in the United States. For example, by the year 2025, twenty-five percent of people incarcerated in the state of Ohio will be over the age

²⁷ John Donne, *Devotions upon Emergent Occasions and Death's Duel* (New York: Vintage Books, 1993), 103.

²⁸ Benjamin Fleury-Steiner, *Dying Inside: The HIV/AIDS Ward at Limestone Prison* (Ann Arbor: University of Michigan Press, 2008), 91.

²⁹ Heather Michelle Samuels' remarks reflect, as Benjamin Fleury-Steiner states in his book *Dying Inside*, "a [national] prison system that is largely indifferent to sick prisoners" (Fleury-Steiner 91). Samuels states, "[Inmates] are shackled to their beds no matter how sick they are." These horrifying conditions bring into question the issue of inmate personhood and whether a tough on crime attitude has destroyed prisoner access to a good death.

of fifty (Maull 477). The rapid increase in age of the average prisoner reflects a period in American history where incarceration has become the main focus of politicians and legislators, and it is this “tough on crime” attitude that has put one in one-hundred Americans behind bars, many of whom will age and die in a correctional setting (Warren et al. 5). What’s more, according to the Bureau of Justice Statistics of The US Department of Justice, if incarceration rates continue to increase at their current rate, five percent of US citizens will be expected to serve a jail or prison sentence during the course of their lifetime.³⁰ To have a criminal justice system with such a high rate of incarceration is rare in such a powerful and highly developed country like the United States. Nicholas Freudenberg of the Program in Urban Public Health at Hunter College agrees: “This explosive growth in incarceration rates is unprecedented in United States history or, for that matter, in the history of any other industrial democracy.”³¹ And so incarceration in the United States becomes a paradox: a country that is often revered for its commitment to the freedom of its people has, at the same time, developed a reputation for being strict and unnecessarily punitive when it comes to criminal justice.

People in urban neighborhoods have suffered the most under this correctional epidemic. Once again, Freudenberg explains that perhaps the most troubling problem with the rising incarceration rates is who it is that America is

³⁰ Allen J. Beck and others, *Correctional Populations in the United States*, NCJ 177613 Vol. (Rockville: US Dept of Justice Bureau of Justice Statistics, 1997), 1-13.

³¹ Nicholas Freudenberg, "Jails, Prisons, and the Health of Urban Populations: A Review of the Impact of the Correctional System on Community Health," *Journal of Urban Health: Bulletin of the New York Academy of Medicine* 78, no. 2 (2001): 215.

putting behind bars. He states, “Urban populations are overrepresented in the nation’s jails and prisons. As a result, US incarceration policies and programs have a disproportionate impact on urban communities, especially black and Latino ones” (Freudenberg 215).³² Unfortunately, the criminal justice system is targeting the high crime rates of low-income and minority neighborhoods. These communities are comprised of individuals who suffer from acts of violence, untreated mental illness and substance abuse problems, as well as high rates of infectious disease. With high incarceration rates, the fragile balance of these neighborhoods is being destroyed – especially in the context of health care and social services. In his article “Desperate Measures: A Syndemic Approach to the Anthropology of Health in a Violent City,” Merrill Singer uses the words of sociologist, Loïc Wacquant to describe how the correctional system in America has become like a an urban ghetto in and of itself:

Today’s prisons further resembles the ghetto for the simple reason that an overwhelming majority of its occupants originate from the racialized core of the country’s major cities, and return them upon release – only to be soon caught again in police drag-nets and sent away for ever-longer sojourns behind bars, in a self-perpetuating cycle of escalating socioeconomic marginality and legal incapacitation.³³

The criminal justice system removes important members from a community or family, leaving behind those family members who are then even more susceptible to the violence, social injustice and disease that can plague the inner city. An

³² If incarceration rates continue to rise at the same rate, by the year 2014, 1 in 4 African American men will serve a jail or prison sentence during the course of their lifetime (Freudenberg 214).

³³ Merrill Singer, "Desperate Measures: A Syndemic Approach to the Anthropology of Health in a Violent City," in *Global Health in times of Violence*, ed. Barbara Rylko-Bauer, Linda M. Whiteford, and Paul Farmer (Santa Fe: School for Advanced Research, 2009), 147.

incarcerated mother, for example, may have to give her children up to foster care – her imprisonment creates an uncertain future for her family.

In his book *Discipline and Punish*, Michel Foucault demonstrates how, rather than correcting the behavior of the individual, a prison dooms the inmate and his family to a life of failure and future incarceration. Foucault states:

The prison indirectly produces delinquents by throwing the inmate's family into destitution: The same order that sends the head of the family to prison reduces each day the mother to destitution, the children to abandonment, the whole family to vagabondage and begging. It is in this way that crime can take root.³⁴

By recognizing the shortcomings of the American correctional system, the American people can begin to understand why incarceration rates are not waning, but are instead rising to record-breaking highs.

Understanding the struggle of these communities is imperative to understanding the life of an inmate. Currently, the United States prison population is mostly comprised of poor black and Latino individuals (Freudenberg 215). One must acknowledge, therefore, that rising incarceration rates have not only become a political problem, but also an issue of socio-economic injustice. In short, an element of structural violence has entered the US criminal justice system, and urban neighborhoods have the most to lose. In his article “On Suffering and Structural Violence: A View from Below,” Paul Farmer describes structural violence as:

³⁴ Michel Foucault, *Discipline and Punish: The Birth of the Prison*, tran. Alan Sheridan (New York: Vintage Books, 1979), 268.

Mechanisms through which large-scale forces crystallize into the sharp, hard surfaces of individual suffering. Such suffering is structured by historically given (and often economically driven) processes and forces that conspire – whether through routine, ritual, or, as is more commonly the case, these hard surfaces – to constrain agency.³⁵

Structural violence not only illustrates the relationship between incarceration rates and inner-city communities, but the fact that “the hard surfaces of individual suffering” are often driven by strict criminal legislation and practices. For example, the War on Drugs, declared by President Richard Nixon in 1971, is responsible for the implementation of “three strike sentencing,” allowing a judge to sentence those with prior drug charges to twenty-five years in prison. This stratagem of mandatory sentencing has been often directed towards women and male minorities who, since the War on Drugs was declared, have suffered the greatest increase in incarceration rates.³⁶ While it is important that lawmakers and public policy advocates know the specific agencies and factors that contribute to the structural violence which targets urban populations, they are not pertinent to this paper. This is not to say, however, that this is the last mention of structural violence as a critical way of understanding suffering in prison. In fact, structural violence has a profound impact on the end of an aging prisoner’s life, and the

³⁵ Paul Farmer, "On Suffering and Structural Violence: A View from Below," *Multidisciplinary Global Perspectives* 3, no. 1 (Fall 2009): 12-13.

³⁶ Doris Layton Mackenzie, *Sentencing and Corrections in the 21st Century: Setting the Stage for the Future* (College Park: University of Maryland, February 23, 2000), 4-5. Doris Layton Mackenzie who submitted her report to the National Institute of Justice Office of Justice Program, a branch of the U.S. Department of Justice, determined this statistic. Although this paper is not of a statistical nature it is important to include Mackenzie’s statistic to understand how gender and race based discrimination are statistical proponents of harsher sentencing.

structural violence experienced outside the prison walls can affect a terminally-ill prisoner's access to a meaningful death.

Knowing the factors that contribute to a growing and aging prison population is important to understanding the life and death of the prisoner. The increasingly harsh legislation and structural violence that plagues urban neighborhoods has put a strain on the correctional system. This strain has led to prison privatization and various public health catastrophes. Even worse, many of the individuals coming from poor socio-economic backgrounds are arriving in prison with pre-existing medical conditions, only to find that their illness or disease is exacerbated by the prison's systematic inability to care for sick and dying prisoners.

Structural violence is not the only circumstance that creates disparities in inmate health care and hospice. As the United States prison population grows, so does the stress on adequate health care for aging prison inmates. A report from the National Criminal Justice Commission in 1996 stated that geriatric care for a single elderly inmate sometimes costs over \$69,000.^{37,38} Coupled with rising incarceration rates, federal and state correctional healthcare budgets in this country for inmates over fifty-five can reach a total of \$2.1 billion per year (Cohn 253). Unable to support this and other costs, some state and federal facilities are resorting to prison privatization. Gerry Gaes of the National Institute of Justice

³⁷ Felicia Cohn, "The Ethics of End-of-Life Care for Prison Inmates," *Journal of Law, Medicine and Ethics* 27, (1999): 253.

³⁸ Caring for a geriatric inmate costs almost three times the amount needed to care for a regular prisoner, although there is some controversy surrounding this statistic.

explains, “Seven percent of the 1.5 million prisoners in the United States are held in privately operated prisons, according to the most recent survey of prisons published by the Bureau of Justice Statistics.”³⁹ This phenomenon will persist as the national prison population ages.

What is seen as a burden for many state and federal correctional facilities is considered a flourishing business opportunity for private companies.

