DISSERTATION

A MIRROR TO HUMANITY:
THE MEANING-MAKING EXPERIENCES OF CORRECTIONAL END-OF-LIFE CARE ADVOCATES

Submitted by

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ABSTRACT

A MIRROR TO HUMANITY: THE MEANING-MAKING EXPERIENCES OF CORRECTIONAL END-OF-LIFE CARE ADVOCATES

The purpose of this study was to explore the mean-making experiences of advocates who strive to implement end-of-life programming in correctional settings. The study included five main exploratory aims: (1) to explore advocates' understanding of end-of-life philosophy; (2) motivating factors of advocates that promote end-of-life caregiving opportunities; (3) barriers to the provision of end-of-life care; (4) how personal, social, and political influences related to correctional end-of-life care shape advocates' meaning-making experiences and; (5) to better inform the general public of this integral need and humane service to combat the stigma related to accessing end-of-life care for incarcerated individuals.

Interpretative phenomenological analysis (IPA), a qualitative approach which aims to provide detailed examinations of personal lived experience, was incorporated with English-speaking participants, residing in the United States (U.S.), who are 18 years of age or older and identify as advocates for correctional end-of-life care. Participants were recruited with the assistance of professionals who work within the field of end-of-life care in the United States and non-profit, correctional health care advocacy groups. Advocates participated in a recorded interview, via Zoom or telephone, consisting of 15 semi-structured questions which addressed their knowledge of end-of-life care in corrections, recommendations for policy reform, and the meaning-making experiences derived from advocating for essential care to the terminally ill.

Participant responses were transcribed and analyzed by maintaining an idiographic focus and providing verbatim quotes.

The results revealed advocates' multifaceted meaning-making experiences in championing for humane end-of-life care in corrections: *daunting work as motivation*; *the people are the joy*; *this is what I'm meant to do*; and *being a mirror to humanity*. Advocates revealed the pertinent need to eradicate punitive ideals to deliver compassionate care. Narratives underscored the significant bonds with imprisoned people and fellow peers advocating for empathy at the end-of-life. These advocates additionally highlighted their inherent aspirations for social justice and health equity. Moreover, opportunities to showcase and celebrate the compassionate skill-set and productivity of peer-volunteers delivering care to their dying peers in corrections surfaced as emotional and inspiring experiences for advocates.

The exploration of the meaning-making experiences of correctional end-of-life care advocates provided a unique perspective into the motivating factors and multifarious challenges of implementing and delivering compassionate care to terminally ill incarcerated people. Advocates offer significant and hidden insights into the dying experience of this marginalized population, while navigating the complexities of correctional health care. The knowledge and vigor of advocates serve as key factors in ameliorating appropriate end-of-life care for a continually punished population.

The study emphasizes the fundamental need to assess current models of care available to dying incarcerated individuals in the United States and how advocates' participation can enhance end-of-life care in corrections. Further research must investigate current end-of-life programming in corrections, with an emphasis on the unique roles of those delivering care. The essential voices of correctional end-of-life advocates should be integrated into policy reform which seeks to amend dated and unjust practices impacting dying incarcerated individuals.

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DEDICATION

"Strong people stand up for themselves, but stronger people stand up for others."
- Chris Gardner

This study of advocacy is dedicated to the miraculous individuals who serve as extraordinary champions of compassionate care. To those advocates, seen and unseen, who dedicate themselves to the plight of implementing humane end-of-life care for imprisoned people, your remarkable work serves as great inspiration for those advocating alongside you. Your knowledge, empathy, and persistent leadership are incredible sources of encouragement and hope.

To my Mother and Father, my heart and my heros, I also dedicate this study to your undeniable support and motivation for my education and career. You were my first advocates, providing endless avenues for me to gain knowledge and pursue a field that means an indescribable amount to me. You raised a trio of scholars and there is no doubt that our successes are forever indebted to your guidance, care, and love.

A very heartfelt dedication to the incredible caregiver volunteers who endure ongoing loss to best support their dying peers within corrections. The compassion, empathy, and support you deliver is phenomenal. It takes great strength, courage, and love to be alongside an individual in the final days of their life journey. Not everyone can do this "job"; but you do it with grace and empathy. May the amazing work you continue to do be recognized and respected by those around you and beyond.

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CHAPTER 1 – BACKGROUND AND SIGNIFICANCE

Introduction

The delivery of quality end-of-life care for incarcerated individuals has proven to be a multi-faceted and complex process, creating challenges for both correctional staff and medical professionals; however, apathy and procedural difficulties related to conducting research in corrections have hindered researchers' ability to directly examine barriers to care. The aim of this study is to explore critical influences on correctional end-of-life care advocates' experiences, with emphasis on the motivations for advocacy of care and how the personal, social, and political influences related to correctional end-of-life care shape their meaning-making experiences as advocates. With advocates encompassing varied roles, these individuals often serve in positions to educate and energize impacted communities and the general public regarding a meaningful issue (Nori et al., 2022). The professional roles of these advocates may include chaplains, social workers, nurses, and those in the non-profit sector. Within this study, these individuals additionally provided training to incarcerated peer-caregivers volunteering in an end-of-life program for their dying peers. This study, drawing on innovations in existential, caregiving, and critical race theories, will examine the integral role of correctional health care advocates in the establishment and provision of essential care for the terminally ill.

