

End of Life Services and Incarceration: An Analysis of Current Policy and Services

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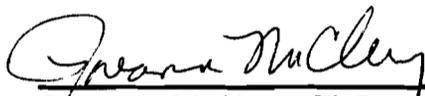
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This project has been accepted on behalf of the Department of Social Work by her faculty supervisor.



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Abstract

The purpose of this project was to provide members of the California Senior Legislature information relevant to end-of-life services in correctional institutions. This information will be used to shape policies that ensure correctional end-of-life care is commiserate with community standards as mandated by the 1996 American Correctional Association.

Integration of community standards in program design ensures protection of fundamental human rights. A thorough review and analysis of current policies and services areas requiring further development were identified and recommendations offered.

Chapter 1

Introduction

Death is the universal equalizer. While anyone can die at any age, it is more likely in aging populations and those with chronic illnesses. During the end-of-life period, if symptoms related to aging decline and chronic illnesses are managed, quality of life is enhanced. Often caring for the dying includes significant others within the individual's life. Quality of life for both the dying person and his or her significant others has been shown to improve when end-of-life care is consistent with what the patient and his or her significant other deem important, making them both vital members of the treatment team. Treatment for dying individuals requires more than medical care. It involves the psychological, spiritual, social, and emotional consequences of dying for both the individual and those involved in their lives (Miller & Ryndes, 2005).

Very few would debate the provision of compassionate end-of-life services for individuals in society regardless of their socioeconomic status or societal position. However, one group, incarcerated individuals, is stigmatized in society because of their deviance to social norms. Some may believe that individuals with life limiting conditions or disabilities, regardless of their incarceration status, may invoke compassionate response in others. However, research has indicated that individuals with disabilities can serve to increase the negative sanctions in those already stigmatized. It is possible that deviance is then amplified in individuals with disabilities (Stiles & Kaplan, 1996). Individuals that are determined to be criminally deviant are incarcerated in facilities to incapacitate them. Accordingly, they are dependent on the system to meet all basic needs of food, shelter, and safety. Because some of these individuals will be removed from society for a timeframe that will include the duration

of their lifespan, the focus must then shift to what end-of-life services the correctional system is obligated to provide.

Purpose of This Project

The purpose of this project is to inform members of the California Senior Legislature of issues related to end-of-life care within correctional institutions that may provide guidance for future legislative recommendations. The project involved an analysis of current policy and services/programs that are related to end of life care in the prison system. The issue is presented and defined, with historical and other relevant information through a thorough literature review. An analysis of current policies and practices was conducted, including interviews with stakeholders to establish the logistics and effectiveness of current end of life services, as well as to establish recommendations for ongoing services.

Legislative accountability cannot be achieved without reaching a relative balance between rights to basic liberties, health, and nondiscrimination. For law abiding individuals this extends to political participation and education, as well (Gruskin & Daniels, 2008). Inmates, by nature of their incapacitation, are restrained from exercising their rights to political participation. Furthermore, inmates are prevented from exercising their right of freedom of association and liberty. Prisoners, are similar to other fringe groups like frail elderly, and refugees, are often denied “human” rights (Ife, 2001). However, conviction and incarceration do not negate basic human rights. Accordingly, this project integrates a human rights perspective, as it can serve as guidance to the economic, social, cultural and political factors that must be addressed in highlighting government accountability in the provision of health services for vulnerable populations, namely incarcerated individuals. Such a

perspective serves to legitimize proposals, such as this, that seek to distribute justice (Gruskin & Daniels, 2008).

Chapter 2

Literature Review

While correctional hospice programs occur within institutions, seemingly affecting a relatively small portion of society, implications for services are shaped by components of history, politics, and human rights. The literature related to correctional hospice programs is relatively minimal; however, context can be established by understanding the historical developments that led to such practices. For the purposes of this project, the researcher presents the hospice philosophy, corrections, and the incorporation of the two.

History of the Hospice Movement

The Latin word *hospes* is the root for the words “hospital” and “hospice.” In medieval times hospitals and hospices were one and the same. These institutions were generally run by religious orders and provided a haven for the sick and dying, women in labor, as well as the needy and travelers. During this time period, life and death were viewed as part of the same mortal process and travelers were housed with terminally ill individuals. Workers that neglected individuals in their care were whipped and condemned to eat bread and water for a week. As monasteries were forced to close during the reformation, hospices, also closed (Buckingham & Hurzeler, 1996).

During the Enlightenment, the term “infirmary” became more commonly used to describe institutions for individuals with medical needs. This was an attempt to eliminate the prior association to institutions providing care to the needy and remove stigma to individuals seeking care. Admissions were based on criteria that included the reasonable expectation that the person’s condition would improve. Individuals determined to be suffering with life limiting, or chronic conditions were most often cared for in their homes (Risse, 1999).

Homes for the dying, hospices, returned to popular culture in the 19th Century, and again were religious in nature (Buckingham & Hurzeler, 1996).

More recently when an individual was found to be in a terminal condition family, friends, even children were invited in to offer their final wishes to the dying person. Elisabeth Kubler-Ross (1969), a medical doctor, psychiatrist, and internationally recognized expert on death and dying, believed customs such as this contributed to the human acceptance of the death and provided a level of peace to the dying individual and those that loved them.

Widespread advances in medicine served to shift the focus to quality of life, at least in the United States and Western Europe. The shift altered not only morbidity and mortality, but also popular culture. Where once individuals were not expected to live past early adulthood, there are increasing numbers of individuals living to 100 (Boston University School of Medicine, 2011). With this comes increasing number of conditions associated with old age. Kubler-Ross (1969) found that the medical advances did not lead to an acceptance of mortality, but rather increased the level of fear and denial of death.

Dame Cicely Saunders, of England, trained as a nurse, medical social worker, and physician. In the late 1940's she met a man in his 40's that was dying of cancer in a hospital ward. A flaw in end-of-life care within a hospital setting is the inappropriateness of the environment. Hospital settings are governed by protocols and policies focused toward curing patients. The two of them talked of a place where people could die with dignity, and through their conversations the idea of building such a place was born. (Buckingham & Hurzeler, 1996). Dame Saunders believed in end-of-life care that was focused on providing for the everyday need of the dying individual, while minimizing symptoms, and lectured widely on the topic, wrote articles, and contributed to books (St. Christopher's Hospice, n.d.). Queen

Elizabeth II honored her with the title of Dame in recognition of her work (Buckingham & Hurzeler, 1996).

In 1967, Dame Cicely Saunders started the St. Christopher's Hospice in England. It was the first institution of its kind to focus on palliative care, symptom reduction, and provide clinical research (St. Christopher's Hospice, n.d.). Since the 1970's, caring for the dying has been institutionalized through the hospice movement (Gehlert & Browne, 2006). Within the hospice modality, a change from curative treatment of disease processes to palliative or comfort care has evolved. Originally, St. Christopher's Hospice worked only with cancer patients but continued to expand services, eventually including the Domiciliary Service Program which offered in home assistance to families, and provided education to staff, students, and volunteers. The Program is in existence today and no one is turned away for inability to pay. Bereaved families are provided services in their homes by trained staff and volunteers (Buckingham & Hurzeler, 1996).

Hospice was introduced in the United States by Dame Cicely Saunders, who presented the concept to medical faculty at Yale University in the early 1960s. The approach she presented was that of providing symptom relief for dying individuals. In the audience was the Dean of Yale School of Nursing, Florence Wald. Wald traveled to England in 1968 to work at St. Christopher's Hospice (National Hospice and Palliative Care Organization, n.d.). Based on Wald's subsequent work and other concurrent efforts, the U.S. approach to death and dying began to change (Remington & Wakim, 2010). In 1969, Elisabeth Kubler-Ross published her groundbreaking book, *On Death and Dying*, in which she presented the concept of returning the dying to the home and making it less institutionalized (National Hospice and Palliative Care Organization, n.d.).

In 1972, Kubler-Ross testified at the first national hearings on the subject of death with dignity before the US Senate Special Committee on Aging. At this time she advocated publicly for the deinstitutionalization of the dying process. In 1974, the first hospice legislation was introduced but did not pass (National Hospice and Palliative Care Organization, n.d.).

There was a distinct difference in the hospice services introduced in the United States as the emphasis was placed on providing care in the home rather than in institutions as had been done in the United Kingdom. This difference is significant in that it was shaped by the US desire for independence, a mistrust of medical institutions, and a lack of resources of nonprofit hospice groups that were seen to be working outside of the medical norm (Connor, 2007-2008).