Corporations like the Corrections Corporation of America and the GEO private prison network advertise cost-efficiency and organized facility operation for a reasonable price. As a result, state and federal prisons and jails are being turned over to the private sector.⁴⁰ Yet, by choosing a prison management method that is committed to efficiency, inmates are in danger of being deprived of access to social services and most importantly, adequate health care.

Although this section provides a short introduction to the socio-governmental issues that affect the prisoner, it is beyond the scope of this study. It can be easy to become sidetracked by background information, especially when it offers an explanation as to why Americans neglect and abuse their inmates. Yet, instead of examining what affects the life, death and health care of inmate from the outside, this paper will take on the difficult task of attempting to analyze the life of the dying prisoner from within the walls. “No man is an island entire of itself; every man is a piece of the continent...any man's death diminishes me,

³⁹ Gerry Gaes, "Cost, Performance Studies Look at Prison Privatization," *Journal of the National Institute of Justice* 259, (March 2008): 1.

⁴⁰ According to the GEO Group Incorporated webpage, the GEO group own 118 corrections and/or detention centers and approximately 81,000 beds.

because I am involved in mankind” (Donne 103). To understand the life and death of an inmate, one must first see the inmate as a fellow human being because, like it or not, simply being a human makes every American citizen part of this very real and very serious problem.

The Current State of Inmate Health

Excessive bail shall not be required, nor excessive fines imposed, nor cruel and unusual punishment inflicted.

– Eighth Amendment to the U.S. Constitution

In the United States, under the Eighth Amendment to the Constitution, incarcerated individuals are the only citizens who have a legal and inalienable right to health care because prisoners may not be subjected to cruel and unusual punishment.⁴¹ However, as Felicia Cohn explains, inmates nevertheless lack “the mobility or freedom to choose their health care coverage and they are dependent upon an institutional system for such care” (Cohn 252). Prison health care operates as a totalitarian unit in the sense that all aspects of health and health care are conducted in the same place, under a single authority. For example, the Federal Bureau of Prisons has a set of uniform “Clinical Practice Guidelines” which serve as a national guide for prison clinicians on how best to treat inmates. It may sound routine for any medical professional to have a set of health related guidelines for his patients, but the Federal Bureau of Prisons also emphasizes the

⁴¹Mike Mitka, "Aging Prisoners Stressing Health Care System," *JAMA: The Journal of the American Medical Association* 293, no. 4 (2004): 423.

importance of *security* and *control* in one's medical practice (Delgado and Humm-Delgado 169-213).

Although inmates legally qualify for a basic level of care, their inability to make autonomous choices when it comes to their health and medical treatment raises questions of the efficacy and morality of the prison health care system. Suddenly, a legal right to care does not feel like an appropriate or accurate description of our nation's correctional health care system. Perhaps a more fitting description of medical care in a correctional setting would be that it is bureaucratic and ill-equipped to deal with the results of structural inequalities and poor public policy. This regulated, and potentially inadequate health care system is being required to serve many rapidly expanding and financially demanding groups comprised of people who are victims of institutionalized inequality, including the elderly and drug offenders.

The Elderly

The elderly inmate represents an exponentially growing and thus problematic population for the United States correctional system. The National Center on Institutions and Alternatives estimates that housing and caring for an inmate over the age of fifty-five costs state and federal governments an annual sum of \$2.1 billion. That is almost three times the amount it costs to accommodate a normal prisoner (Mitka 423). Aging inmates cost more money because they require more care. Geriatric care is a complicated and extensive

branch of biomedicine which attempts to address the effects that aging has on the human body while meeting the additional emotional needs of an elderly patient. To care successfully for a geriatric patient both mentally and physically is not only expensive but also costly in the sense that elderly patients require a more sophisticated level of care. Furthermore, stressful lifestyles and risky behavior cause prisoners to age exponentially faster than the regular US population. Those who criticize the aging prison population have begun to refer to correctional facilities as “maximum security nursing homes” (Delgado and Humm-Delgado 23).

Perhaps the most overwhelming question (even bigger than how state and federal governments intend to pay for an aging prison population) is how the climate of prisons will change under the pressure of a large population of graying inmates. In their book *Health and Health Care in the Nation's Prisons*, Melvin Delgado and Denise Humm-Delgado attempt to examine this question further when they call attention to the fact that the definition of “care” is changing:

The longer sentences and incarceration of older inmates necessitate the rethinking of traditional premises regarding punishment. In addition, the idea of “special status” can have a very broad meaning when applied to prisoners because of the number of prisoners who are terminally ill, or will be within the confines of their prison sentence, only can be expected to increase in the early part of the twenty-first century (Delgado and Humm-Delgado 5).

Addressing elderly care in a correctional setting is no longer just a fiduciary issue. Instead, the incarceration practices of the United States government have become an issue of social hierarchy. How will prison employees justify their obligation to

treat geriatric and terminally-ill prisoners differently from healthy inmates? What will this “special status” do to the organization of the total institution? Are prisons and jails well-equipped to deal with the inevitable – the end of life without parole? I recognize the importance of all these questions to the reformation of the institutionalized prison, but what I am most curious about in this case is the last question. How do you prepare someone for the end of their own, personal life, when so much about prison is impersonal and uniform? Fleet Maull, founder of the prison hospice movement, states the obvious fact that in a correctional setting, “Total institution, care is institution centered, not patient-centered” (Maull 478). Do prisoners even have the right to a personalized death?

In the United States, there is a lack of public sympathy or even knowledge when it comes to end of life care in a correctional setting. Many people living outside the walls of our nation’s prisons do not believe that prisoners are entitled to a meaningful end, or even if they are taken to the hospital they should not be entitled to hospice services. This viewpoint reflects a lack of public empathy and the total inability to view the dying inmate as a person, rather than as a criminal. An example of this lack of humanity can be seen in the form of overly neglected compassionate release programs. This social service attempts to grant terminal prisoners emancipation from a fate worse than death: where they would die chained to a bed, surrounded by correctional officers in a hospital emergency room. Although all federal prisons and thirty-three states have adopted some form of compassionate release, these protocols are very often

misused or completely ignored. There are currently over 150,000 inmates in the California prison system, and although an extremely small proportion of those imprisoned applied for a benevolent death, even fewer were granted access to what many of us consider a basic human right. For example, Maull says that in the state of California only 28 out of 78 applicants were granted compassionate release last year (Maull 478).

The case of Gloria Broxton, an inmate at Central California Women's Facility at Chowchilla, demonstrates the very real need for compassionate release and prison hospice programs for the elderly. In an article for the San Diego Union Tribune, Greg Moran described how even the most terminal patients are denied compassion:

Deep within the state prison Gloria Broxton lies on a hospital bed, the life slowly ebbing out of her body. Her life can be measured in weeks, or perhaps, a handful of months. No one knows, but this much is for sure; Broxton, serving a six-year term . . . for dealing drugs, won't finish her sentence. The cancer inside her body is moving quicker than the calendar marking the remaining days of her prison term . . . Broxton . . . wants her final breaths to be drawn outside the prison walls. Her hopes are lodged in a file stuffed with records, diagnoses, analyses and recommendations. It is her application for compassionate release, an obscure and rarely invoked proceeding that each year allows a few dozen terminally ill prisoners to be released before their prison term expires (Delgado and Humm-Delgado 129).

California is not the only state with stringent compassionate release procedures. In Oklahoma, compassionate release must be made upon the recommendation of a physician, who must then receive approval from the warden of the prison, who must receive permission from the governor, who must appeal to the state medical

parole board.⁴² While every state's procedures vary, compassionate release is a complicated process that very rarely results in the prisoner's freedom.

Inmates who used to find themselves aging in a correctional setting are now finding themselves dying in prison. We have entered a social and health care crisis that could be easily solved with better legislation and a gentler public opinion. One correctional study reported, "Only 3:100 inmates over fifty-five return to prison."⁴³ Based on this statistic and the strict guidelines of compassionate release programs, the American public should acknowledge the fact that geriatric prisoners are as harmless as regular citizens. In prison, however, they need more expensive and intensive medical care. Having a growing elderly inmate population means that the entire social theory of the total institution must be reconsidered. In other words, an aging prison population is not only a fiduciary issue, it is also an issue of social hierarchy. How will prison employees justify their obligation to treat geriatric and terminally ill prisoners differently from healthy inmates? What will this "special status" do to the organization of the total institution? An elderly population in need of advanced care does not correspond with the public's opinion that believes that prisoners do not deserve special healthcare.⁴⁴ It is this stubborn and non-empathetic attitude that puts the aging prison population problem at a standstill. Without new

⁴² Oklahoma Department of Corrections Medical Parole secretary, telephone conversation, January 14, 2011.

⁴³ *Fault Lines: Dying Inside*, DVD, directed by Josh Rushing (2010; United States: Al Jazeera English (AJE), 2010).

⁴⁴ Kevin N. Wright and Laura Bronstein, "An Organizational Analysis of Prison Hospice," *Prison Journal* 87, no. 4 (2007): 392.

legislation and correctional regulations, our criminal justice system will not be able to fix this mounting problem of how to help a prisoner achieve a meaningful death. As a nation we must put aside the identity of “criminal” and start accepting the designation of “human.” Unfortunately this shift has proven even more difficult when asking the American public to consider the humanity of individuals who utilize and sell IV drugs.