End-of-life care programs have gradually become a prevalent service in attending to the unique needs of dying incarcerated individuals. Current literature provides minimal examination of end-of-life interventions that exist in correctional facilities; however, even more narrow attention has been provided to the plight of end-of-life care advocates who strive to implement this integral care into correctional settings. The exploration of those voices calling for appropriate interventions for aging and dying incarcerated individuals should be a growing priority. Moreover, the presence of end-of-life models of care, prioritizing dignity and compassionate care, should be given particular attention, as this model yields valuable and meaningful outcomes for incarcerated individuals, their loved ones, and correctional staff.

An aging prison population continues to be an imperative and significant topic of conversation between health care professionals and correctional institutions (Luallen & Cutler, 2017; Rothman et al., 2017). The complexities of care, in addition to the lack of access to funding and resources, are only a few of the numerous barriers in providing end-of-life care, which encompasses critical treatment, care, and support for individuals nearing the end of their life, in a correctional setting (Skarupski et al., 2018). With an aging incarcerated population comes an increased need to access health care professionals and services; however, research indicates an alarming number of barriers associated with access to and quality of care (Luallen & Cutler, 2017; Wilper et al., 2009).

Mass Incarceration in the United States

Undoubtedly, the United States (U.S.) is a prison nation, possessing the highest number of incarcerated individuals at the highest rate of imprisonment globally (Walmsley, 2018). The total number of individuals under U.S. correctional supervision, including persons residing in prisons and jails and adults on probation and parole, is estimated to be 6,613,500 (Kaeble and Cowhig, 2018; U.S. Bureau of Justice Statistics, 2020). Additionally, 396,488 undocumented migrants are detained in the U.S. (Immigration U.S., 2019), with the combined incarcerated, jailed, and detained population at approximately 2,630,000 people. More specifically, Black individuals represent approximately 33 percent of incarcerated people in state custody and 40 percent housed in federal custody, despite only being 13 percent of the general U.S. population

(Duffin, 2020; Bialik, 2018). Accordingly, mass incarceration in the US is described as a "social innovation that permits the recoupment of capital losses and serves as a hopeful antidote to rage, often disguised as simply the rightful infliction of just punishment" (Friedman, 2021, p. 692).

Despite chattel slavery being abolished in 1865 under the Thirteenth Amendment to the U.S. Constitution, it explicitly and legally categorized imprisoned people as slaves of the state (Friedman, 2021). Although this Amendment is touted as the first-step to expanding civil rights in the U.S., it has maintained the legitimacy of slavery as a punishment for crime (U.S. Const.amend. XIII). Consequently, this clause has permitted the swift re-enslavement of Black communities across the U.S., most remarkably in the southern states. Black individuals are once again rendered as slaves of the state through the utilization of racialized vagrancy laws, mass imprisonment for false debts, and disproportionate sentencing, with corrections functioning as an instrument of power to maintain white supremacy as dominion of over property (Blackmon, 2008; Friedman, 2021). As a relic of the Thirteenth Amendment, when an individual is incarcerated, they are no longer recognized as a *human being*, yet instead become *property* of the state. Prior to 1972, incarcerated individuals remained legally dead without clear acknowledgement of constitutional protections (*Cruz v. Beto,* 1972; Friedman, 2021).

With locked doors, high walls, barbed wire, surrounded by cliffs and water or open terrain, correctional facilities are organized to "protect the community against what are thought to be intentional dangers to it; here the welfare of the persons thus sequestered is not the immediate issue," suggesting the punishment functions of corrections further intensifies totalistic characteristics and disregard for humanity (Friedman, 2021). By replacing individuals names with numbers, stripping personal belongings and replacing them with standard-issued clothing and minimal supplies, regulating movement such that all incarcerated individuals follow a similar strict schedule, and requiring they conduct all daily activities within the confines of a single institution (Friedman, 2021), the indoctrination into corrections creates the "pains of imprisonment" or conditions in which individuals must battle with deprivations including the loss of autonomy, absence of individual security, scarce goods and services, and restrictions to their civil liberties, including the access to appropriate health care (Crewe et al., 2019; Sykes, 2007).