Initially, hospice was characterized as being an anti-doctor modality of providing care. However, in addition to chaplains, nurses, and psychosocial professionals, physicians were involved in the early hospice movement in the US voicing concern for the lack of care and attention dying patients were receiving within the traditional medical system. Another significant element of hospice, which is still in place today, was the use of volunteers. Hospice has become increasingly accepted within the medical system (Connor, 2007-2008). The treatment for the terminally ill designed by Dame Cicely Saunders evolved into a recognized medical specialty (Remington & Wakim, 2010). The American Board of Medical Specialties has approved hospice and palliative care as an accepted sub-specialty, with practitioners in a variety of specialties being allowed to incorporate it (Connor, 2007-2008).

Managing pain is a priority in hospice and palliative care services. Pain is experienced differently by different people. Many believe that pain is what the patient says

hurts. Dame Cicely Saunders used the term “total pain” to describe the multifaceted effects of pain addressed in palliative care. This is not to say that pain is psychosomatic, but rather that the emotional and social effects of pain can make it more challenging to cope with (Bass, 2010). Acute pain is often associated with physiological indicators such as increased blood pressure and heart rate. Chronic pain is not associated with such changes, and without these indicators can be mistaken for misreport by the patient (Gehlert & Browne, 2006).

The terms “hospice” and “palliative care” are often used interchangeably. However, most literally, hospice is accepted as services provided to patients with an estimated life expectancy of six months or less. Palliative care can be provided throughout the course of illness, at times in conjunction with curative therapies such as radiation and chemotherapy. Palliative care plans often include the referral to hospice when death becomes imminent (Gehlert & Browne, 2006). In short, hospice always includes palliative care, but palliative care does not necessarily indicate hospice. An increasing number of hospice programs are implementing an “open access” policy that allows patients with limited prognoses to be admitted to hospice without regard to their treatment choices (Connor, 2007-2008, p. 95).

The first Standards of a Hospice Program of Care were published in 1970 by the National Hospice Organization. This group would later become known as the National Hospice and Palliative Care Organization (Connor, 2007-2008). Palliative care is holistic management and support for individuals with terminal illnesses and their families. The primary goal is to meet the psychological, spiritual social, spiritual, and physical symptoms experienced by the patient with an emphasis on a good death and bereavement care to loved ones (Bass, 2010). While the general acceptance of hospice and palliative care services is

limited to end-of-life care, palliative care could reasonably be extended to caring for individuals receiving treatment for many illnesses and conditions (Connor, 2007-2008).

The National Association of Social Workers (2004) has established standards for social workers in palliative and end-of-life care in addition to offering a credential as a hospice and palliative care social worker (CHP-SW). This lends support to the legitimacy of this as a specialty practice area as well as offering clear practice standards. Hospice services are covered by public funding sources such as Medicare and Medicaid, as well as by many private health insurance plans (Gehlert & Browne, 2006). The Hospice Medicare Benefit (HMB) was established in 1982 and was the only Medicare benefit added during the Reagan administration. This benefit was unique from others within the Medicare system because it reimbursed providers at a set per diem rate (Connor, 2007-2008). The professional codes of practice and inclusion of hospice into the Medicare entitlement structure further solidified that hospice is the standard by which to measure end-of-life care (Linder, Enders, Craig, Richardson, & Meyers, 2002). While hospice serves to provide total care to the dying, an additional goal of hospice care can be the conservation of resources by reducing unnecessary expenses during this phase of life. Because the focus is on palliative care, hospice programs have been successful at assisting patients to eliminate expensive costly treatments unless their goal is to end pain (Bushfield, 2005). While hospice care is often provided in the home, hospice care has been integrated into a variety of settings including correctional facilities.

Corrections

The criminal justice system of the United States provides an element of social control by providing consequences for actions deemed inappropriate. The system has influence over all members of society as it services to protect law abiding citizens, and punish those found

to be in violation of societal norms established in law (Depersis & Lewis, 2008). The colonial system was originally modeled after the British system where crimes often resulted in fines and banishment. More serious crimes or repeated offenses were likely to result in beatings and executions (Jacobi, 2005). While the element of making an example of criminals has always been present in the American system, the concept of rehabilitating criminals was not present early on, with many if not all, crimes warranting capital punishment (Depersis & Lewis, 2008). Correctional institutions were not for punishment, but rather were for holding individuals awaiting trial (Jacobi, 2005).

Correctional reform in the colonial period began by introducing the concept of imprisonment as a punishment for crimes which was justified by reformists as being a more humane means of dealing with criminal behavior (Jacobi, 2005). There was a focus on hard labor that would be considered harsh by modern day standards, but was a far cry from the British system. William Penn was instrumental in delivering a charter that transformed the American criminal justice system. It was this charter that established the jury of one's peers, and precautions before the implementation of the death penalty. However, when Penn died in 1718, the system reverted back to nearly all crimes being capital crimes. Jails were again used for short term holding of prisoners for trial (Depersis & Lewis, 2008).

In the post-revolutionary period states again turned away from the British system. Juries became reluctant to impose extreme penalties that did not seem congruent with the crime at hand. Again, prisons filled the void as a viable option for punitive consequences for criminals (Jacobi, 2005). The Quakers became instrumental in promoting the idea that effective punishment could be balanced with humane treatment, reflecting a human rights perspective. The Quakers sought a system in which the correctional system would help to

improve the inmate and return him to society in a better position to function productively. In 1790 the Quakers established the prison that would serve as the model for all prisons in the United States (Depersis & Lewis, 2008). A key goal of imprisonment was to serve as a deterrent of criminal behavior. Prison management was seen as unimportant because the deterrent would minimize the number of criminals and thus institutional logistics would be unimportant. The crime deterrent effect did not materialize, and prisons became overcrowded and prone to violence (Jacobi, 2005).

In the early 20th Century reformers again called for an end to the overcrowded deplorable conditions found in prisons. The idea of repairing the defects of criminal behavior shifted to the new disciplines of psychiatry and social work. The conceptual shift was to one of providing for inmate dignity, and self direction would ease the societal reintegration process. However, reform efforts were not widely received and the lack of support from the general public prevented significant progress. By the 1950's riots related to "inadequate medical care, unsanitary conditions, and overcrowding," returned the prison reform movement back to the same arguments present in the early 19th Century (Jacobi, 2005, p. 459).

Early prison reform efforts focused on a humanitarian approach to the handling of prisoners, however, by the mid-20th Century the paradigm shifted to the foundation that prisoners themselves were guaranteed individual Constitutional rights. This shift took the focus from dependence on the consciousness of the general public that humane treatment was a universally accepted concept, and placed the focus on legal definitions. However, legal definitions are shaped in part by the humanitarian efforts of all branches of government (Jacobi, 2005). The criminal justice system is viewed as crime control; crime control in the

United States is political in the way that it reflects and directs power distribution (Gottschalk, 2007). The increased use of the courts by prisoners and advocates to illicit reform caused another shift in political climate in which the courts have made it increasingly difficult for inmates to utilize the court system individually to pursue reform cases. Whatever humanitarian motivations are present in the argument of prison reform, they must be also met with financial resources for implementation. At a time when financial constraints are of national focus, prison reform can be increasingly challenging (Jacobi, 2005).

The United States has always incarcerated more individuals than democracies in Europe (Western, 2007). However, in recent years the divide has become more outstanding with US rates being 5 to 12 times higher than the rate of Western European countries and Japan (Gottschalk, 2007). From 1925 to 1974, United States prisons and jails incarcerated approximately 100 for every 100,000 residents. Following the Civil Rights era, increased crime rates and a realignment of race relations led to a focus on law and order that established itself in the push for, “mandatory minimum sentences, sentence enhancements for repeat offenders, and expanded prison capacity” (Western, 2007, p. 31).

The move toward deindustrialization of the 1970’s and 1980’s led to high levels of unskilled male workers at a time when policymakers were moving toward punitive practices. These two powerful influences resulted in a boom in prison populations (Western, 2007). The politics of mass incarceration are often attributed to conservative tough on crime policies. However, by the 1990’s both Republicans and Democrats had come together to support the tougher sentencing policies and increased prison construction campaigns that further enlarged the prison population (Western, 2007). Mandatory minimums and the requirement that prisoners serve at least 85% of their sentences became commonplace

policies. By 2004, there were 127,000 inmates serving life sentences in the United States (Delgado & Humm-Delgado, 2009).

Prisons also became a driving economic force. In some communities, especially small rural communities, prison institutions are the primary means of economic survival. Prison construction allows for these communities to benefit from the costs associated with building these institutions, and later with staffing the same institutions (Delgado & Humm-Delgado, 2009).

Recent years have seen the US incarceration rate escalate to 737 per 100,000 residents (Gottschalk, 2007). This combined with the number of people on probation and parole creates a rate of state supervision that far exceeds any other timeframe in United States history (Gottschalk, 2007). Recent economic hardships have led some to believe that prison reform can be instigated as means of fiscal control. Many prison costs are fixed and do not lend themselves to significant budget cuts. Many cuts are symbolic in response to public outcry to limit luxuries provided to inmates. Often the cuts are related to the provision of healthcare screening and services, such as palliative care and hospice, for inmates (Gottschalk, 2007).