The Forgotten Citizen – The Health Consequences of the War on Drugs

The War on Drugs is a law enforcement initiative that has completely changed the size and socio-economic diversity of the prison population. In their book *Righteous Dopefiend*, Philippe Bourgois and Jeff Schonberg explain that the War on Drugs instigated “a more than fivefold increase in the number of drug offenders admitted to state prisons in 1998 compared with 1984.”⁴⁵ These numbers represent a population of IV drug users, the majority of which are from poor neighborhoods. According to Sandra A. Springer of Yale University School of Medicine, there is a direct link between injection drug use in these communities and disease in a correctional setting.⁴⁶ These injection drug users are thus coming off the streets with little medical care and are contributing high levels

⁴⁵ Philippe Bourgois and Jeff Schonberg, *Righteous Dopefiend* (Berkeley: University of California Press, 2009), 308.

⁴⁶ Sandra A. Springer and Frederick L. Altice. "Managing HIV/AIDS in Correctional Settings," *Current HIV/AIDS Reports* 2, (2005): 165.

of infectious disease to the prison populations. Perhaps the most glaring example of this is the prevalence of HIV and AIDS in prisons and jails.⁴⁷

The presence of HIV and AIDS in American prisons and jails is much like the prevalence of an aging prison population in the sense that it represents a lack of cooperation between correctional facilities and adequate health care policies. Black men are at greater risk for serving time in prison than the rest of the US population. Furthermore, drug users are at a much higher risk for HIV/AIDS due to, as Schneider states, “Intense police surveillance, combined with laws against possession of drug paraphernalia, [which] has made the possession of clean syringes in minority neighborhoods extremely risky. [The] fear of arrest compels injection drug users to rely on syringes borrowed at the moment of injection.”⁴⁸ The fall-out of the War on Drugs targets poor neighborhoods with inadequate social and medical services. Eventually, these poor injection drug users are caught with syringes and incarcerated, bringing a history of poor health and rampant infectious disease into a system that is ill-equipped to treat them. Thus, prisons and jails become a hotbed of transmissible infections.⁴⁹ One study conducted by The National Commission on Correctional Health on *The Health*

⁴⁷ As Springer and Altice state in their *References and Recommended Readings*, “This report to United States Congress, commissioned through the National Commission on Correctional Health Care, provides a comprehensive analysis of infectious diseases and other conditions that negatively impact prisoners and its impact upon society after release” (Springer and Altice 169). This study, although not extensively referenced in this paper, illustrates how correctional facilities can perpetuate and spread disease

⁴⁸ Anne Larson Schneider, “Public-Private Partnerships in the U.S. Prison System,” *American Behavioral Scientist* 43, (1999): 193.

⁴⁹ Joseph A. Bick, “HIV and Viral Hepatitis in Corrections: A Public Health Opportunity,” in *Public Health Behind Bars: From Prisons to Communities*, ed. Robert B. Greifinger. (New York: Springer, 2007), 103.

Status of Soon-to-be-Released Inmates suggests that the prevalence of infectious diseases such as HIV/AIDS is five times higher in a correctional setting than in the rest of the US population.⁵⁰ This ever-expanding number reflects the inefficacy and policies designated to accommodate the War on Drugs. It also represents the inability of correctional facilities to monitor infectious disease and calls attention to the much larger issue. Prisons and jails lack the infrastructure to communicate with public health initiatives, social services and public policies in the outside world.

Once these medically-neglected drug users enter prison, things only get worse. Inmates serving drug-related sentences are known to be extremely wary of the correctional health care system. They are notorious for their unwillingness to cooperate and as Bick says, they generally mistrust prison health care personnel (Bick 104). As Nancy Neveloff Dubler explains, “In contrast to non-incarcerated patients, inmates do not assume that the system is acting in their best interest” (Dubler 149). These feelings of mistrust cause the inmate, already medically neglected before entering prison, to become even sicker, ignoring diseases that he contracted before prison and (due to a general mistrust of prison health care providers) not addressing them. Mistrust on the part of the inmate and medical carelessness on the part of the correctional facility become extremely complicated when considering end of life treatment for a prisoner with an infectious disease

⁵⁰ National Commission on Correctional Health Care, *The Health Status of Soon-to-be-Released Inmates: A Report to Congress* (Chicago, IL: National Commission on Correctional Health Care, 2002).

that has become terminal. As these problems progress, a system of structural violence and the total institution quickly and irrevocably deny a terminally ill inmate the right to a good death. The system is working against the incarcerated patients, denying them basic medical rights, adding to the irony that inmates and prisoners are the only citizens that have a legal right to health care under the Eighth Amendment of the United States Constitution. Perhaps the greatest example of these inequities is the impersonal, bureaucratic approach to prison health care taken by private correctional companies like Prison Health.

Prison Health and Prison Privatization

To understand a company like Prison Health fully, it is imperative to explore how the privatization of prisons has come to dominate the United States correctional system. Prison privatization, in theory, is an efficient and cost-effective method for dealing with the high costs that accompany high incarceration rates. Perhaps the most attractive quality of operating prisons in the private sector is that the construction of these new correctional facilities is funded and operated by private companies that do not need to concern themselves with the vagaries of the government budgeting process. Although the state is responsible for raising the necessary revenue and making yearly payments to the private firm or owner of a privatized prison, the private contractors contend that they take less time and money to construct and operate a prison than the government. But as Richard W. Harding explains in his book, *Private Prisons and*

Public Accountability, many Americans are concerned with the ethical questions that surround prison privatization especially those that dispute accountability:

Given that private prisons are here to stay for the foreseeable future, the central question becomes that of accountability. Accountability is not a unitary idea; its crucial components will vary from activity to activity, from structure to structure. The closed nature of total institutions such as prisons means that there are special difficulties in achieving effective accountability, even within public sector prisons, and obviously these factors will be no less applicable to accountability within private prisons.⁵¹

It is difficult to understand how private prison companies are held accountable, especially where large corporations control multiple prisons simultaneously. To save money, many state and federal correctional systems have turned to these private corporations to manage their prisons and, most importantly, their inmate health services. These corporations have not only exacerbated the presence of infectious disease and inmate neglect, they have influenced the commencement of a privatized prison phenomenon and have ensured the loss of the inmate's voice and set up an extra gap in public accountability

Prison Health Services, a private health corporation that provides correctional contracting and managing services to the public sector, is a prime example of how a lack of accountability, combined with the desire to make prison a cost-effective enterprise, can result in disaster. Prison Health Services (also known as Prison Health), is based in Nashville, Tennessee, represents the complicated history of many private corporations that take over correctional facilities. Prison Health Services is also the manifestation of what money-saving

⁵¹ Richard W. Harding, *Private Prisons and Public Accountability* (New Brunswick: Transaction Publishers, 1997), 17.

gimmicks and prison overcrowding have done to the correctional health care system. In an article for the New York Times, Paul von Zielbaur explains that:

Despite a tarnished record, Prison Health has sold its promise of lower costs and better care, and become the biggest for-profit company providing medical care in jails and prisons . . . The examination of Prison Health also reveals a company that is very much a creature of a growing phenomenon: the privatization of jail and prison health care. As governments try to shed the burden of soaring medical costs – driven by the exploding problems of AIDS and mental illness among inmates – this field has become a \$2 billion-a-year industry.⁵²

Once again, in an effort to save taxpayers money, state and federal jails and prisons are turning to big for-profit companies like Prison Health at the expense of their incarcerated patients.

According to von Zielbaur's article, spending for correctional health care programs had tripled and is currently costing state and federal governments \$5 billion annually (von Zielbaur 3). Corporations like Prison Health subsidize prison health care, a practice which appeals to correctional facilities that want to exercise efficiency without increasing costs. Companies like Prison Health are a quick fix to the larger issue that prisons and jails are unequipped to care for an aging and infectious diseased population. For example, Paul von Zielbaur discovered that in Alabama, one correctional facility utilizing Prison Health services employs two physicians for over 2,200 inmates – setting the stage for a completely inadequate level of care and putting the lives of prisoners in danger (von Zielbaur 3). With only two doctors for over 2,200 inmates for general

⁵² Paul von Zielbaur, "As Health Care in Jails Goes Private, Ten Days can be a Death Sentence," *The New York Times*, February 27, 2005, sec. New York/Region.

medical care, one must prioritize the correctional health system. It is safe to assume that end of life care including hospice, geriatric care, and palliative medicine are not even considered important aspects of inmate health in such an overtaxed system

The warehouse tactics of corporations like Prison Health and its associates make for poor public health and medical practices. Utilizing a health care model that emphasizes cost-effective, mass treatment, overlooks important medical details and disregards the importance of preventative care. Those who do not expect to die behind bars can look forward to being released back into their impoverished community with old untreated illness, or newly acquired infectious diseases transmitted through overcrowding and a poor and increasingly privatized medical system.