Limited Understanding of Correctional Health Care Rights and Needs

Despite individuals preserving the right to medical care in U.S. corrections under the 8th Amendment, no public health insurance for individuals in the U.S. carceral system exists, with at least 35 states requiring the incarcerated to provide co-pay and other fees not covered for medical services (Farr, 2022; AAFP, 2019; Roth, 2010). Moreover, the lack of knowledge regarding this unique population has impeded optimal care for seriously ill, incarcerated patients and has thus exacerbated the existing barriers already endured by aging incarcerated individuals (Rothman et al., 2017). Though substantial attention and resources have concentrated on dying with dignity for individuals who retain their civil liberties, these have been greatly limited for incarcerated populations. Correctional settings, in general, lack end-of-life care models and the justification for imprisonment often impedes the provision of quality health care for imprisoned people (Hoffman & Dickinson, 2011). As prisons exist as very isolated systems, incorporating strict regulations and social functioning, it is necessary to customize palliative care needs to satisfy this specific environment (Handtke & Wangmo, 2014). Unfortunately, health and behavioral factors, in addition to low health literacy and living in an isolated environment with significantly diminished independence, has created a great vulnerability for incarcerated people accessing appropriate end-of-life care (Handtke & Wangmo, 2014).

The involvement and advocacy of health care providers aiding the movement of access to essential health care within correctional settings is instrumental; however, there continues to be a lack of correctional institutions with on-site end-of-life care facilities, resulting in an increased need for imprisoned persons to access community hospitals or hospices at the end-of-life (Klock & Liantonio, 2018). The path of utilizing community services entails a great burden for patients, families, and communities as they may incur costs related to security and transportation (Klock & Liantonio, 2018). Correctional facilities are enduring reduced economic resources, creating additional barriers for correctional staff to meet end-of-life care mandates (Stern, et al., 2010). Moreover, increased correctional staff time and appropriate training for end-of-life care would also add to financial costs (Penrod et al., 2013).

Escalating Health Care Costs

With more than two million prisoners in the U.S. alone, this incarcerated population is quickly shifting from young to old (World Prison Brief, 2016). Moreover, the Bureau of Justice Statistics reports that between 2001 and 2013, nine out of 10 of prisoner deaths were due to an illness-related cause, as chronic illnesses have overtaken drug and alcohol deaths, homicides, suicides, and accidents in state correctional settings (Carson et al., 2020). Due to the lack of preventative and proactive health care opportunities within correctional settings, disease often affects incarcerated individuals earlier in their lives, as well (Williams, et al., 2013). From fiscal years 2009 through 2016, the Bureau of Prisons (BOP) obligated more than $9 billion for the provision of correctional health care (U.S. GAO, 2017). Health care obligations climbed from $6,334 in fiscal year 2009 to $8,602, per person, in fiscal year 2016, an increase of about 36 percent (U.S. GAO, 2017). The BOP cited an aging incarcerated population, escalating pharmaceutical prices, and growing costs of outside medical services as factors that accounted for its overall costs (U.S. GAO, 2017). Consequently, high costs paired with the lack of uniform and appropriate interventions has merely exacerbated the challenges and issues facing health care systems within a correctional facility. Incarcerated individuals are also enduring longer prison sentences and more security-related incarcerations, therefore resulting in potentially lifelong internment (Maschi & Richter, 2017). Several barriers exist for implementing appropriate care for imprisoned persons, including social, economic, and political influences, in addition to the unique issues related to the social organization of correctional settings (Burles et al., 2015).

With limited resources and mounting demands, medical care professionals will continue to struggle to provide vital interventions at the end-of-life. McKillop (2017) reports that state and local governments can spend upwards to $20,000 per incarcerated individual, per year, to access health care. The American Civil Liberties Union (2021) revealed that this cost is higher, with costs to imprison older adults being five times more when compared to the younger prison population (Maschi & Richter, 2017). In response to these rising costs, correctional administrative officials need to establish policies and strategies to address how the penal system deals with health care costs for incarcerated individuals (Burles et al., 2015).

Absence of Standardized Care

For those individuals with privileged access to end-of-life care in community settings, such as hospice where the primary focus is on a dying individual's care, comfort, and quality of life, compassion and dignity is omnipresent. Individuals nearing death in community hospitals or hospice, are permitted access to various forms of support such as practical assistance, pain management, spiritual care, grief support, and consolation from family and friends. End-of-life care may also entail the opportunity to assist the dying in improving their understanding of their illness and its progression, as well as help cope with complicated feelings related to their illness.

Individuals with terminal illnesses are often encouraged to participate in their care by devising an advance care directive; a legal document that communicates an individual’s wishes about health care decisions in the event the individual has become incapable to make decisions about their own health. Moreover, the provision consistent caregiving from medical professionals and loved ones is a conventional and integral aspect of standardized care within community settings that cater to the needs of dying individuals.

Presently, there is a distressing lack of standardized care in the U.S. carceral system concerning the provision of end-of-life care for the dying. Contrary to the autonomy provided to nonincarcerated, dying individuals, terminally ill individuals in correctional facilities have limited access to social supports, medication, spiritual care, and grief support. Moreover, inadequate health literacy in corrections has limited the capacity for terminally ill persons to voice their needs, concerns, and wishes at the end of life (Hadden et al., 2018). Due to the scarcity of policies that promote care guidelines for the critically ill in corrections, these individuals are uninformed regarding comfort measures at the end-of-life (Howerton et al., 2007). This alarming gap can greatly influence prisoners in their decision-making regarding comfort care, as evident with “half of prison-based hospices [requiring] neither cessation of curative treatment nor a do-not-resuscitate order” (Klock & Liantonio, 2018, p. 5). Hoffman and Dickson (2010) similarly conveyed in their study that do-not-resuscitate orders were only a requirement for admission in 55% of prison hospices, demonstrating that correctional settings have “departed from the normative community hospice model” (p.7), as do-not-resuscitate orders and advanced directives are often required in community-based hospice systems.