Correctional Healthcare

The over two million people incarcerated in the United States are more likely to be undereducated, poor, and sick. Many have received inadequate healthcare and come to prison with chronic diseases, communicable diseases, sexually transmitted infections, and mental illnesses (Jacobi, 2005). While some would argue that healthcare is a luxury that inmates have forfeited their right to, healthcare in prisons has far reaching consequences. Healthcare in prisons or the lack thereof, affects inmates, correctional staff, the families of both inmates

and staff and ultimately, the public at large as the majority of prisoners will be returned to the community (Delgado & Humm-Delgado, 2009). While the argument that equitable distribution of health resources, provides that individuals that have not broken the law are more deserving of services, a human rights perspective would indicate that the provision of care to inmates is for the greater good of the population as a whole (Gruskin & Daniels, 2008).

Medical services within corrections are shaped by influences not present in the general medical community. All medical needs must be weighed by security needs. In most correctional settings an inmate must request medical care to obtain even basic items such as over-the-counter remedies and band aids. This creates additional pressures on correctional medical staff. The correctional environment produces an influence over treatments that are conducive to delivery within the institutional setting (Rold, 2008). At times, prisoners that seek medical treatment can be labeled as faking symptoms for personal gain or creating their medical symptoms (Thompson, 2010). The added elements present in a correctional setting alter the doctor-patient relationship from what is experienced in the community. There is an inherent sense of mistrust present and a no options for seeking alternative medical professionals (Rold, 2008).

The health status of inmates entering the correctional system has declined over the last three decades (Delgado & Humm-Delgado, 2009). Incoming inmates have a disproportionately high rate of communicable diseases such as tuberculosis and hepatitis, as well as sexually transmitted infections (Jacobi, 2005). The rate of AIDS is three times higher for inmates than for individuals in the general public (Gottschalk, 2007). All chronic illness present in the general public are also present in the correctional system, including but not

limited to, heart disease, cancer, asthma, and diabetes. The National Commission on Correctional Health Care, as (as cited by Delgado & Humm-Delgado, 2009) estimates a diabetes rate of approximately 5% in inmates. Mortality and morbidity related to diabetes is compounded by special dietary needs generally not available in a correctional institution setting.

Aging in the Prison Population

Prison populations are also aging at a rate greater than the general United States population (Williams et al., 2009). The rapid decline of aging inmates can be contributed to a combination of multiple factors including poor health prior to entering the prison system due to poverty and/or lack of access, unhealthy lifestyles within the prison system, and stressful experiences within the prison system that may accelerate the aging process (Kerbs & Jolley, 2009). This can be attributed in part to longer sentences and the increased number of life sentences (Gottschalk, 2007). Inmates are generally considered “elderly” at the age of 55 which is lower than adults of the general population (Snyder, van Wormer, Chadha, & Jagers, 2009). Some research drops the number to as low as 50 (Kerbs & Jolley, 2009). This younger limit is often accepted for research purposes because elderly inmates have lower health status and shorter life expectancy (Snyder et al., 2009). Some estimates indicate that older adults will constitute one-third of inmates by the year 2030 (Kerbs & Jolley, 2009). Older inmates are a diverse group but are often divided for purposes of research as those in need of assistance with activities of daily living (ADLs) and those that are independent. Some have mobility limitations and require the use of assistive devices such as wheelchairs and walkers (Snyder, van Wormer, Chadha, & Jagers, 2009).

The healthcare needs of older inmates surpass that of their younger counterparts (Delgado & Humm-Delgado, 2009). Older adult inmates, on average, require more attention in the areas of chronic illness, nursing, diets, medications and physical therapy than their younger counterparts (Snyder et al., 2009). The most commonly reported health problems in older prisoners include, “arthritis, back problems, cardiovascular diseases, endocrine disorders, psychiatric conditions, respiratory diseases, sensory deficits (vision and hearing problems), and substance abuse” (Kerbs & Jolley, 2009, p. 121).

Death and Dying in a Prison Population

Death within prisons has been historically viewed in the light of ongoing criminal acts namely the murder of inmates by other inmates. Death is becoming increasingly commonplace in prisons. It is now estimated that approximately 2,500 to 3,000 US inmates will die of natural causes in prison annually (Delgado & Humm-Delgado, 2009). Data on deaths in prisons are not age specific, but facilities with a higher number of older inmates also report a higher number of deaths due to natural causes (Aday, 2006). Other contributing factors include more inmates with chronic health conditions and the introduction of AIDS to the prison system (Delgado & Humm-Delgado, 2009).

Byock (2002) states that, “Dying in prison is what inmates dread most” (Byock, 2002, p. 2). Prisons are punitive institutions with a focus on confinement. Sick inmates are often removed from the general population and placed in environments that are more restrictive. Such policies can exacerbate the sense of helplessness experienced by the dying. Inmates that die while incarcerated have typically spent a considerable amount of time alienated from society and often fear spending their final hours alone and in pain (Aday, 2006). Provision of support to dying inmates can be complicated by prison cultural attributes such as

aggressiveness. Security regulations enacted to prevent the diversion of narcotic pain medications may limit the access to such drugs which are instrumental in palliative care and hospice provision, and can further compound mistrust of correctional staff by inmates (Byock, 2002).

Correctional Healthcare Requirements

The Eighth Amendment became part of the Bill of Rights in 1791 and prohibits cruel and unusual punishment. Laws are defined by their interpretation, and in the earliest interpretations, the Eighth Amendment was viewed as preventing the infliction of torture. It was not until *Estelle v. Gamble* in 1976 that the Supreme Court found that by failing to provide healthcare to inmates, suffering that served no correctional purpose was being inflicted. It was at this time that the court developed the standard of, “deliberate indifference to serious medical needs,” to define the Constitutional responsibility to provide medical care (Rold, 2008, p. 13). This ruling was consistent with lower court rulings in the years leading up to *Estelle v. Gamble*. The application of *Estelle v. Gamble* has been such that a medical need does not have to be life threatening to be deemed serious. Pain constitutes serious medical need even if the experience of it does not make the underlying medical condition worse (American Civil Liberties Union [ACLU], 2005).

In 1972 the American Medical Association conducted a survey of correctional healthcare. The survey identified that in some institutions the only medical service available was first aid, and even this was not available in some institutions. The survey also identified that medical services in correctional institutions were often provided by unlicensed providers (Wright, 2008). The survey and establishment of correctional health services standards led to the development of a pilot health care project. This pilot program ultimately led to the

establishment of the National Commission on Correctional Health Care (Delgado & Humm-Delgado, 2009). The National Commission on Correctional Health Care is an independent nonprofit that provides standards that are recommendations for the management of correctional health care systems (National Commission on Correctional Health Care, n.d.). In 1983 the Supreme Court found in *Wellman v. Faulkner* that correctional institutions must provide, “a medical care system that meets minimal standards of adequacy” (Linder et al., 2002, p. 551). While the minimal standards of adequacy were not clearly defined by the Court, correctional institutions have come to measure adequacy by requiring facility health care to be equal to community standards (Linder et al., 2002).

After these cases, court rulings varied on whether the deliberate indifference was objective or subjective. In 1994 the Supreme Court determined in *Farmer v. Brennan* that in order to determine deliberate indifference, it must be proven that the defendant was aware of, and disregarded, substantial risk to an inmate’s health (Thompson, 2010). Rulings related to the Eighth Amendment require prisons to provide a system that provides offers adequate medical services (ACLU, 2005). In the United States, inmates are the only population with a constitutional right to health care (Delgado & Humm-Delgado, 2009).

California Department of Corrections and Rehabilitation

The California Department of Corrections was established in 1944. In a July, 2005, reorganization the term “rehabilitation” was added to emphasize the goal of addressing the needs of individuals reentering society after incarceration (California State Auditor, 2010). The Division of Adult Institutions (DAI) within the California Department of Corrections and Rehabilitation (CDCR) maintains, “33 adult institutions, 39 conservation camps, and 13 Community Correctional Facilities (CCFs) (California Department of Corrections and

Rehabilitation, 2009, p. 4) The CDCR currently has a facility population of over 162,000, which does not include individuals the Department is responsible for that are on parole. The average sentence for these inmates is approximately four years. However, there are almost 30,000 serving sentences of natural life, or life without the possibility of parole (CDCR, n.d.)