Another equally disturbing public health disparity that is the result of prison privatization is the newly-commissioned, cost-effective invention of the Special Housing Unit. Special Housing Units (SHU) attempt to solve the problem of cost-efficiency and limited personnel by warehousing a large number of inmates in a concentrated area. With SHUs, prisons can afford to employ fewer prison guards and therefore save money for taxpayers. While SHUs are used to house every kind of inmate (sick or healthy), they can cause serious public health and medical complications. Special Housing Units are considered by many to be glorified dungeons, and the poster child for all that is wrong with prison privatization. Manuel Colon, a prison rights activist described them as, “Self-

contained prisons that they build on the grounds of already existing prisons... There are two people locked in a cell for twenty-three hours. They are so contained that they have to shower in the cell, they have a door that opens in the back of the cell that leads into this little area that they call a 'dog-kennel'" (Fleury-Steiner 90-91).⁵³ Before entering one of these small cells, prison medical providers are required to give a comprehensive medical assessment to insure that the inmate is medically stable. The concept of Special Housing Units are particularly difficult to stomach when considering the toll they take on the prisoners, especially those who suffer from terminal and mental illness.⁵⁴ With companies like Prison Health, however, which reduce medical staff numbers to a bare-bone minimum, screening for medical ailments such as HIV/AIDS, hepatitis, tuberculosis and mental illness is inadequate and often incorrect.

When hearing that mentally-ill and terminally-ill inmates are being placed in isolated confinement, there is one question that we must ask: do we value security without surveillance over humane treatment and care? Perhaps we are willing to sacrifice basic human rights in order to save money and time. Rather, the aging prison population and the inmates' diseases demand that more, and not

⁵³ Manuel also states that SHUs take about 20 million dollars to construct. This is not only adding to the exorbitant costs of prisons, but also adds to the need to care for the prisoner's mental and physical health when detained in such a hostile environment (Fleury-Steiner 90-91).

⁵⁴ Dr. Stuart Grassian, a psychiatrist that studies the effects of SHUs on the mental well-being of prisoners, stated in "Hidden Prisons: Twenty-Three Hour Lockdown Units," by Jennifer R. Wynn and Alisa Szatrowski: "During the course of my involvement as an expert, I have had the opportunity to evaluate the psychiatric effects of solitary confinement in well over 100 prisoners... I have observed that many of the inmates so housed have histories of psychiatric and/or neurological difficulties, and for many inmates, incarceration in solitary caused either severe exacerbation or recurrence of preexisting illness, or caused the appearance of an acute mental illness in individuals who had previously been free of any such illness" (Wynn and Szatrowski 513-514).

less, attention be paid to inmate health. Instead, the money that could be utilized for prison health programs is poured into Special Housing Units that do not promote wellness, communication or, most importantly, rehabilitation.

In his book, *Dying Inside: The AIDS/HIV Ward at Limestone Prison*, Benjamin Fleury-Steiner recounts the story of William Watson. William Watson's story illustrates how privatized correctional health care, combined with SHUs and inadequate medical screening, can lead to deadly consequences. According to another prisoner and close friend, William Watson was placed in a SHU where he died of pneumocystis carinii pneumonia and secondary bacterial pneumonia. It was not the pneumonia that took Watson's life, however. In addition to suffering from severe mental illness, Watson had contracted the AIDS virus while inside Limestone Prison. Unfortunately, Limestone's medical staff, although noticing an extremely low T-cell count, did not detect this infectious disease before placing Watson in a Special Housing Unit cell. Watson was not allowed to have contact with other prisoners, nor was he allowed out of his holding cell, and so he was left to succumb to the cruel and unusual punishment that privatized prison health care has brought to our nation's correctional facilities. One prisoner described the holding cell where Watson was kept and its atrocious conditions:

I've been in there. It's a very, very small, tiny cell where you only have enough room basically to turn around in, with a window that stays closed, with a trap door, and they open it to serve you your tray . . . They take your mattress away in the morning at 4:30 am and give it back that evening at 5, so you're on a metal bunk or the hard concrete floor (Fleury-Steiner 132-133).

The story of William Watson's horrifying death exemplifies the prisoner's struggle for decent health care in a correctional setting. With the increasing prevalence of privatized health care companies in prisons and jails, the already weak voice of the prisoner is being taken away. Take Watson as an example. He is no longer here to tell his story, nor can his fellow inmates or medical personnel remember his life in a positive light. Instead, his horrific death will be etched into their minds along with the fact that medical staff denied William Watson both a decent life and a good death.

An inmate in a correctional setting, whether private or public, is routinely denied autonomy or voice, especially when it comes to health care. The growing elderly and medically-neglected prison populations have strained the budgets of federal and state correctional facilities and have created a general level of mistrust between inmate and health care provider. The need to give the inmate a voice is perhaps the greatest need and the greatest challenge of our nation's correctional facilities. Furthermore, prison hospice offers correctional facilities a chance to improve prison infrastructure so that prisoners are heard. In other words, prison hospice is an advocate for the dying patient's voice in our nation's prisons.

CHAPTER THREE: THE PRISONER'S VOICE

*I sit on a man's back, choking him and making him carry me.
And yet assure myself and others, that I am very sorry for him and
wish to lighten his burden by all possible means.
Except by getting off his back.
-Leo Tolstoy⁵⁵*

The Autonomous Voice: The Difference Between Suffering and Salvation

For hospice to succeed in a correctional setting, public policy makers and corrections officers must consider the inmate an individual with an autonomous voice. When examining the institutionalized nature of the correctional facility, however, it can be argued that the act of giving the inmate a voice will never be achieved. The lack of inmate voice is accentuated by the increasing rates of prison privatization; at the same time, the need for inmate autonomy and voice has become even more necessary. The voice of an inmate is, among other things, a reference to individuality, spirit, personality, creativity, and autonomy. Voice can make the difference between a decent death and a painful demise. Leo Tolstoy offers a parable in which he torturously rides on a man's back, ignoring his role as a tormentor yet assuring that he is in fact remorseful for his actions. He claims empathy, yet ignores the physical and mental pain he is inflicting on his prisoner. It is a story that demonstrates that it is insufficient to say we are sympathetic to others' suffering – that although we assure ourselves and others that we are very sorry and wish to lighten the tortured individual's burden by all possible means, we have no intention of ceasing our actions.

⁵⁵ Leo Tolstoy, *What Then Must We Do?*, tran. Aylmer Maude (Oxford: Oxford University Press, 1960), 54.

Such insensitivity defines the nature of prisons across the United States and the attitude towards the inmate's autonomous voice in the context of both regular and palliative medical care. The criminal justice system gives lip service to the idea that an incarcerated patient has a say when it comes to his care but, unfortunately, the system is unwilling to change the infrastructure of the prison in order to facilitate this change. Although the voice of the patient is essential to autonomous choice, which is crucial to the success of prison hospice, organizations like Prison Health and other prison health care personnel seem to do anything but give the patient what they need or what they deserve. Prisons and jails refuse to allow the dying inmate any autonomy, instead forcing him to shoulder the burden of dying in prison alone.

In her book, *The Body in Pain*, Elaine Scarry calls attention to the importance and validity of the voice. Scarry explains that for those who suffer mental or physical anguish, a voice can mean the difference between devastation and salvation. She explains that, “. . . the voice becomes the final source of self-extension; so long as one is speaking, the self extends out beyond the boundaries of the body, occupies a space much larger than the body.”⁵⁶ Scarry stresses that without the voice, the body cannot cope with pain and suffering. The absence of a voice can mean that the prisoner must exist as a body without the freedom of expression. Without a voice the prisoner is doomed to carry his physical pain alone without either a voice or the sympathy of others. Elaine Scarry suggests

⁵⁶ Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York: Oxford University Press, 1987), 33.

that pain is complicated and sometimes impossible to describe. She uses the example of medicine specifically to exhibit the difficult relationship between communicating one's pain and understanding the pain of someone else:

For the success of the physician's work will often depend on the acuity with which he or she can hear the fragmentary language of pain, coax it into clarity, and interpret it . . . The conclusion that physicians do not trust (hence, hear) the human voice, that they in effect perceive the voice of the patient as an "unreliable narrator" of bodily events, a voice which must be bypassed as quickly as possible so that they can get around and behind it to the physical events themselves (Scarry 6).

Physicians are an extremely important to the voice of the patients, especially in the case of the prisoner – inmates need agency, no matter where it comes from.

Scarry emphasizes the importance not only of *trust* but also of acknowledging the voice of the prisoner. The story of William Watson and his death in solitary confinement explaining why acknowledging the voice is imperative and intertwined with true human survival. By refusing to pay attention to Watson's pain and his pleas, Limestone's medical staff was in effect denying Watson's voice. According to Scarry's theory, to ignore the voice of the suffering prisoner is an act of torture. In a country where cruel and unusual punishment of its prisoners is absolutely illegal, how can the staff of Limestone prison justify their actions? How is what happened to William Watson not considered torture?