Policymakers, often consisting of correctional facility administrators and/or members of the Department of Corrections in varying states, experience pressure to maintain a punitive stance to appease constituents, thus discouraging policies and interventions that promote the release of incarcerated individuals (Price, 2018). In addition to societal pressures, traditional end-of-life care practices in a prison-based setting often conflict with security protocols and procedures, “leading to location-specific practices which differ from standard community-based care models” (Depner et al., 2018, p. 977). The implementation of rigid visitation policies by correctional institutions, for instance, impedes the necessary psychosocial supports required to provide individuals with compassion and dignity at the end-of-life. The results of a prison-based hospice survey demonstrated that only 29% of programs permit unlimited visits by non-incarcerated family members, with an additional 11% allowing daily visits if the patient’s condition deteriorates (Hoffman & Dickinson, 2011). With the safety of imprisoned persons and correctional staff of paramount concern, security therefore permeates decision-making in regard to end-of-life care (Penrod et al., 2013). Consequently, the number of prisoners who will die in prison will continue to increase, thus “creating a significant demand for correctional palliative care provision” (Burles et al., 2015, p. 99).

Public Apathy

Discussions regarding access to end-of-life care in correctional settings also reflect wider social constructions of incarcerated individuals as marginalized populations (Burles et al., 2015). Prisons are often constructed as ‘hell-holes’ in the media, whose purpose is to socially exclude disadvantaged groups such as racial minorities (Jewkes, 2014). Additionally, correctional environments are perceived as settings for confinement, in which imprisoned persons are detained for rehabilitative purposes, with a primary element of punishment (Turner et al., 2011). Maeve and Vaughn (2001) elaborate on this element of punishment by describing it as the ‘penal harm movement’, reflecting a public belief that incarcerated individuals are meant to endure suffering for their crimes, despite many crimes having social structural roots. Moreover, correctional facilities rely on the uniform treatment of incarcerated people, which functions to degrade and further isolate prisoners (Bolger, 2005). Irrespective of one's beliefs on compassionate care for dying imprisoned persons, the provision of quality care is an ethical imperative (Burles et al., 2015). Health care providers in correctional settings are to be reminded that loss of liberty (incarceration) is the punishment, not inadequate health care (Turner et al., 2011). Therefore, the health and well-being of the dying should not be compromised (Linder & Meyers, 2007). Certainly, there remains a need to further efforts to advance access to end-of-life care within correctional settings to eliminate barriers to care and identify best practices (Burles, et al., 2015).

Problem Statement

The multitude of individuals confined within correctional facilities in the U.S. cause a colossal challenge for public health, including integral care at the end-of-life. One of the defining characteristics of mass incarceration in the U.S. is the alarming racial disparity of who is imprisoned. These racial inequities, stemming from the practice of correctional gerrymandering, has been met with public apathy and thus contributed to the undignified deaths of innumerable BIPOC incarcerated individuals. With an emerging aging population in an appallingly overcrowded setting, paired with rising costs and under-trained staff, correctional personnel, policymakers, and taxpayers must endure perpetual challenges and barriers to ensure the delivery of proper health care. Despite the efforts of various advocacy groups who champion for proper end-of-life care in the U.S. carceral system, there is a severe lack of literature dedicated to this plight. Advocates of dignified end-of-life care for the incarcerated possess vital insights regarding the hardships associated with implementing standardized health care within punitive settings. Moreover, this unique population can play essential roles in influencing and reforming extremely detrimental and dated health policies impacting incarcerated populations.

Statement of Purpose

The provision of end-of-life care has been described as humbling and enriching, as well as heartbreaking and distressing, showcasing the multifarious emotions and sentiments attached to such intimate work. The purpose of this study is to utilize existential, caregiving, and critical race theoretical frameworks to explore critical influences on correctional end-of-life care advocates experiences, with particular attention to motivational factors, as well as suggestions for reform. Moreover, end-of-life care advocates' narratives will be collected to examine their meaning-making experiences and identify potential barriers to care. Correctional facilities encounter complex challenges with respect to the provision of humane health care, as it is readily apparent that barriers associated with end-of-life care delivery continue to surface for this aging population (Williams et al., 2013). However, the emergence of hospice-based and end-of-life programs, has sought to fill the gap in providing compassionate care to dying incarcerated individuals. Emphasizing comfort over curative treatments, end-of-life care interventions provide patients and loved ones with the assurance that their unique and holistic needs, including emotional and spiritual needs, at the end-of-life are honoured, with a compassionate team striving to deliver humane, person-centered care (Bolger, 2005). Thus, end-of-life care advocates, majority of whom have worked within correctional settings, are well-situated to address and meet the necessities of terminally ill incarcerated individuals, as they possess roles external to the carceral system. Studies dedicated to capturing the narratives of correctional end-of-life care advocates, as presented within this study, will elevate as an exemplar in client-centered care, as this permits the investigation and discovery of insights related to the challenges and triumphs of delivering clinical, psychosocial, and spiritual care to dying individuals in correctional settings.