The California state prison system is the largest correctional system in the United States (Williams et al., 2006). It is also the most expensive correctional systems and is one of the least effective, with a recidivism rate of at least 70%. The 33 California correctional institutions were designed to house 84,271 inmates, and have been operating far above this for years (Stateman, 2009). The rated capacity of correctional institution is the maximum number of inmates a facility can house while providing the minimum level of safety and services. Some argue that such ratings can be assigned arbitrarily and changed as political climates change. Rated capacity can change based on staffing, physical layout changes, and program design. California has a set rate of 120% of design bed capacity, but has operated consistently above this level. Historically, California has paid subsidies to institutions operating above capacity; thus, California institution officials have transferred and retained inmates at a higher rate in an attempt to maintain funding and personnel (Bleich, 1989). In 2009 a federal court ordered the CDCR to reduce the number of inmates by at least 45,000 (Stateman, 2009).

Influences Specific to California

Until the mid-1970's the criminal justice system within California was one based on indeterminate sentencing for adult offenders. The authority for formal sentencing was divided between judges and the corrections department through the parole board. The judge provided the minimum sentence requirement, and the law provided the maximum term,

which was usually significantly greater than the minimum. This allowed a wide discretion that could be exercised on a case by case basis. In response to challenges that the indeterminate sentencing guidelines left room for unfair treatment, the California legislature passed regulations that restructured criminal sentencing in 1976. The changes reduced the number of indeterminate sentences, and limited the power of the parole board (Zimring, Hawkins, & Kamin, 2001).

The current practice within California is a mixture of sentencing systems. Indeterminate sentencing is used in sentencing serious crimes with high sentence maximums. A greater number of sentences are determinate sentencing with specific, designated sentences for lesser crimes (Zimring et al., 2001). In 1994 California enacted The Three Strikes Law to ensure longer sentences for an individual previously convicted of a felony. The Law generally imposes a 25 year to life sentence for individuals with two prior felony convictions (California State Auditor, 2010). The minimum time served under a third strike conviction is 20 years (Zimring et al., 2001). The sentencing expansions provided for in this Law exponentially multiplies the number of offenders within the system (Zimring et al., 2001). The increase in number of offenders and longer sentences of offenders translates into more individuals living with medical problems within the system, aging within the system, and dying within the system.

In February of 2010, Senate Bill 1399 (SB1399) was introduced. The goal of the bill was to provide the Secretary of the Department of Corrections and Rehabilitation with the authority to release individuals that were determined to be medically or mentally incapacitated to supervised parole. This is more commonly referred to as medical parole. By the time SB1399 was passed in September of 2010, it was revised to refer to individuals that

were permanently medically incapacitated. SB1399 indicates that individuals that are unable to provide for their own activities of daily living, require 24 hour care, and are currently experiencing a disability that was not present at the time of sentencing could be paroled to an environment that does not compromise public safety. However, individuals that are sentenced to life without parole, death or those with sentences for which parole is prevented by other statutes are excluded from consideration of medical parole (California Senate Legislation, n.d.). Such exclusion indicates that individuals will continue to die while incarcerated and thus require end-of-life services.

CDCR Healthcare

California state law requires that no health facility operate without a license from the Department of Health Services. In addition to licensing, a facility may be accredited. While licensing ensures that a facility provides care at a community standard, accreditation ensures that there is a system in place to provide services. The CDCR did not receive state licensing for any of its acute medical services until the California Men's Colony in San Luis Obispo obtained a license in 1989. That same year the legislature added the license category of "correctional treatment center" as outlined in the California Health and Safety Code, Division 2, Section 1250 (Nieto, 1998). Aside from pharmacy, dental, and psychiatric elements, patients treated in a California correctional treatment center must be admitted by a physician and discharged by a physician, and be provided a physical examination within 24 hours of admission along with other requirements (Puisis, 2006).

In 2001 the largest class action lawsuit of its kind was filed in California alleging that the CDCR was inflicting cruel and unusual punishment and was deliberately indifferent to serious medical problems experienced by inmates. An initial settlement was reached in 2002

(Prison Law Office, n.d.). Settlement details were not effectively carried out and in an Order to Show Cause dated May 10, 2005 Judge Thelton E. Henderson stated that inmates in the California system were subjected to “an unconstitutional system fraught with medical neglect and malfeasance” (Prison Law Office, n.d.).

Provisions for the California Department of Corrections and Rehabilitation operations and regulations are found in the California Code of Regulations (CCR) Title 15, Division 3, with Article 8 relating to health care services, and the Department Operations Manual (DOM) Chapter 9. The DOM includes sections related to do not resuscitate orders, but not hospice care at the end-of-life. CCR Title 15, Division 3, Article 8, Section indicates that treatment is curative in nature but does not preclude palliative care to eliminate pain (California Department of Corrections and Rehabilitation, n.d.). Therefore, no clear regulations exist that can be used to guide these services in this system.

Correctional Hospice

The American Correctional Association mandated in 1996 that correctional health care needs to be the equivalent of community standards and that compassionate release be utilized when appropriate (Wright & Bronstein, 2007). Hospice has been a community standard for terminally ill patients since the 1970's (Hoffman & Dickinson, 2010). The majority of correctional systems within the US have some form of compassionate release policy in place. However, only a minimal amount of inmates deemed medically appropriate are ever released under the existing policies (Craig & Ratcliff, 2002). For inmates that are not able to be released by means of compassionate release, hospice serves as a humane means of providing end-of-life care within the correctional setting (Wright & Bronstein, 2007).

Goals of prison hospice are comparable to those of hospice programs within the community. Prison hospice programs strive to provide dying inmates with effective pain management, while meeting spiritual, social, emotional, and physical needs (Wright & Bronstein, 2007). However, a community hospice program is patient centered, and a prison hospice program is institution centered based on the fact that the patient is required to complete a sentence within the criminal justice system (Chicowlas & Chen, 2010). Traditional hospice principles can be difficult to implement because of their contradictory nature to the hierarchal structure and philosophy of correctional institutions (Hoffman & Dickinson, 2010).

The first prison hospice opened in 1987 at the US Medical Center for Federal Prisoners in Springfield, Missouri, followed several months later by a hospice in the California Medical Facility in Vacaville (Hoffman & Dickinson, 2010). The programs developed in a response to the increasing number of AIDS related deaths within the institutions (Wright & Bronstein, 2007). Both initial programs utilized outside hospice resources to train prison staff and volunteers to work as interdisciplinary teams (Dawes, 2002). Within ten years, the National Institute of Corrections reported 28 institutions had existing hospice programs. More recently, the National Hospice and Palliative Care Organization (NHPCO) estimated that over 75 prison and jail jurisdictions operate hospice programs for terminally ill inmates (Hoffman & Dickinson, 2010). Hoffman and Dickinson (2010) identified 69 programs.

The Guiding Responsive Action for Corrections at the End of Life (GRACE) Project promotes end-of-life care for inmates within correctional settings. Utilizing the institutions identified by the National Institute of Corrections, the GRACE Project targeted diverse

settings for delivery of hospice services in prisons including services provided to individuals maintained in the general prison population, in prison medical wards, designated hospice beds, and within freestanding settings licensed as hospices (Ratcliff & Cohn, 2000). Drawn from the National Hospice Organization's "Standards for Hospice Practice" and following the format of the American Correctional Association's "performance based standards," the GRACE Project established a Standards for Practice in End-Of-Life-Care in Correctional Settings. There is a differentiation between a standard which GRACE Project uses to define a condition that is to be obtained, and a practice which defines an action (GRACE Project of Volunteers of America [GRACE], 2000). These standards are considered the ideal for delivering care within correctional systems, but the standards are not enforceable on their own (Hoffman & Dickinson, 2010).

While correctional hospice programs share the overarching goal of providing services to terminally ill inmates, the design and organization of such programs differs greatly (Wright & Bronstein, 2007). Typically, there are two general models of hospice delivery within correctional institutions. They are discrete units that involve specialized units often within the prison hospital unit, or a decentralized approach where hospice services are provided to the individual in place, similar to community hospice programs (Dawes, 2002). Hoffman and Dickinson (2010) surveyed 43 hospice programs. Of the programs evaluated only nine facilities had an unlimited number of beds designated for hospice care. The greater majority could only accommodate between one and nine patients at a time (Hoffman & Dickinson, 2010). Regardless of capacity, programs are generally centered on a core set of services that include detailed care planning including pain management, visitation, and companionship provided by both staff and volunteers (Wright & Bronstein, 2007).