Torture occurs daily in a correctional setting, but the instruments of power are often subtle and undetectable. For example, in a correctional setting, something as small as one's ability to leave the prison at the end of the day, and transcend the line between the outside world and the prison world, can translate

into power. Loss of agency and movement turns into a kind of weapon. It is a daily reality that prison personnel can purposefully use to punish and silence the prisoner. The ability of prison staff to come and go as they please is, as Scarry states, “Displaying the weaponry, [which] begins to convert the prisoner’s pain into the torture’s power” (Scarry 58). The use of freedom as a weapon combined with the prisoner’s lack of autonomous voice strengthens the already very real possibility that the prisoner will never have even basic choices they deserve in a correctional setting. Prison personnel are not the only aspect of prison life that can affect a prisoner’s choices. The manipulation of choice by the prison personnel’s assertion of power has also been embodied in the practice of medical experimentation on inmates.

**Experimentation or Exploitation?:
Medical Experimentation Inside and Outside the Prison Walls**

The United States government has a dark and complicated history of medically exploiting its poorest and most disadvantaged citizens. While United States prison inmates are among these mistreated citizens, the United States is also responsible for abusing its citizens that have never been incarcerated. An elaborate example of the mistreatment of citizens outside the prison walls is a medical experimentation project seeded in racism, poverty and lack of political power. The Tuskegee Syphilis trial exemplifies how the government’s past abuses of power have targeted those that have the least amount of autonomy or authority in American society. During the forty-year study in Tuskegee,

Alabama, prejudice and racism fueled the unethical medical testing experiment which targeted poor African American sharecroppers.⁵⁷ The test subjects were young men who were told that they would be treated by an expert medical team for their *bad blood*. This *bad blood* was untreated syphilis, a disease that the study's medical personnel were responsible for keeping secret from their test subjects. Even when it was discovered that penicillin could be used to cure advanced syphilis, the United States Public Health Service (PHS) kept their subjects from seeking alternative medical attention. Instead, the PHS assured the participants that their treatment with non-effective drugs was sufficient to cure the *bad blood*.

The men who participated in the study had no idea that they were not receiving adequate treatment for their bad blood until the study was exposed and eventually shut down in 1973. As President Bill Clinton described it in a formal federal apology for the Tuskegee study, "Men who were poor and African American, without resources and with few alternatives, they believed they had found hope when they were offered free medical care by the United States Public Health Service. They were betrayed."⁵⁸

The Tuskegee Syphilis study represents an assertion of power – the concept that those with power can enslave and control those who are vulnerable especially under the pretense of *helping*. The same questions arise when

⁵⁷ Susan M. Reverby, *Examining Tuskegee: The Infamous Syphilis Study and its Legacy* (Chapel Hill: The University of North Carolina Press, 2009), 1-10.

⁵⁸ Susan Reverby, ed., *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study* (Chapel Hill: The University of North Carolina Press, 2000), 575.

considering experimentation on prisoners, a situation that is not unlike the circumstances under which prisoners have lost their autonomy and their choice. It is crucial to include the Tuskegee Syphilis Study in this paper in order to understand how authority can manipulate the voice of the poor and imprisoned or how power can translate into the force that overshadows autonomy and complicates the concept of choice. In Tuskegee, the authority used the power of medical knowledge and the power of structural factors to betray and mislead the choices of the poorest citizens in America.

In his book *Acres of Skin*, Allen M. Hornblum demonstrates how the American prison system used the same inhumane methods to test toxic chemicals on inmates for over thirty years. It could be argued that inmates involved in any medical experimentation actively volunteered as research participants. Those who make that argument forget that personal responsibility is skewed in a correctional setting such that there is no such thing as voluntary, free choice in prisons. Other structural factors are at work to affect prisoners' decisions to become research subjects in medical trials. Raymond Crawford, an inmate who is currently serving a life sentence stated, "Everyone did it for the money. There were a small number of jobs in the county jail and men needed money . . . [Medical researchers] were taking advantage of a bad situation. We didn't know anything about what they were testing or how the things you would ingest would

affect you years later.”⁵⁹ This quotation demonstrates how structural factors such as economic and educational inequalities take advantage of the prisoner and dictate his place in the correctional setting. Many prisoners come from extremely impoverished communities and when money was offered in clinical trials, they saw an easy opportunity. An article by Barron Lerner describes how, during the 1950s, prisoners at Holmesburg were receiving as much as one–thousand, five hundred dollars per month in exchange for exposure to deadly pathogens.⁶⁰

Perhaps on a deeper level, these offenders saw an opportunity to correct the economic injustices they had experienced all their lives.

Both the medical experimentation performed on the inmates at Holmesburg Prison and experiments performed on poor black sharecroppers in Alabama demonstrate how choice can be coerced or even destroyed by those who misuse their positions of power. Indeed, as Lerner states, “The US prison population contains disproportionate numbers of vulnerable people . . . Vulnerable to what The Department of Health and Human Services described as a coercive environment” (Lerner 1806). Medical experiments on prisoners not only question the flexibility of choice, they also demonstrate how choice in prison can be coerced by the desire for a better life. The experiments performed at Holmesburg prison mirror the Tuskegee Syphilis Experiment because they both demonstrate how the United States government was, as Hornblum states, “abusing our socially

⁵⁹ Allen M. Hornblum, *Acres of Skin: Human Experiments at Holmesburg Prison* (New York: Routledge, 1999), 25.

⁶⁰ Barron Lerner, "Subjects Or Objects? Prisoners and Human Experimentation," *New England Journal of Medicine* 356, no. 18 (2007): 1806.

and economically disenfranchised citizens” (Hornblum 244). Not only do both these public health disasters show how the poorest people in our country were medically mistreated, it also, for prisoners, indicates how hostile a prison environment can be to choice and free will.

Medical experimentation on prisoners was banned in 1978, and up until the early twenty-first century, inmates could only participate in trials that posed a minimum risk to the individual. In 2004, however, legislation was proposed, which suggested that these strict risk guidelines be relaxed (Lerner 1806). By relaxing the guidelines for prisoner experimentation, the government is creating medical problems in a place where healthcare is already inadequate and the dangers of structural violence are prevalent. Relaxing the guidelines which aim to protect the prisoner from medical atrocities is to condemn each American inmate to the same future as inmates that were housed at Holmesburg or poor sharecroppers that lived on the farms of Tuskegee, Alabama. To relax these experimentation guidelines would, in effect, lead to very real abuse against prisoners in this country. Some people argue that by not allowing prisoners to participate in medical experimentation, they are not receiving the health care they need. Ironically, because of minimal risk laws, prisoners suffering from terminal or chronic illness are not allowed to enter clinical trials. This is troubling for the dying inmate who could benefit or be made more comfortable by a treatment plan that is potentially risky but beneficial. Even so, the question of choice and voice becomes an important factor when considering experimentation.

Medical experimentation on prisoners represents an important metaphor for the current state of inmate. Like medical experimentation, inmate health care and palliative care programs assert their power to ignore and dictate the choices of the individual prisoner. Thus, they rob the inmate of an autonomous voice and manipulating the prisoner based on preexisting structural inequalities. For example, in an oddly backward prison health care case, Kenneth Myers, an inmate being housed in Massachusetts, tried to refuse kidney dialysis. In normal society, Myers' refusal of care would be considered legal under the rule that any mentally competent adult is within their rights to refuse medical attention of any kind at any time. However, it was determined by the state and Suffolk County that Kenneth Myers did not have the same medical rights as citizens outside the prison walls. As Nancy Neveloff Dubler explains in her article, "The Collision of Confinement and Care: End-of-Life Care in Prison and Jails":

In overruling [Kenneth Myers'] refusal of treatment, the court noted that the interests of the state, as represented by the department of corrections, included the "preservation of internal order and discipline, the maintenance of institutional security, and rehabilitation of prisoners." These interests, the court held, permitted corrections officials to administer life-saving treatment without consent and over the specific objection of the inmate. This case and others have consistently placed the requirements of corrections administration over the rights of inmates to consent to or refuse treatment (Dubler 151).

The case of Kenneth Myers versus the Commissioner of Corrections illustrates the fact that the interests of a state or correctional institution always come before an inmate's personal interests or rights. While access to care is more of a concern for prisoners than their ability to refuse medical treatment, it still raises the

important issue that, in the end, the prison has the power to change, influence and dictate the choices of the prisoner; the Prison always has the ability to silence the prisoner's voice.

Elaine Scarry's theory of the tortured voice becomes an instructive component of medical experimentation and the coercion of the prisoner's voice. Too often the choices of the prisoner are forgotten or ignored by those who control the environment in which the prisoner lives. Scarry sees a direct correlation between torture and the systematic silencing of the voice. She demonstrates to her reader that without a level of advocacy for the silenced individual, their pain will never be alleviated. As Scarry states, "To restore to each person tortured his or her voice, to use language to let pain give an accurate account of itself . . . [Is] an act of human contact and concern, [which] provides the hurt person with worldly self-extension" (Scarry 50). If choice is not restored to the dying prisoner, if autonomous choice is not made a reality, the future of hospice in a correctional setting will be tainted. Ideally, if limited autonomy and appropriate medical care were available for the terminally ill prisoner, the future of inmate health and hospice could improve the dying and death of the inmate in a correctional setting.