Research Aims and Hypotheses

The implementation of end-of-life care has gradually become a prevalent service in attending to the unique needs of terminally ill incarcerated individuals. Current literature examines end-of-life interventions that exist in correctional facilities; however, very minimal attention has been provided to transformative experiences of individuals who advocate, and potentially deliver, end-of-life care. This qualitative study, utilizing semi-structured interview questions, via face-to-face interviews, will capture the narratives of advocates pertaining to their insights regarding end-of-life care by examining the meaning-making experiences of those endeavoring to implement end-of-life care in corrections. For this study, I will aim to explore critical influences on advocates' experiences, including:

(a) advocates' understanding of end-of-life philosophy

(b) motivating factors of advocates that promote caregiving opportunities

(c) barriers to the provision of end-of-life care

(d) how personal, social, and political influences related to correctional end-of-life care shape advocates' meaning-making experiences and

(e) to better inform the general public of this integral and humane service to combat the stigma related to the punitive treatment of terminally ill incarcerated individuals.

Overview of Methodology

Due to the limited research available concerning end-of-life care in corrections, specifically the perceptions of correctional end-of-life care advocates, interpretative phenomenological analysis (IPA) will provide an appropriate research framework for providing in-depth insight into the personal perspectives associated with this understudied, yet imperative provision of care. This study consisted of interviews with 12 participants who were identified as correctional end-of-life care advocates. Interviews were conducted over Zoom, with all participants agreeing to audio recording and eleven participants consenting to video recording. The duration of the interviews lasted from 60 to 90 minutes. Participants were recruited through the gracious efforts of The Humane Prison Hospice Project, the Social Work Hospice and Palliative Care Network (SWHPN) and Christa Burke, LCSW, ACHP-SW. Participants reside in the U.S., were 18 years of age or older and English speaking. Moreover, this qualitative study employed interpretive phenomenology to examine the narratives of correctional end-of-life care advocates. Participants were asked 15 semi-structured interview questions, with probing questions to allow for additional enlightenment and clarity.

Data analysis utilized interpretative phenomenological analysis (IPA), as this qualitative research approach examines the essence of the lived experiences of an individual, exploring how the individual understands their personal and social worlds and how they give meaning to particular experiences and events (Eatough & Smith, 2008). It is anticipated that the meaning units and essences of the narratives will include a sense of purpose and the transformation of self through advocating for others.

Rationale and Significance

This study will contribute to closing the health gap, an imperative Social Work Grand Challenge, for incarcerated populations (Grand Challenges for Social Work, 2021). This study is fundamental in understanding the role of correctional end-of-life care advocates, as the findings will provide researchers with an avenue to explore barriers to end-of-life care and potential solutions for incarcerated populations. Current literature concentrates primarily on the perspectives of correctional administrators, thus an increase in literature on the experiences of advocates for incarcerated populations would provide unique insights for various types of health professionals, such as nurses and social workers. Numerous challenges, including a lack of standardization of end-of-life care, fiscal costs, and lack of training for providers create detrimental gaps in care. However, new knowledge on the provision of care in correctional settings will assist in addressing gaps, to inform and encourage policymakers to make necessary revisions to current care mandates in corrections. For physicians and clinicians, this research could result in new therapeutic interventions for imprisoned persons at the end-of-life, especially regarding communication since a prevalent barrier to care in correctional settings is mistrust.

Further, this study will highlight the critical role correctional health care workers should continue to play in supporting incarcerated individuals to access integral end-of-life interventions, such as end-of-life care-based services and compassionate release, a policy that permits eligible elderly and/or terminally ill incarcerated individuals with the opportunity to die in their community. Ideally, terminally ill incarcerated individuals would be granted such release; however, only 4% of dying applicants are approved nationally on an annual basis (Berryessa, 2020). Barriers such as complicated language, complexities of eligibility requirements, over-reliance on prognostication, and social stigma merely exist to confuse, exhaust, and exasperate applicants and their legal counsel (Berryessa, 2020; Zunkel & Lessnick, 2023). Regrettably, this avenue lacks feasibility for many incarcerated individuals and thus is beyond the periphery of this study.

Currently, a scarceness exists of clinical and practical knowledge regarding the state of end-of-life care for incarcerated individuals. More concentrated efforts should be considered to monitor the quality of existing health care provided in correctional settings, as this continues to be under-represented (Burles, et al., 2015). Likewise, increased consideration should be given to how correctional staff and health care providers navigate issues related to end-of-life care, equity and the integration of community and prison-based palliative care interventions (Cipolletta & Oprandi, 2014). As such, this study aims to highlight advocates make meaning from their lived experiences in championing for dignified end-of-life care in corrections.