A key standard of practice identified by the GRACE Project is the utilization of the Interdisciplinary Team (IDT) (GRACE, 2000). IDT members can incorporate a variety of treatment professionals but generally include physicians, nurses, pharmacists, social workers, clergy, mental health professionals, dieticians, and in the case of correctional institutions prison staff. IDT's meet regularly to discuss patient care and develop a plan of action. Correctional staff can be vital members of the treatment team, not only to ensure safety of all members of the team, but also to ensure timely movement of the inmate patient and inmate volunteers into treatment areas (Wright & Bronstein, 2007). The GRACE Project standards of practice indicate that a correctional hospice IDT should meet at least every two weeks to appropriately coordinate care (GRACE, 2000). Hoffman and Dickinson (2010) found that all but one of the programs they surveyed provided care utilizing the interdisciplinary team (IDT) approach. Contrary to typical community hospice practice, and despite the very personal nature of end-of-life care, only 57% of the programs surveyed included the patient as part of the team.

The GRACE Project standards do not specify where the recruitment of volunteers should occur only that volunteers, whether inmates or not, should be appropriately trained (GRACE, 2000). The majority of prison hospice programs utilize volunteers which is consistent with the foundations of community hospice programs. However, unique to prison hospice programs is the use of inmates currently remanded to correctional institutions to provide the volunteer services. Training of such volunteers varies by institutions but generally requires a greater number of hours than training for volunteers in community hospice programs. Selection criteria for volunteers varies by jurisdiction, but most require potential inmate volunteers not be convicted of sex crimes, drug related offenses, or a

conviction of substance use while incarcerated (Hoffman & Dickinson, 2010). Hoffman and Dickinson (2010) note that inmate volunteers in over half of the 43 programs surveyed provide assistance with activities of daily living, such as bathing and dressing of inmate patients.

The use of inmate volunteers can have multiple benefits. Volunteer inmates that provide direct care assistance can reduce stress for staff members (Dawes, 2002). Mistrust is common in inmates and correctional staff within the criminal justice system. The mistrust can lead to escalating feelings of depression and helplessness in terminally ill inmates (O'Connor, 2004). Inmates may be more likely to trust an inmate volunteer than staff of the correctional institution. However, cases of competitiveness and danger in high security units may counter this trust (Dawes, 2002). Inmate volunteers often provide companion care and sit vigil with dying inmates (Wright & Bronstein, 2007).

Volunteers provide education throughout the institution regarding the program. In addition to benefits to inmate patients and staff, inmate volunteers can also benefit from the experience. The volunteer experience can allow inmates the opportunity for personal reflection which appears to offer some therapeutic benefits (Wright & Bronstein, 2007). These therapeutic benefits can include the opportunity for reparation and life skills development, which are basic fundamentals in rehabilitation of criminal offenders (Dawes, 2002). Despite the number of benefits possible for inmate hospice volunteers, the assignment can also take an emotional toll. The majority of programs surveyed by Hoffman and Dickinson (2010) reported the provision of elements of stress management within the hospice training.

While IDT care teams and hospice volunteers are the foundation of hospice programs and translate relatively easily to practice in varied settings, correctional institutions present unique challenges to care provisions. One such challenge is the provision of pain medication. Narcotics can have dispensing restrictions and some may be completely unavailable in correctional settings (Linder et al., 2002). Such medications are widely used in community hospice settings but can present concerns in correctional hospice settings due to the prevalence of individuals with a substance abuse history. Pain medications can be exchanged in the prison black market (Hoffman & Dickinson, 2010). The GRACE Project standards indicate that pharmaceutical interventions will be in a manner that is consistent with applicable regulations. The standards also indicate that appropriate practice involves the alleviated of pain and other symptoms the extent possible (GRACE, 2000). The standards do not specifically address the use of narcotic pain medication in the alleviation of other symptoms. Ensuring that pain medications are consumed by hospice patients and not used illicitly within the correctional institution requires hospice staff and correctional staff to work closely together (Hoffman & Dickinson, 2010).

Community hospice services are commonly provided to patients in the home. This is complicated for inmates in correctional institutions. The GRACE Project standards indicate that services should not be interrupted by inter-facility transfers or transfers to other facilities (GRACE, 2000). This can be complicated by the contradictory nature of the hospice principles and security needs instrumental in correctional principles. Inmates are assigned classification levels based on security needs that are calculated independently of medical needs (Hoffman & Dickinson, 2010). GRACE project standards indicate appropriate practice would be to provide hospice services to inmates regardless of their security classification

(GRACE, 2000). One challenge to implementation is that hospice services may only be offered in designated institutions. This causes the movement of an inmate to a different institution that can be complicated by a security classification.

Some advocates would argue that the only acceptable means of treatment for inmates with life limiting conditions is medical parole or compassionate release. However, as stated, most jurisdictions have existing policies related to such concepts with little benefit experienced because medically appropriate inmates are rarely released under these policies (Craig & Ratcliff, 2002). Examining the apparent failure of such policies to serve their stated purposes is certainly advisable. However, this project seeks to provide a more immediate response to the needs of inmates that are currently coping with life limiting conditions, do not have the time to wait for such analysis, and could benefit from immediate provision of care. As this literature review has shown, the provision of end-of-life care to inmates is not only a matter of human rights, it is constitutional right that is clearly documented in relevant case law. Utilizing this foundation, this project sought to incorporate beliefs from stakeholders with relevant literature to establish recommendations for improving the quality correctional end-of-life services.

Building on the foundation of the GRACE standards, and the increasing number of programs, the National Hospice and Palliative Care Organization released Quality Guidelines for Hospice and End-of-Life Care in Correctional Settings in 2009. The document offers providers a framework by which they can complete a, “360 degree of their entire operation, focusing on both clinical and nonclinical areas” (National Hospice and Palliative Care Organization [NHPCO], 2009, p. v). The NHPCO provides guidelines for the provision of correctional hospice services in a manual titled “Quality Guidelines for Hospice and End-of-

Life Care in Correctional Settings.” The guidelines are consistent with the hospice modality of care with consideration to correctional settings. Examining correctional hospice policies without consideration of the security needs present in a correctional setting is inadequate. The guidelines provide standards by which to compare practices within correctional settings, and are centered on ten primary components. Among the ten components are Inmate and Family-Centered Care, Inclusion and Access, and Performance Improvement (NHPCO, 2009, p. vi).

The component of Inmate and Family Centered Care is based on the key components of the hospice philosophy that the individual is the unit of care. In community settings, the patient would be able to receive support from people of their choosing. As stated previously, inmates have lost the right to such association. Taking into account the unique environment present in the correctional setting, the component defines “family of choice” as, “biological family members, significant others from the community and/or inmates or individuals named as family by the inmate patient” (NHPCO, 2009, p. 1).

The component of Inclusion and Access is included demonstrating the NHPCO commitment to ensuring availability of services “regardless of race, ethnicity, color, religion, gender, disability, sexual orientation, age, disease or other characteristics” (NHPCO, 2009, p. 35). Consistent with elements of a human rights perspective, the guidelines advocate that all inmates dealing with life-limiting conditions should have access to and be able to utilize relevant services. In a correctional environment, access limiting conditions can extend beyond intrinsic values to thing such as security level or classification. Programs are encouraged to complete periodic needs assessments to ensure that underserved populations are being reached (NHPCO, 2009).

Hospice is a relatively new arena in the medical field. The idea of providing services in correctional settings is even more recent. Recognizing this, the NHPCO emphasizes, “analyzing and actively using performance-improvement data to foster quality assessment and performance improvement in all areas of care and services” in the component of Performance Improvement (NHPCO, 2009, p. 66). The evolution of services is dependent on extending formal and informal data and information on existing practices beyond anecdotal reports

Chapter 3

Methods

In order to identify areas for legislative action influencing the provision of end-of-life services in the CDCR, this project utilized the policy analysis framework conceptualized by Piercy and McAuley (2009) that includes a definition of the issue, historical and other relevant information, and an analysis of current policies and practices. Use of available prison hospice literature, available descriptions of prison hospice programs, and interviews with persons who are knowledgeable and/or work in a prison hospice setting were used as data for this analysis. Current practices, both positive and negative, and barriers to implementation of quality services were identified.

Stakeholders that were interviewed were identified through public listings found on state and national prison hospice website listings. Persons that appeared to have the most involvement in a prison hospice program were selected and contacted through email and phone calls to request interviews. Confidentiality of participants was an area of primary concern due the highly political nature of the corrections system and the hierarchal structure of the correctional system that could prevent participants from sharing knowledge. A process of maintaining interview notes separate from participant contact information was established to ensure protection of individual participant identities. Only the researcher and research sponsor had access to the final list of participants identified from the initial list of prospective participants.

For individuals that consented, interviews were scheduled at the participant's convenience and conducted by telephone. In instances where participants identified another potential participant the researcher attempted to contact the referred individual. A total of

four interviews were conducted, each lasting anywhere from 30 to 60 minutes. Though the sample size was small, there were recurring themes identified indicating some level of saturation. Time constraints prevented additional interviews.