CHAPTER FOUR: PATIENT TESTIMONY AND THE HOSPICE VOLUNTEER

The Importance of the Inmate's Testimonial

The existing literature on prison hospice programs that contains an overwhelming plea for changing the way our nation approaches hospice care in a correctional system. A large segment of this literature calls for community involvement and presents ethical arguments that make “a case for valuing prisoners as human beings, fulfilling our social contract with them” (Cohn 258). Felicia Cohn’s words reflect what many other hospice volunteers and criminal justice ethicists believe: that until the American public recognizes and begins to instigate new public policy, hospice programs will continue to be rare in the correctional setting. While this call for action is imperative to improving the standards and even the existence of prison hospice programs, the record of an inmate’s autonomous voice should prove or disprove the success or failure of end-of-life care in a correctional setting.

Unfortunately, there is not a lot of research on the testimonials of those dying in prison hospice programs. After contacting various hospice organizations and directors, I know the very harsh reality that many of the voices of those dying in prison are lost in the shuffle of bureaucratic channels, and statistical data that is of much greater interest to researchers than the stories of the dying inmates. Although I would liked to have found more first person narrative accounts, my

sparse findings demonstrate a need to hear the dying inmate's voice in a correctional setting. It also demonstrates the need to place the injustices of prison hospice at the forefront of the public's mind.

Most of the testimonies I found during my research were a last confession of sorts to family members outside prison walls. For instance, Lewis Young is an inmate of the Pennsylvania Prison System. He has been diagnosed with liver cancer, a remarkably aggressive and painful disease. Young finds himself often thinking about the absence of family involvement in his dying process. Young's sentiments give voice to a major group of prisoners that fear dying alone in prison. He explains, "To have cancer, to be in jail, you know, and not be around your family, you know, it's like, it's real scary" (*Fault Lines*).⁶¹ The prospect of dying in prison is no doubt terrifying for an inmate, but the possibility of dying behind bars without family members is almost unbearable.

In their article "Palliative Care for Prison Inmates: Don't Let Me Die in Prison," John F. Linder and Frederick J. Myers interviewed an anonymous prisoner serving a ten-year prison sentence for manslaughter. The prisoner anticipated his death behind bars as inescapable and throughout the interview demonstrated a certain level of acceptance stating, "Dying doesn't scare me, which really puzzles most people. Most people are scared to death [of] the

⁶¹ Many of the inmates interviewed or documented in this film had already qualified for compassionate release programs but did not have any relatives to come and take them home. Josh Rushing was responsible for all interviews and narration for this extremely important film.

unknown . . . the loss.”⁶² When faced with the prospect of never seeing his children again, however, the anonymous inmate was visibly shaken saying:

It would probably be different [if I were living outside] because I would be with my family. I’d be with my children . . . I’d like to see them before I die in a place like here . . . My oldest daughter is 17, my youngest son is 7 . . . They live so far away that I don’t get to see them . . . That’s the hardest part of it all, being away from my family, being away from my children (Linder and Myers 898).

Although thousands of prisoners in the United States will die alone this year, many of their fears and heartache will be silenced by the lack of attention that is paid to the voice of the inmate. If their voices continue to be doubly silenced or ignored, we face an even greater challenge in finding effective correctional hospice programs. Even if incarceration limits his autonomy, the inmate cannot give voice to his pain. The absence of family further demonstrates how lost the inmate’s voice really is. Elaine Scarry describes this double loss in *The Body in Pain*. When we cannot voice our own pain, it is the duty of others to relieve our suffering through acknowledgement and remembrance. The testimony of the anonymous inmate who must die in prison without the help of his family is a demonstration of how dying prisoners like Lewis Young will continue to die without a voice or family support.

Family Involvement

Even when families are willing to support the dying inmate, visiting a

⁶² John F. Linder and Frederick J. Myers, "Palliative Care for Prison Inmates: Don't Let Me Die in Prison," *JAMA: The Journal of the American Medical Association* 298, no. 8 (2007): 899.

prisoner in a correctional facility can be extremely restricted, especially if that inmate is considered to be dangerous or a risk to security. In free society, hospice programs encourage family members to be present as often as possible in order to ensure the comfort of the dying patient. The communal origins and application of hospice stress the inclusion of family members and their willingness to participate in the patient's end of life care. Most importantly, families are an important source of advocacy for the dying patient. Even in prison, where inmates have a constitutional right to health care, there is often a miscommunication between inmate and health care provider. In their article, "Palliative Care for Prison Inmates: 'Don't Let me Die In Prison,'" John F. Linder and Frederick J. Myers explain, "Incarcerated individuals are more likely to have both low literacy and low health literacy often resulting in misunderstandings, frustration, and poorer health outcomes" (Linder and Myers 895).⁶³ In normal society, even if a patient is unable to understand certain health procedures, family members are often a source of agency or information. In a correctional facility, however, the incarcerated patient must rely on their own knowledge of health care, which, according to Linder and Myers, is often inadequate. It is also important to note that relationships between inmates and their families can become extremely complicated because of their incarceration. An already complicated relationship can be strained by limited visitation or inadequate contact. Therefore, without

⁶³ Although it is not relevant to this section, Linder and Myers also describe how internet and access to technology in regular society can be a valuable asset to patients who want to educate themselves about certain medical procedures or jargon. The main point is that without access to proper informational technology or family members, hospice patients in prison are not allotted an adequate level of care.

facilitating a bond between the dying patient and their family, a prison hospice program deprives the dying prisoner of the resources they need to access adequate information about their palliative care. Denying the dying inmate familial support is probably the most detrimental action a correctional system can take to deprive an inmate of a good death.

It is worth noting that visitation from the outside world can also upset dying inmates. Contact with family members in free society is especially stressful for inmates who are dying of terminal illnesses they contracted in prison such as Hepatitis or AIDS. In his book *Aging Prisoners: Crisis in American Corrections*, Ronald H. Aday explains how relationships with family members who are not incarcerated, can create a great deal of anxiety for the dying prisoner, “Research discovered that some older offenders prefer not to have frequent visits and rely more on letter and phone calls to stay in touch with family members. For these inmates, it becomes easier to do the time by maintaining a degree of social distance from their families and the outside world” (Aday 182-183).⁶⁴ This social distance is a kind of coping mechanism for the incarcerated patient – a way for him to avoid the fact that he is unable to fulfill their familial role because of his incarceration. In his research, Ronald H. Aday discovered that older female inmates had a particularly difficult time coming to terms with their inability to be

⁶⁴ This qualitative statement was deduced from a statistical study conducted in 2001 by both the author and P. Nation in *A Case Study of Older Female Offenders* for the Tennessee Department of Corrections in Nashville, Tennessee. The researchers also discovered that, while only about ten percent of the participants interviewed received weekly visits from family members, ninety-three percent assured the researchers that they stayed in contact with family members, including seventy percent who regularly spoke on the phone with their family members (Aday and Nation).

“proper” mothers or grandmothers and, as a result, preferred to distance themselves from their children and grandchildren (Aday 182).

The fact remains that, despite complicated relationships or feelings about interactions with one’s family, the prisoner still needs and deserves a certain amount of family involvement, especially in the dying process. Even when family members who exist in free society have become estranged, inmates sometimes turn to a strong network of fellow inmates. These other offenders become part of a prison family that cannot only offer support, but also a deep understanding of what it is like to live and die behind bars.

Prison Families:
Blurring the Lines Between Relative and Friend

The line between relative and friend can become blurred in prison, especially when an inmate is facing the possibility of dying behind bars. Much like regular family members, the prison family becomes an advocate or companion for the dying prisoner. Prison friendships can also help inmates adjust to their life and future in prison more easily. While members of a prison family are not blood relatives, their constant support and empathy for one another can be very comforting when facing death in a correctional setting.

Once again, however, some inmates find it difficult or are unwilling to forge important relationships with other prisoners. As Ronald H. Aday explains, “As important as friends make be for the establishment of a supportive social network in the confines of prison, not all older inmates are able to find suitable

friends who provide companionship. Some older offenders are cautious about forming extremely close friendships” (Aday184). Mistrust and cautious behavior is only amplified and aggravated by the institutional environment of a correctional facility. While friendships or family relationships are easy to create and nurture in free society, the prison setting makes it very difficult to not only cultivate but to also create trust – something an inmate needs when dying behind bars.

If prison hospice programs are going to become a reality, the complicated relationships that surround the concept and idea of family need to change. Too often inmates feel like their situation as a prisoner is what dictates their role in society. This is perpetuated by the public view of the prisoner as a convict rather than a human being. Once again the concept of understanding and empathy are presented as partial solutions to helping an inmate achieve a better death behind bars. If offenders dying in correctional hospice programs felt understood by their families, fellow prisoners, prison personnel and, most importantly, hospice administrators, perhaps these prisoners would feel more comfortable making long-lasting friendships behind bars or allowing their families to occasionally visit.