CHAPTER 2 – LITERATURE REVIEW

Introduction

While prisoner advocates have fought for the compassionate release of dying incarcerated individuals (the opportunity to die in a community-based setting, such as a hospital or hospice), many incarcerated individuals will face the reality of dying in prison (Loeb, 2013). It is evident, however, that correctional facilities were never designed to provide care to an aging population, creating numerous challenges for health care professionals within this setting (Klock & Liantonio, 2018). The structural restrictions of correctional facilities were created for young, able-bodied individuals; however, the reduction of correctional staff and unevenness of health care provision will create a double burden for prison staff (Turner et al., 2018). Prison health care professionals encounter difficulties and barriers that inhibit their ability to provide competent and ethical end-of-life care, as it is often influenced by personal, social, and political acrimonies related to criminality, the meaning of life, and end-of-life care for imprisoned people (Burles et al., 2015). Furthermore, as addressed by Howe and Scott (2012), correctional staff are confronted with issues concerning safety, which can further complicate end-of-life care delivery. Regrettably, traditional end-of-life care practices in a prison-based setting often conflict with security protocols and procedures, "leading to location-specific practices which differ from standard community-based care models" (Depner et al., 2018, p. 977). The security of incarcerated persons receiving care and correctional staff is of utmost concern, and therefore, security permeates decision-making in regard to end-of-life care (Penrod, et al., 2013). In addition to security concerns, correctional facilities are enduring reduced economic resources, resulting in additional barriers for correctional staff to meet end-of-life care mandates (Stern et al., 2010). Increased correctional staff time and appropriate training for end-of-life care would also add to costs (Penrod et al., 2013). With limited resources and mounting demands, medical care professionals will continue to struggle to provide essential, end-of-life interventions in corrections.

For individuals who have the freedom to die in their community, it is likely these persons receive support which underscore the essential factors required to deliver humane end-of-life care. Many patients have access to reliable medical practitioners; professionals who have opportunities to build trusting and comforting rapports with the people they serve. End-of-life care is often provided via multidisciplinary teams who work to ensure that terminally ill individuals have a comprehension of their diagnosis and prognosis, permitting the dying to dictate their own wishes and needs at the end of life. Delivering relief through pain medication is customary as this promotes comfort over curative measures, a significant tenet of end-of-life philosophy. Moreover, many “free” persons have access to additional supports which may include, but are not limited to, loved ones, spiritual care, and grief support. If a patient lacks decision-making capabilities, clinicians, relatives, or other health care proxies may assist to adhere to the principle of respecting a patient’s wishes on their behalf. Overall, the autonomy gifted to dying populations in the community is ubiquitous in comparison to their incarcerated counterparts, as imprisoned persons must combat mistrust and barriers to pain management. Though peer-caregiver models which utilize incarcerated volunteers represent an ideal model of care within corrections, vast improvements are still necessary to enhance carceral end-of-life care. Therefore, the roles of advocates who champion for compassionate care in corrections are incredibly vital, as these individuals seek to fill the gaps in care.

Establishing Trust

In the carceral system, establishing a trusting and genuinely compassionate rapport with an imprisoned population remains a challenge in providing adequate end-of-life care. Corrections enforce strict boundaries between staff and the incarcerated by training staff to view incarcerated individuals as a lower class of people who require staff to maintain strict control and sure the incarcerated personify an obedient commitment to their degraded status (Friedman, 2021). Regardless of the level of social support available to an imprisoned person, this population is susceptible to disconnection and increased mistrust with loved ones, as well as correctional staff and fellow incarcerated individuals. Additionally, imprisoned people view death as an escape from their current reality, with limited hope for the future (Handtke & Wangmo, 2014). In order to provide fundamental palliative care, an underlying relationship of trust and support must exist between the patient and practitioner. Not surprisingly, however, prisoners are less likely to trust the correctional system and therefore are more dubious regarding comfort measures at the end of life (Howerton et al., 2007). Regrettably, this inherent distrust can greatly influence prisoners in their decision-making regarding comfort care, as evident with “half of prison-based hospices [requiring] neither cessation of curative treatment nor a do-not-resuscitate order” (Klock & Liantonio, 2018, p. 5). Dying prisoners have also expressed themes reflecting a fear of death, access to health care in cases of emergency, and the use of coping strategies, such as denial and acceptance, to cope with the prospect of dying in prison (Handtke & Wangmo, 2014).