Participants provided informed consent via phone using a checklist of human protection items. Participants were informed that their identity would be protected to provide them the ability to speak frankly on a sensitive topic. Utilizing an interview guide (Appendix B) open and close ended questions were asked of participants. With the consent of the participants, the interviews were audiotaped and later transcribed. In instances where the participant declined to have the interview audiotaped, the researcher took detailed notes during the interview. Because failure to maintain all data in its entirety can have effects on the validity of conclusions, every attempt was made to ensure data was transcribed in its entirety (Teddlie & Tashakkori, 2009).

The transcribed interview notes were then analyzed for recurring concepts and themes utilizing a coding scheme as described by Strauss and Corbin (2008). The interview notes were first analyzed by the researcher. The interview notes were then analyzed a second time by the researcher's sponsor to ensure an independent review, and that personal bias was not an influence in identification of themes and categories. The themes were then quantified by tracking recurrent mention from each interview on a spreadsheet. Themes recurring most often in interviews were then compared to relevant literature for differences and similarities. The mixed methodology based in the pragmatism paradigm, and was utilized because of the absence of the either/or choice associated with other paradigms that the researcher felt could be too limiting given the continuum of beliefs associated with end-of-life issues. The number

of themes found to be recurring in separate interviews provides for validity in the inferences or identification of themes (Teddlie & Tashakkori, 2009)

Utilizing the list of identified recurring themes and concepts, formal policies discussed in the above literature review were compared to determine if policies reflected concepts identified by relevant stakeholders as areas of importance. Integration of both sources of information was done to provide a foundation for subsequent legislative efforts.

Chapter 4

Results

Initially, interviews were coded utilizing open coding methods to identify broad concepts (Corbin & Strauss, 2008). The five most frequently recurring themes identified in interviews and literature were synthesized for the purposes of identifying major concepts that could be relevant to proposing legislation targeting improving care to meet the community standard in such a manner that services are in compliance with relative constitutional rights. An additional theme, only identified in two interviews, the reduction of violence/reduction of recidivism, was included due to the possibility of significant implications for conservation of financial resources and human capital in a system that, as previously stated, has been found to be ineffective and costly. Each theme is presented separately to allow for detailed identification.

Compassion

All participants identified compassion as a key element of the provision of correctional hospice programs. This finding is consistent with the NHPCO Guidelines, which indicates that the hospice patient has the right to receive, “appropriate and compassionate care, regardless of diagnosis, race, age, creed, disability, and sexual orientation” (NHPCO, 2009, p. 78). Participants identified compassion within correctional hospice in a variety of terms including the following:

- “[prison hospice] makes a lot of sense from a humanistic and compassionate level”
- “People in hospice tend to be kinder and more aware”
- “We made a sacred vow to our inmates that they would not die alone”

Compassion is also identified in the research regarding correctional hospice programs. The Louisiana State Hospice Program, identified as a successful program, (Ratcliff, 2000) has been identified as an example where inmates, staff, both correctional and medical, can come together with the, “common goal of providing humane care to the dying” (Tillman, 2000, p. 514). Authors describing the hospice program at the California Medical Facility in Vacaville, California, describe the program as a place where the goal is to: “provide a place of compassion and comfort where those fringe members of society can receive care with dignity and respect in their last days of life” (Linder, Knauf, Enders, & Meyers, 2002, p. 908). A universal theme present in all interviews and consistent with major relevant literature sources is that the provision of correctional hospice services provides for a more compassionate correctional environment (Wright & Bronstein, 2007).

Cost Effectiveness

Concerns regarding resource allocation are influential in the development of policy. Human rights advocates have identified countless examples of individuals or systems in authority disguising an unwillingness to improve health conditions behind an argument of resource constraints (Gruskin & Daniels, 2008). This is true within correctional settings that must maintain a balance between custody of care. Often times the extremely high cost associated with end-of-life care for inmates is based on hospitalizations in community hospitals (Bick, 2003, para. 25). An initial barrier to beginning a correctional hospice program can be cost. However, Elizabeth Craig of the National Prison Hospice Association is quoted in a 1998 report as saying, “Hospice care is known to be effective in providing a compassionate environment for dying persons and their families. In general, the cost of hospice care is less than that of traditional treatment” (U.S. Department of Justice [DOJ],

1998, p. 1). The initial costs can be offset by providing care on site, thus minimizing hospitalizations in outside facilities (Bick, 2003).

Two of the participants addressed the cost effectiveness of correctional hospice programs indicating that it could be a means of helping to contain increasing medical costs in facilities. However, one participant did indicate that if the motivation for the creation of the program was cost containment versus providing compassionate care, the program may experience limitations. The participant thought those programs with a primary focus on cost containment tended to be more, “rigid,” and, “less collaborative.”

Management/System

Correctional hospice programs are a collaborative effort. Facilities have a primary focus of security, and there is typically a clearly defined chain of command and defined roles with clear boundaries (Wright & Bronstein, 2007). Prison culture is one that promotes conformity to a structured system (Ratcliff, 2000). Implementation of hospice programs within correctional settings requires a shift from the traditional correctional paradigm. This shift requires staff in roles that are traditionally correctional integrate work with medical staff that has a focus on individual wellbeing (Hoffman & Dickinson, 2010). Implementation of a correctional hospice program may come as a directive from higher ranking officials, and at times comes without the support of other staff. Hoffman and Dickinson (2010) found that that there can be less support for correctional hospice programs from correctional officers, as well as the general public. However, the same study found that the majority of programs surveyed reported that correctional officers did not receive training regarding hospice (Hoffman & Dickinson, 2010, p. 11).

All surveyed participants discussed the impact of the system and management as having a direct influence on correctional hospice service delivery. However, respondents' opinions ranged from believing there was considerable amount of management support to a lack of management support. One participant indicated that their institution had administrators, "that want to meet those community standards." Conversely, another participant indicated that there is "so much red tape," and another indicated that, "correctional officers have way too much authority."

Family of Choice

A primary component of the hospice philosophy is the provision of support to the patient during their final days (Hoffman & Dickinson, 2010). For inmates with life limiting conditions, the focus is tempered by the fact that they were prisoners first, and patients with loved ones or interested parties second (Ratcliff, 2000). Hoffman and Dickinson (2010) found that almost a quarter of all programs they surveyed included family members in their treatment teams, and many programs have visitation policies that are more liberal than for other inmates. However, these policies appear to incorporate families of origin, also known as birth families. It can be difficult to identify, and in some cases reunify, families of origin with inmates. Furthermore, there is rarely room to clearly extend the definition of family to other inmates (Ratcliff, 2000). Regardless of the difficulty of incorporating family into the unique environment of corrections, one of the ten components of care identified by the NHPCO care guidelines indicate that programs should provide care and services to the patient and their family of choice (NHPCO, 2009). Creativity and resourcefulness are essential to incorporating such a key element of end-of-life services within corrections (Craig & Ratcliff, 2002).

For some inmates, they have established familial ties and supportive relationships with individuals they are incarcerated with. One participant indicated that for individuals incarcerated for extended periods of time, “this is who they know. They want to die around people they know.” Another participant indicated that, “for people that have been locked down for decades, their family is the other inmates at the facility.”

Reduction of Violence/Impact on Inmate Recidivism

Two participants provided responses consistent with findings in the literature. Wright and Bronstein (2007) had participants that reported that inmate volunteers experienced a “transformative” influence by volunteering. They went on to indicate that the volunteer experience in this type of setting allowed inmates to learn to feel compassion. Broadening this concept, respondents in this project indicated that the creation of a hospice program in one institution served to “humanize the entire prison culture.” Another participant indicated that, “in the entire facility there’s probably been a reduction of violence.” The same participant indicated that volunteers that come to the program have a “sense of compassion but they don’t have the tools,” which requires training by the professional staff. This participant indicated that these volunteers begin to, “receive and use the tools of compassion and care.” This participant believes that the role of hospice volunteer for these inmates contributes the relatively low rate of recidivism these inmates have versus inmates that are not volunteers.

Most correctional hospice programs utilize inmate volunteers within the provision of services to varying degrees. Inmate volunteer responsibilities differ by program but typically include activities of social support (Hoffman & Dickinson, 2010). Due to the inherent distrust by inmates of correctional staff, inmate volunteers can serve to establish a safe place

for terminally ill inmates to share on a deeper level (Bronstein & Wright). Chichowlas and Chen (2010) interviewed inmate volunteers at the Dixon Correctional Center in Illinois. The volunteers described the experience as “healing” and “life changing” (Chicowlas & Chen, 2010, p. 132). The impact on inmate volunteers is related to their inclusion in the team that treats terminally ill inmates, and in the provision of care services. This transformative effect on individual inmate volunteers can in turn influence the culture of the institution. Staff and inmates are seen as more “humane” (Bronstein & Wright, p. 95).