The Volunteer – A Means of Extending the Prisoner’s Voice

Being a hospice volunteer brought out qualities that I never thought I had. I grew up in a lot of dysfunction. I didn't know what it was to love and to be loved. This program has really taught me how to be a companion to someone; it's taught me great communication skills; most of all it's taught me compassion and how to care for people.
– Dawn Sheppard⁶⁵

⁶⁵ Dawn Sheppard is an inmate hospice volunteer at Federal Medical Center-Carswell in Fort Worth, Texas. This quote is an excerpt from her speech *Learning to Love: Reflections of an Inmate Volunteer* delivered at the Hospice Forum in Dallas, Texas, on November 13, 1998. She

One of the best examples of hospice programs in prison trying to make the dying patient feel more accepted and comfortable about their circumstances is evidenced by the role of the inmate hospice volunteer. These volunteers not only give their fellow inmate's a voice, but are able to adequately and easily understand and create a trusting bond with the hospice patient. Volunteers can also help the inmate to understand certain medical terminology and advanced directives without causing the patient to feel the familiar skepticism when it comes to health care in a correctional setting. Volunteers are not only advocates for their patients, they also represent a powerful initiative in prison hospice programs. Inmate volunteers reject the concept of the total institution in the sense that they are prisoners who demand the understanding and support of the public. Even so, prison facilities have found a way to hinder the role of the inmate volunteer by imposing an overwhelming amount of security measures and requirements. Still, as Heath C. Hoffman and George C. Dickerson explain:

Inmate volunteers are the "heart of the program." The inmate caregiver has the double benefit of being identified by the patient as knowledgeable but not having the professional status that can manifest social distance. By being a stranger who provides a listening ear, without emotional involvements or professional entanglements, the volunteer can support the patient as can no other participant in the social network of dying – they serve as "stranger an friend" at the same time. The benefits extend beyond the patient to the caregivers who have evidenced increased feelings of compassion towards others as well as increased self-esteem (Hoffman and Dickinson 6).

was the only inmate to attend and speak about her experiences as an inmate hospice volunteer. The Hospice Forum was held as a part of the 1998 National Hospice Organization's Annual Symposium and Exhibition.

Inmate volunteers avoid the punishable prisoner stereotype by compassionately caring for others. In the process, they also achieve the act of humanizing the dying inmate and therefore, demanding a certain level of understanding and empathy from free society. It is extremely difficult to understand the wrongdoing of an incarcerated individual, but it is even more difficult to comprehend punishing the prisoner living out a terminal-illness.

Although the dying inmate's voice is often difficult to uncover, the voices of the hospice volunteers that care for their fellow prisoners are innumerable. The anonymous inmate interviewed by Linder and Myers expressed his gratitude for a fellow inmate who served as a hospice volunteer during the anonymous prisoner's dying process: "It makes it pretty handy, him [the hospice volunteer] being a fellow inmate because he can come in and talk to me fairly regularly... We can talk about different religious things... How I feel about this disease I got, how I can cope with it, how I can handle it" (Linder and Myers 899). Having another inmate to look to for strength and comfort is another vehicle for the prisoner's voice and testimony. Having someone who understands and supports the inmates' voice and background is even more invaluable.

Inmate hospice volunteers are able to meet some of the smallest yet most important needs of prison hospice patients. A. Siobhan Thompson, author of the article, "Caring for Prisoner Inmates the Hospice Way," shows her readers how prison hospice care goes beyond providing the menial tasks of medical care. Thompson describes an inmate who had extremely basic needs: "He wanted

company, to pray with someone, have someone read to him, to listen to his talk about the troubles of days gone by, to look his best and feel supported [by hospice volunteers] when his daughter visited.”⁶⁶ Incarcerated hospice volunteers give their time and support to ensure that their patients are able to die with dignity. They not only help their fellow prisoner feel at peace, but also help to find a voice for their patients and give testimony on their behalf. One inmate recounted to Thompson the act of volunteering, stating, “Experiencing the death of a client that had passed gave me the feeling of courage and gratification, unconditional acceptance and appreciation” (Thompson 376). Incarcerated volunteers watch over their patients, demonstrating the basic human quality of compassion, and embodying the notion that even prisoners are human beings.

In a way, volunteers have become the voice of the dying prisoner, an extension of their fellow inmate. Sherman Parker is a 100 year-old prisoner at Dick Connor Correctional Center in Oklahoma. Sherman has one leg and suffers from severe dementia but a murder charge means that he will definitely die behind bars. Although Sherman can neither remember his crime nor commit new ones, he is forced to live out the rest of his life in prison. Seth Anderson, another inmate at Dick Connor – and a hospice volunteer – has become a dedicated caretaker of Sherman Parker. He has also become an important voice of advocacy on Parker’s behalf. When asked by the documentary filmmakers of *Fault Lines: Dying Inside*, whether or not he should be released, all Parker could say was, “I

⁶⁶ Siobhan A. Thompson, "Caring for Prisoner Inmates the Hospice Way," *Illness, Crisis and Loss* 17, no. 4 (2009): 374-375.

don't need to be here. I need to be on the farm, that's where I was born and raised. That's all I know" (*Fault Lines*). Volunteer and fellow inmate Seth Anderson provided a more complete answer: "He's 100, almost 101 years old, you know what I mean? I think he's served a life, you know what I mean? He's a century old, he served his life, let him go . . . [He] can't harm nobody else, [he] can't harm [himself]. You know what I mean? There's no sense in [him] being here" (*Fault Lines*). Seth Anderson speaks when Sherman Parker cannot. He becomes an invaluable source of support for Sherman Parker by providing testimony. This is part of the reason why inmate hospice volunteers are so vital to prison hospice programs. They are the main reason why people like Sherman Parker have a chance at death with dignity. They restore voice and autonomy and represent a kind of family in a place that demands structure and uniformity. Even though Sherman Parker will never make it out of prison alive, Seth Anderson will not only remember Sherman, but also will also tell his story and preserve Sherman Parker's memory – Seth Anderson will become Sherman Parker's voice.

The story of the relationship between Seth Anderson and Sherman Parker demonstrates how the hospice volunteer and the patient can become intertwined and eventually indistinguishable. Robert Newman, inmate number 286040, is being held at Angola Prison in Angola, Louisiana where he is dying from AIDS and hepatitis C. Although he will die in prison, Newman takes solace in the fact that he has fellow inmates to take care of him. He spoke with Sheryl Gay Stolberg, a New York Times reporter, about the comfort hospice volunteers bring

him, stating, “I believe you should go natural, when it’s your time to go...But it sure is nice to know that somebody is caring about you when you die. It takes a lot of the pressure off.”⁶⁷ The “pressure” Newman refers to is the pressure of dying with dignity. Having fellow inmates to give Newman what he needs to die peacefully as well as to speak on his behalf, allows the sick or dying inmate to realize that he and his memory are well taken care of. Multiple “pressures” of dying are relieved and the end of life is made bearable.

Prison hospice programs have given volunteers a space to assert their own voice and feelings. Stolberg also interviewed an inmate named Michael Shulark, a convicted murderer and a trained hospice volunteer. But Michael Shulark’s time as a hospice volunteer has given him something immeasurable: the ability to care for others. He describes his role and his changed outlook on life: “Instead of always wanting something, I’m giving something” (Stolberg 2). Michael Shulark has been given a new lease on life. He even went as far as to use his newly found skills to reach out to estranged family members: “I got my daughter back because of this program. She had never heard nothing good about me” (Stolberg 2). The prison hospice program at Angola Prison has given Shulark the opportunity to renew relationships and has inspired him to find his own voice and his own purpose, even within the confines of a maximum-security prison – a completely institutionalized environment. The hospice volunteer program at Angola has

⁶⁷ Sheryl Stolberg, "Behind Bars, New Effort to Care for the Dying," *The New York Times*, April 1, 2001, sec. Health.

helped inmates, like Michael Shulark, to discover their voice and to speak and advocate for the voices and testimonies of their patients and clients.

Where the total institution of prison is concerned – where one’s autonomous voice is silenced and choice is not an option – having volunteers as an extension of a patient’s hopes and suffering is vital. Whether it is a last confession to a family member, or trying to reach out for simple needs, volunteers have played an integral role in restoring voice and carrying on the memory of patients who have reached the end of their life in hospice. In a very real way they become a family and a community, caring for one another and creating a patient-centered initiative in an environment that is very much centered on security and the institution (Maull 478). Angola Prison is home to one of the most comprehensive prison hospice programs in the country. Its commitment to voice, community and comfort is epitomized in its coffin production for hospice patients. As Eugene Redwine, a seventy-three year-old inmate who has been at Angola prison for over twenty-eight years described, “One of these [coffins reserved for hospice patients] is going to be for me someday” (Stolberg 3). Thanks to the volunteers of prison hospice programs these coffins no longer represent uniformity, but can represent a unity and solidarity. These coffins are the representation of how a community comes together, even under the most complicated and complex circumstances.