The inclusion of health care teams in hospice-based programs can assist in navigating the challenge of mistrust, however. Multidisciplinary teams, consisting of physicians, nurses, social workers, chaplains, and volunteers are necessary to provide proper medical, emotional, and spiritual care to effectively support an imprisoned person at the end of life. Bereavement support is also necessary for anticipated and sudden deaths within a correctional setting, and therefore should reflect services available in community hospice facilities (Handtke & Wangmo, 2014). Brown (2012) argues that a failed empathy exhibited by health care professionals, inhibits the creation of empathetic connections that are essential for health care professionals to effectively support the needs of dying prisoners and their families. This lack of empathetic understanding can negatively impact the goal of dying well as it inhibits meeting the needs and silences the voice of those at the end-of-life.

Pain Management

The provision of pain management for dying imprisoned people continues to be a challenging issue within correctional settings. Health care professionals argue that a dignified death is one without pain (Howe & Scott, 2012; Zimmerman, 2002); however, monitoring pain levels and administering suitable pain relief requires considerable time to ensure efficacy (Cloyes et al., 2016, 2017). Given that many correctional facilities are under-staffed, the provision of such care can be exceptionally demanding for prison staff and health care professionals (Turner et al., 2011). Moreover, as pain relief constructs a central tenant of care for individuals at the end-of-life, the limitations of correctional settings and related prescribing practices is evidently ambiguous and complicated. Yampolskaya and Winston (2003) identified a ‘conservative’ approach by correctional physicians when prescribing pain medication, balancing concerns over patients’ comfort with the risk of narcotics filtering through to the general prison population. Furthermore, the potential misuse of medication amongst prisoners and possible distribution of narcotics to other prisoners is of great concern, adding to the complexity of navigating pain relief for dying incarcerated individuals (Turner et al., 2011). Health care professionals expressed fears of being manipulated by incarcerated persons, potentially influencing whether, and the extent to which, medications are used for pain management (Tillman, 2000).

Contrariwise, the majority of U.S. prison hospice programs utilize sustained-released medications, thus limiting the opportunities for abuse (Hoffman & Dickinson, 2011). A culture of suspicion still remains, however, concerning the illicit drug trafficking of narcotics from health care providers and correctional staff (Linder & Meyers, 2007). The ‘masculine’ culture of correctional settings exists as an additional issue related to pain management, as imprisoned people may be reluctant to disclose feelings of pain, further complicating health care professionals’ ability to provide pain relief appropriately and effectively (Tillman, 2000). Furthermore, the anticipated normative and indifferent attitudes of incarcerated individuals in pain were challenged as patients disclosed the lack of appropriate medication available to them (Linder & Meyers, 2007). Additionally, an overwhelming concern is of the opinion that some correctional health care staff may believe that incarcerated populations deserve their suffering or are exploiting the system (Dawes, 2002). Prescribing pain medication to dying incarcerated persons within a correctional setting continues to provide unresolved challenges for both incarcerated individuals and correctional staff.

Peer-Caregiving as an End-Of-Life Care Program

An exemplar program aimed at alleviating pain and providing compassion utilizes healthy incarcerated individuals to deliver emotional and practical support to their dying peers. Unique in its approach, this model of care grants imprisoned people, medical care providers, and security personnel the rare opportunity to collaborate in a “neutral zone” to provide humane care to the dying (Tillman, 2000). In addition to assisting correctional staff with building communication and trust with the dying, peer-caregiver volunteers play an essential role in providing varying types of support, companionship, and assistance with activities of daily living (Evans et al., 2002).

Utilizing caregiver volunteers to deliver vital end-of-life care is a purposeful and cost-effective response to enhancing trust is the implementation of peer-caregiver end-of-life programs. Utilizing peer-volunteer caregivers is a prevalent avenue in providing compassionate care to the dying, as evident with 50% of prison-based hospice programs adopting this delivery of care. Perceiving peer-caregivers as allies, the dying attain a deep understanding of compassion and empathy from these particular volunteers due to the realization that peer-caregivers will eventually require end-of-life care themselves in a similar, confided setting (Cloyes et al., 2015, 2017). Findings demonstrate the positive effects of peer-caregiving in supporting the health needs of dying prisoners (Depner et al., 2018). These distinctive roles may benefit prison culture by developing a cohesive sense of community, in addition to reducing the effects of institutionalism, therefore increasing peer-caregivers' self-esteem and enhancing their sense of purpose and identity (Depner et al., 2018). Due to aging and dying prisoners' preference to be cared for by their peers (Dawes, 2002; Turner et al., 2011), the advancement of prisoner caregiving roles may assist the establishment of culturally responsive services. Moreover, training provided to volunteers to develop their peer-caregiving abilities may contribute to improving standards and accessibility of health care for all imprisoned people (Evans, 2006; Turner et al., 2011). Further, the lack of bereavement support for peer-caregivers providing end-of-life care as volunteers remains an unmet need within correctional facilities (Penrod, et al., 2013), as this support is an essential component for proper palliative care and assists those grieving the loss of a loved one (Kehl, 2006).