Need for Increased Availability

All participants indicated the need for increased availability of correctional hospice programs. One participant indicated that ideally, “inmates would be granted compassionate release,” and if that was not possible, “hospice should be available on-site or nearby.” Another participant indicated that a hospice would be ideal in, “big facilities that house a population that is likely to die behind bars.” Another participant focused on the provision of hospice services to inmates regardless of security classification, indicating that individuals, “of a high custody level” require units with increased security precautions that are not typically present in hospice units, as protocol.

In a 1997 survey 24 department of corrections were reported to provide hospice care (DOJ, 1998). More recently the National Hospice and Palliative Care Organization (NHPCO) estimated that approximately 75 prisons and jails offer hospice programs for inmates with life limiting illness (Hoffman & Dickinson, 2010). Because hospice programs are limited to a relatively small amount of institutions, inmates that may benefit from the provision of hospice services may be required to transfer to a new facility in order to receive the services.

An example of this is the California Department of Corrections which has historically consolidated inmates with health needs to one or two facilities. The California Medical Facility (CMF) in Vacaville, houses a hospice licensed for 17. The California system reports that when appropriate inmates are transferred from other facilities to CMF (Linder et al., 2002). One participant stated this type of transfer, “runs counter to the philosophy of hospice which talks about people getting to die at home.” Another participant indicated that inmates at an institution without a hospice program will go to extreme measures to avoid being transferred out of the facility which would cause them to leave their “family.” This participant indicated that what can result is case of “death walking” in institutions ill equipped to deal with such patients. While institution policy is not focused on the desire of inmates, the common inmate desire to avoid transfer may be supported in some institutions. Another participant indicated that transfers can be difficult in larger systems and that barring the presence of a “critical condition,” inmates are, “going to be old and sick” but still in their primary institution. Such a policy may be indicative of a policy of minimizing inconvenience to the institution, rather than providing comprehensive care to the individual.

Summary

Figure 1 shows the relationship among the interviewees’ categories and themes and the proposed recommendations that address gaps in prison hospice services. The majority of categories fell under the theme of Performance Improvement. Management and regulations within the system provide a considerable influence over correctional hospice programs. Management decisions in a correctional environment are more likely influenced by fiscal concerns than compassion. Ensuring access to all inmates is a compassionate response, but also help to prevent legal actions citing cruel and unusual punishment if services are not

readily available. Additionally, research into the anecdotal reports of hospice volunteers being less likely to recidivate could have significant fiscal implications. If anecdotal reports are accurate, extending programs can provide quality improvement to inmate patients, volunteers, and ultimately society.

Such improvements can only be obtained by adequately assessing current practices in day to day operations. The assessment can provide a foundation for creating a level of fluidity within the program that provides for ongoing growth. Hospice is a continually evolving modality of care and flexibility will be required for correctional hospice programs attempting to meet and maintain the community standard.

Chapter 5

Discussion

While correctional institutions are required to provide medical care to individuals within their custody, the policies outlining the provision of such services varies by jurisdiction. The inclusion of end-of-life care as a distinct specialty of care is relatively new as a community standard, and the concept of a dignified death is even more recent in correctional institutions. There are not federal laws regulating the specific provision of such services. One participant indicated that, “prison hospice programs vary from state to state.”

As noted, correctional institutions tend to operate in a hierarchical structure with a rigid chain of command. Such systems are in place to ensure security. This chain of command can limit readily available information, and shape the information provided from individuals working within such systems. Some participants noted such concerns and declined to discuss certain topics relate primarily to management and the provision of medications for pain control. That being said, a considerable amount of information was provided by participants. It should also be noted that all participants were knowledgeable of hospice within correctional institutions and are proponents of such services which could provide a certain level of bias to their responses.

Programs that have been studied, and documented in existing literature, that have been found to be successful had key elements in common including administrative support at high levels, and inclusion of correctional staff in planning and delivery of services (Ratcliff, 2000). The hospice program in the Angola prison in Louisiana integrated hospice care into the existing prison healthcare program with physicians, nurses, social workers and chaplains providing this service in addition to other responsibilities (Ratcliff, 2000). Two participants

raised concern of medical staff being assigned to hospice programming without this being their choice, or primary field of training. This can provide challenges in the provision of adequate hospice and palliative care services, as correctional medical providers may have limited expertise in palliating symptoms and providing counseling to individuals addressing their own imminent mortality (Byock, 2002).

Themes that were consistent with all participants and similar to what is represented in the literature are the presence of compassion in correctional hospice programs, the challenges the management and/or system can provide to the provision of correctional hospice programs, and the need to increase availability of correctional hospice program. The concept of compassion extended beyond the care provided to the inmate-patients, and extended to inmates that volunteered in programs. According to some participants and supported by the literature, this compassion extends throughout the institution.

Less consistent was the concept that the presence of correctional hospice programs reduces inmate violence within correctional facilities. The idea is one that deserves further detailed study, as it could have implications for reducing costs associated with institution security, as well as improving quality of life for inmates within institutions. Unique to one interview, was the concept that participating as an inmate volunteer in a correctional hospice program could contribute to a reduction in recidivism. As stated earlier, California has the highest recidivism rate. Research into this concept could eventually assist in reducing overall correctional costs, by reducing the number of inmates in the system at any one time, if fewer individuals were returned to the system for conviction of new crimes, or violations of parole.

The CDCR Policy

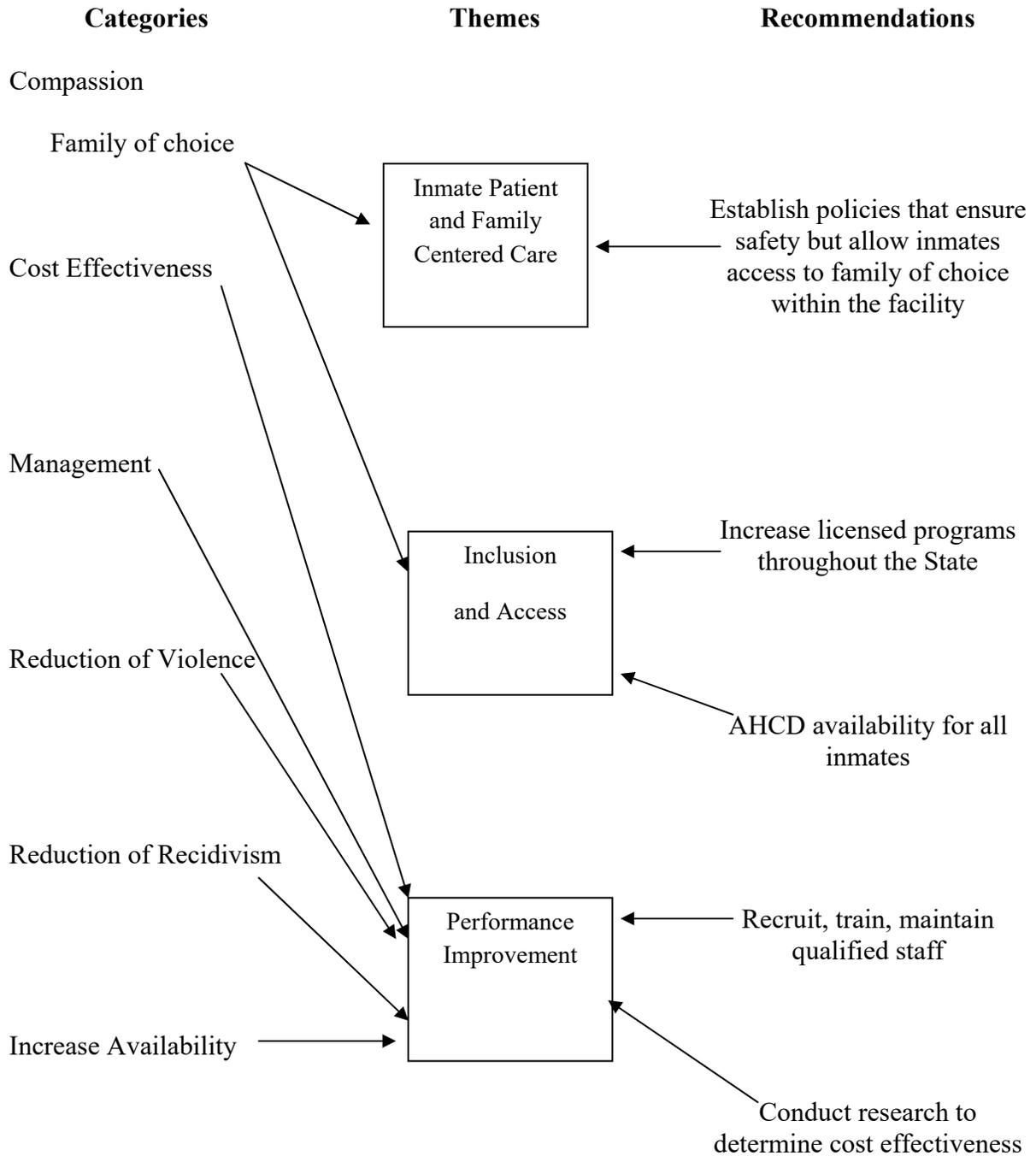
The California Department of Corrections and Rehabilitation policy dated January, 2006 states they, “shall provide palliative care and when the inmate-patient’s condition results in pain or disability to such an extent that the Primary Care Physician (PCP) and the inmate-patient determine that only palliation shall be provided” (California Department of Corrections and Rehabilitation, n.d., para. 1). The provision of narcotics is specifically included within the provision of palliation. The procedure goes on to state that if the inmate meets the criteria for hospice care a request for transfer to the California Medical Facility shall be completed. In order to participate in hospice services within the CDCR, individuals can not exceed a security classification greater than a Close A or have security concerns related to enemy situations, and must agree to the goals of hospice care. Other areas addressed include proper documentation of an inmate-patient’s refusal of medical care, and the provision that receiving palliative care does not eliminate the right to receive other medically necessary treatments (CDCR, n.d.).