Advanced Directives

Even with volunteers to help them, the lack of autonomous voice puts inmates at a greater disadvantage than those in regular hospice programs. It is important to emphasize the importance of volunteer advocacy because it so greatly affects both prisoners. The aspect of advocating for the patient in prison hospice by fellow volunteers is crucial in correctional end-of-life care since there is very little documentation of the patient's personal testimony or autonomous voice in prison hospice. A place where the help of volunteers cannot relieve the disparities in choice and voice, however, can be found in the form of the advanced directive. Advanced directives allow one to convey their end-of-life decisions in the event that they are unable to articulate their final wishes. In other words, advanced directives represent a freedom of choice. This individualized decision-making process has not only come an intricate part of death in America, in some ways it has also become the definition of a good death. A physician interviewed by Linder and Miller who asked to remain anonymous described how an inmate's "choice" to obtain an Advanced Directive can be clouded and very much affected by structural factors such as education, race and drug use:

Most of our guys are not real sophisticated folk, and I'd say the majority of them have the feeling that when they get sick, we ought to do something to cure them...A better educated middle-class American might soon realize that this a case where cure is not possible. [Inmates] tend to come to the conclusion a little bit slowly. They tend also to be a little bit distrustful of you when you do say that. Their first thought is that the department just doesn't want to spend the money (Myers and Linder 899).

In the absence of a strong autonomous voice in many aspects of their care, inmates rely on what they know to assert what little choice they have. Their lack of education on the matter however, along with a general mistrust in physicians and their practices, can cause inmates who are reaching the end of their life to make uninformed decisions. The sympathetic words of this anonymous physician demonstrate how class and social hierarchy can affect education one receives about health care and hospice. Education can therefore influence the autonomous choices of a prisoner. In a way advanced directives illustrate a chain reaction of how class and structural factors affect a patient's ability to have a dignified death.

Furthermore, introducing an autonomous decision-making process into correctional facilities raises difficult ethical questions. Hospice care in a correctional setting already contradicts a prison's totalitarian structure. To effectively enforce the concept of an advanced directive as an essential part of palliative care is a challenge that the Prison may not be able to overcome. In other words, autonomous medical decisions may never become an aspect of prison hospice, no matter how important they may be to their success.

In spite of the fact that we have made great advances in the hospice movement, any prison inmate could argue that the United States correctional system has barely skimmed the surface of hospice in a correctional setting. Medically and philosophically, hospice has made leaps and bounds to create a balance between helping make a patient comfortable, while not extending life. Socially, however, hospice has fallen into the trap in which much of America's

healthcare system finds itself: being totally accessible to only a small fraction of the population. In 1997, the American Medical Association conducted a national poll in which only 35% of American citizens were familiar with the phrase, “hospice.” And although the National Hospice and Palliative Care Organization has gone to great lengths to facilitate an open and equal discussion about hospice, the facts still remain: people who are uneducated about hospice do not trust or use hospice. Federal and state prison inmates are prime examples.

In her article “The Collision of Confinement and Care: End-of-Life Care in Prisons and Jails,” Nancy Neveloff Dubler describes the connection and the collision between an inmate’s personal experiences and their willingness to trust advanced directives. “Patients who are old, of color, injection drug users, or infected with HIV are especially suspicious of the systems in which they receive care . . . Many people who decline to execute Advanced Directives see them not as a support for care, but as a part of a systemic denial of care”(Dubler 149). The age, race, medical history or educational background of a patient should not dictate how they die. Although it seems like inmates are choosing whether or not they would like extraordinary measures to be taken to ensure they are kept alive, their reasoning behind choosing an advanced directive demonstrates that they are making decisions out of fear and suspicion, rather than out of informed and autonomous choice.

Advanced directives represent a larger issue in prison hospice. Dubler explains, “At a time when society is finally directing attention to the importance

of active palliation for terminally ill patients in hospitals and at home, it is still turning its face away from those it punishes” (Dubler 149-150). Although the American public has begun to place a greater emphasis on hospice care and informed medical consent through the Patient Self Determination Act of 1990, the voice and choices of inmates in end-of-life care are much more complicated than one would think. However, even if the prison system and American public have turned a blind eye to the inmate population’s voice and needs, volunteers and dedicated historians are making a valiant effort to correct the injustices and lack of autonomous voice. Still, the quality of life must be improved across the board in the American prison system – volunteers and activists can only do so much to provide short-term solutions to such a wide-ranged infrastructural problem.

One quickly learns that even though there is a need for an autonomous patient voice in end-of-life care, it is often ignored in a correctional setting due to the nature of the total institution and the fact that many prison and jail systems consider autonomy a luxury that no convict should be allowed enjoy. Thankfully, volunteers and supporters of prison hospice have begun to advocate for the voice of the inmate in a way that could dramatically change and even save the future of prison hospice. More than ever the duality of the inmate and hospice volunteer is invaluable to the complicated balance between a security-centered institution and a patient centered death. Even with the education of the American public in combination of certain voices being heard from researchers, volunteers and documentary filmmakers, the United States correctional system continues to work

against the autonomous choices of the inmate. If the American public and criminal justice system do not begin to acknowledge this and put the inmate's voice first, especially in hospice care, inmates in the United States will continue to lack access to a humane death.

ACHIEVING A COLLECTIVE “UBUNTU”

"Ubuntu . . . speaks of the very essence of being human. [We] say . . . "Hey, so-and-so has ubuntu." Then you are generous, you are hospitable, you are friendly and caring and compassionate. You share what you have. It is to say, "My humanity is caught up, is inextricably bound up, in yours." We belong in a bundle of life. We say, "A person is a person through other persons." – Desmond Tutu No Future Without Forgiveness⁶⁸

When I began researching prison hospice in early September, I understood the difficult task that lay ahead of me. By advocating for prisoners, by arguing that every American inmate has the right to comprehensive end-of-life care, I knew that I was risking opposition. Those that oppose giving prisoners access to a good death reflect the majority national opinion, which is committed to “tough on crime” politics and legislation: Death behind bars is a well-deserved punishment, and each inmate’s suffering is a victory for America’s criminal justice system. This denouncement of the prisoner as a criminal is not only justified in American society, it is encouraged. According to *The Pew Center on the States*, the US prison population has tripled in the last twenty years (Warren et al. 5). These rising incarceration rates give the American public a sense of security, which perpetuates a cycle of poverty, structural violence and inequality. Further, these correctional facilities are home to two medically-demanding groups: the elderly, and repeat drug offenders. While these two categories of prisoners creates a demand for advanced end-of-life care, their routine medical

⁶⁸Desmond Tutu, *No Future Without Forgiveness* (London: Rider, 2009), 34-35.

needs are also ignored by prison personnel. The advent of prison privatization will only aggravate inmate mistreatment by removing the remaining public accountability that ties the American people to its correctional facilities. If we do not act soon, the future of aging and dying prisoners will be as uncertain as the fate of a national prison system that merely warehouses its offenders.

To say that many scholars and social activists are troubled by the current state of America's incarceration crisis is an understatement. With one in one hundred adults behind bars in the United States, the national incarceration rate shows no signs of slowing or stopping. There is a multitude of reasons why almost one-percent of the adult American population is behind bars. While I have touched upon a number of explanations for why so many offenders find themselves living and dying behind bars, I would like to stress only one: That we, as a nation, have lost our *ubuntu*.

As Desmond Tutu in his book *No Future Without Forgiveness* describes, "My humanity is caught up, is inextricably bound up, in yours . . . A person is a person through other persons" (Tutu 34-35). Reading this quote and reflecting on the research I have done this year, I wonder where America's *ubuntu* has gone. I do not see humanity in the death of an anonymous inmate chained to a bed. Nor do I find humanity in the death of Sherman Parker, an inmate with such severe dementia he could not even remember the crime he committed. I do not see *ubuntu* in the totalitarian philosophy embodied in America's prisons, but I do see an opportunity to reclaim it.

Prison hospice is not only an opportunity to give individuals a good death behind bars, it is also a catalyst for improving the entire infrastructure of America's correctional system. To allow an inmate to access comprehensive end-of-life behind bars, is to see him as a person, a human being that deserves compassion and understanding. For some, this call for drastic reform seems out of reach or overly idealistic. What these individuals do not understand is the very real steps that prisons across the country are become increasingly flexible to instigate effective prison hospice programs.

The inmate hospice volunteer is perhaps the greatest example of this willingness to change infrastructure to accommodate dying inmates. These inmate volunteers do not only comfort their fellow prisoner but also serve as an advocate, and extension of the dying prisoner's voice. Volunteers emphasize the importance of the patient's choices, needs and wants. They represent the crucial key to success in both prison hospice as well as end-of-life care in normal society: the autonomous voice of the dying patient. Prison hospice volunteers possess the humanity America is missing; they find enjoyment in helping others, and comfort in expressing their compassion for the sick and dying.

Like the inmate volunteer, prison hospice sets a standard of compassion and understanding. America can no longer afford to render the inmate a nameless number or a voiceless statistic. If we intend to change the life of the prisoner, we must start at death and work backwards. Giving inmates access to a good death

behind bars is the first step towards achieving a collective *ubuntu*, and creating a better future for America's inmates.

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