CDCR policy available to the public is limited. The policy identified provides limited guidance to issues related to quality of life outside of the of the provision services within the specific medical discipline. Addressing of psychosocial needs is not present in the policy. Family is not mentioned, including the family of choice identified as a key component of correction end-of-life services. While the very provision of hospice services fits with the identified theme of compassion, priority appears to be given to medical and security concerns, which is not unexpected given the previously cited contradiction between the philosophies of corrections and hospice. This is also consistent with the identified theme of management and the correctional system as a barrier.

The policy indicates that referrals are made to the California Medical Facility in Vacaville. It is a reasonable assumption that this facility meets at least the bare minimum of community standard hospice service guidelines as it is licensed. Missing from this policy is mention of the newer programs at the Chowchilla institution for women, and the California Men's Colony. Most striking in this finding is that the Vacaville institution provides services to males only. The policy fails to address end-of-life services in even a rudimentary format for female inmates.

The CDCR website does indicate that the Agency recognizes an inmate has the fundamental right to make decisions regarding their medical care, including the right to have life sustaining treatment or have such treatment withdrawn (CDCR, n.d). Such decisions are often documented in an Advanced Health Care Directive outlining an individual's specific health care wishes. According to the CDCR website an inmate wishing to complete such a document will be provided one by staff (CDCR, n.d). This does not address the barrier trust issues related to communication between inmates and staff. Furthermore, it does not provide for education and discussion of end-of-life care options, as correctional staff does not serve in this capacity.

Figure 1



Based on the findings presented, the following recommendations are offered.

Recommendations for California

1. Increase availability of correctional hospice services throughout the State. The vast geographic territory covered by California institutions means that by concentrating services in one or two institutions there are added costs of transportation and security in relocating inmates. Furthermore, to avoid cruel and unusual punishment for terminally ill inmates, it is more humane to allow inmates to receive treatments in the locations they have been housed in. To ensure that community standards are being met, all end-of-life programs should obtain state licensure which provides for a review of services independent of the CDCR.
 - a. It is imperative that female inmates are provided adequate services comparable to that of their male counterparts. The lack of licensed hospice care for female inmates provides an example of care not meeting the community standard.
2. Provide opportunities for the completion of Advanced Health Directives which would allow inmates the opportunity to make their wishes known and have care provided in a manner that is consistent with their values and beliefs.
 - a. Train inmate volunteers to provide education on Advance Health Directives for other inmates. Utilizing inmate peer educators can help to bridge the gap of mistrust that is prevalent in correctional institutions.
3. Recruit, train, and maintain staff trained in hospice and palliative care. Appointing staff with limited education or experience in such service delivery can create for a system that is inherently ineffective.

4. Develop and implement a means for identifying inmate hospice volunteers from other inmates, in an attempt to identify trends in recidivism rates. Data obtained could provide ongoing guidance not only for dying inmates, but inmates that volunteer to provide services to them, and the institution as a whole.

Chapter 6

Conclusion

Societal views of crime and punishment are subject to shift with political and economic influences. As such, policies are continually evolving, all with the attempt to provide for community safety. To date, this has created an extremely high rate of incarceration within the United States, and more specifically California. A side effect of such is that areas that are normally considered personal responsibility, such as the provision of food, shelter, and medical care shift to the responsibility of the state. With the increase in incarceration there is an increase in fiscal consequences for the system that maintains these individuals. Longer sentences prolong the timeframe of this responsibility. When the sentence period includes life sentences, this directly appoints the correctional system as responsible for the provision of end-of-life services.

Attitudes toward death and dying can be influenced by many factors. However, within the United States there has been an evolution toward individual rights toward self determination that extends to the end-of-life period. For community dwelling adults there is more focus on establishing a record of their desires for end-of-life care through the completion of Advance Healthcare Directives. Documents are readily available and their completion is accepted within the medical and legal community as an accurate reflection of the desires of the individual for care. However, inmates lack the same access.

Individuals that are incarcerated in jails may be awaiting trial, and thus have not been convicted of a crime. Individuals incarcerated in prisons, such as those in the CDCR, have been convicted and accordingly are removed from society and the rights and benefits that go with residing in a free democratic society. However, placement within a correctional system

provides the individual with a right to adequate medical care. Such medical care extends to services through the final days of one's life. Maintaining the community standard includes the implementation of holistic end-of-life care that is provided in a manner in which the individual desires, consistent with their values and beliefs, promoting a social justice human rights perspective.

Implications for Social Work and Social Policy

While matters of quality of life for inmates, particularly dying inmates, may appear to be an area of finite concern only affecting a small group of individuals, the implications of this for social work practice and social policy development are extensive. At the state level, stronger policies are needed to ensure that conditions within the CDCR do not violate Eighth Amendment prohibitions against cruel and unusual punishment. Efforts by the legislature to improve conditions within correctional institutions are often viewed as providing luxuries to a population that do not deserve such consideration; however, ensuring the provision of adequate services minimizes the possibility of lawsuits that cost the State funds. Funds saved from the reduction of legal costs can be channeled to improving quality of life for all State residents. Additionally, the funding of research into the anecdotal reports that the provision of hospice services in correctional institutions can reduce recidivism may seem costly initially, but could potentially lead to long term cost savings. Again, quality of life can be improved for all State residents because the possible reduction of recidivism could be linked to a reduction of criminality.

Social workers engaged in direct practice with inmates, their families, and stakeholders within the corrections arena need to review the impact of inmate death while incarcerated on all parties. Service providers can influence the quality of life by providing

training opportunities for correctional staff, legislators, and others. The quality of life is important in the realm of social work practice because while inmates are often considered deserving of the incapacitation incarceration provides, it is important to ensure the constitutional mandate preventing cruel and unusual punishment is implemented because human beings have dignity and worth.

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Date: 10 May 2011
To: Rachel Tate, MSW Student
From: Steve Suter, University Research Ethics Review Coordinator
Roseanna McCleary, Social Work Department
cc: Paul Newberry, IRB Chair
Subject: Authorization for Protocol 11-96

I am pleased to inform you that your protocol, "**End of Life Services and Incarceration: An Analysis of Current Policy and Services**" has been approved following expedited review. Authorization is based on the original protocol [4-28-11] and your clarifications and revisions in response to reviewer feedback completed on 5-10-11.

This authorization is strictly limited to the specific activities that have been authorized by the IRB. If you want to modify these activities, notify the IRB in advance so proposed changes can be reviewed. If you have any questions, or there are any unanticipated problems or adverse reactions, please contact me immediately.

Note: The following personnel [*only*] are authorized to interact with subjects in obtaining informed consent or in collection of data.

Human Subjects Protection Training Certified:

Rachel Tate [1-20-09] & Roseanna McCleary [9-15-03]

Any signed consent documents must be retained for at least three years to enable research compliance monitoring and in case of concerns by research participants. Consent forms may be stored longer at the discretion of the principal investigator [PI]. The PI is responsible for retaining consent forms. If the PI is a student, the faculty supervisor is responsible for the consent forms. The consent forms must be stored so that only the authorized investigators or representatives of the IRB have access. At the end of the retention period the consent forms must be destroyed [not re-cycled or thrown away]. Please destroy audio tapes after scoring.

This authorization will be valid until the end of April 2012.

Steve Suter, University Research Ethics Review Coordinator

Interview Guide

Can you tell me about your prison hospice program?

What current barriers/problems are being experienced by your program at this time?

If you had an ideal prison hospice program, what would it look like?

What benefits are achieved through the provision of prison hospice services?

How is funding currently provided to your program?

What needs are currently present within your program?