In addition to receiving clinical training and hospice education, the journey of becoming a hospice volunteer builds the skills of peer-caregivers and establishes a shared culture amongst prisoners (Cloyes et al., 2017). Moreover, specific outcomes that aid the long-term sustainability of peer-caregiver programs, including teamwork, stewardship, and outreach outside the hospice program were identified (Cloyes et al., 2017). Volunteers also described their transition from learners to teachers to mentors, valuing the continuous education and development allotted to them, in an effort to improve the provision of care to the dying (Depner et al., 2018). Experienced volunteers reported that the process of becoming a volunteer eventually progressed into the ongoing process of becoming the best volunteer they could possibly be (Cloyes et al., 2017). Professional development opportunities were often utilized by incarcerated volunteers, as they taught less-experienced volunteers, participated in conferences, recruited, mentored, and navigated new volunteers through the practical and emotional complexities of providing care within a hospice program (Tillman, 2000). It is apparent this ethic of continuous learning is valued amongst peer-volunteers, as it allows ongoing education and opportunities to gain end-of-life care experience. Moreover, peer-caregivers reported that volunteering for a hospice program instilled and heightened their sense of trust. This included, but was not limited to, learning to trust, being able to trust others, oneself, and being trustworthy (Cloyes et al., 2017). Evidently, this sense of trust is foundational to the teamwork and sense of contribution described by peer-caregivers and correctional staff, and how they represent the hospice program (Depner et al., 2018).

Correctional staff reported that the utilization of peer-caregiver volunteers, within the peer-care model, has allowed correctional end-of-life care programs to provide more comprehensive end-of-life care in comparison to a solitary prison health care staff (Cloyes et al., 2016). Furthermore, prison end-of-life patients reported lower end-of-life symptom prevalence and severity when compared with community-based samples (Rothman et al., 2018). This may be a result of peer-caregivers providing constant personalized and focused care for dying incarcerated individuals (Cloyes et al., 2017; Linder et al., 2006). Lastly, peer-caregivers who have the opportunity to participate as volunteers describe undergoing a transformative process which entailed the growth of personal strength and community empowerment (Cloyes et al., 2017; Loeb et al., 2013).

The humble presence of a hospice facility and/or program within the confines of a correctional environment affords imprisoned people with a sense of care and compassion. Peer-caregivers reflected that obtaining training and observing end-of-life care enhanced their understanding that humane treatment can exist within corrections (Ratcliff & Craig, 2006). Correctional staff expanded the benefits of this sentiment, describing that the presence of compassionate care lowers patients' stress, thus assisting security (Wright & Bronstein, 2007). Moreover, peer-caregiving allows for familial bonds between incarcerated individuals, providing an opportunity for personal growth and transformative experiences for both the dying and their peers (Loeb et al., 2013). Similarly, the support and insight of multidisciplinary team members aid incarcerated individuals at the end-of-life utilizing a foundation of ongoing communication, mutual respect, and relevant training. In contrast to community hospice settings available to the dying in corrections, the presence of an on-site hospice provides a calming influence within the facility, creating more trustworthy connections between incarcerated individuals and staff (Loeb et al., 2013).

Although peer-caregiver end-of-life programs have received public accolade for their compelling rehabilitative and redemptive narratives, they are still controversial (Ratcliff & Craig, 2006). Prison administrators, especially, conveyed concern related to the interactions of imprisoned persons that disobey institutional codes that prohibit close, personal contact between imprisoned persons (Cloyes et al., 2017). Additionally, responses from correctional nursing staff reflected a fear related to the “de-skilling” of nursing care and the desire to replace paid staff with unpaid labor (Cloyes et al., 2017). Regardless of the perceived benefits of peer-caregiver programs, this approach still raises the question as to whether this use of human capital is feasible, or even ethical. Nonetheless, peer-caregiver volunteers, correctional health staff and officers overwhelmingly validate that it is, indeed, both (Cloyes et al, 2015; Tillman, 2000).

Correctional End-of-Life Care Advocacy

Despite the evident and palpable benefits of implementing end-of-life care in corrections, specifically peer-caregiver hospice-based programs, many individuals and communities rebuff this considerate concept. The mere premise of compassionate care for the dying and confined creates a cognitive dissonance for correctional staff trained to maintain order, not to provide emotional and spiritual support (Kaushik & Currin-McCulloch, 2022a). Moving beyond correctional officers, administrators and societal members similarly resist the notion of a dignified death for the incarcerated (Kaushik & Currin-McCulloch, 2022b). Embracing perspectives which value punitive stances over empathetic gestures, the public struggles to provide and advocate for health equity to those individuals who are often out of sight and out of mind. Nonetheless, the plight of implementing correctional end-of-life care has not deterred various advocates from climbing a steep hill to deliver humanity and compassion for the dying and incarcerated. As Jamey Boudreaux, social worker and executive director of the Louisiana-Mississippi Hospice and Palliative Care Organization illustrates, “When we are convicted of a crime, the system has a way of trying to dehumanize us, turn us into a number, a statistic, into an 'animal the state has to control [yet] when you bring [end-of-life care] into prison, [incarcerated individuals] share a humanity. It changes the way they start thinking about themselves” (Coyle, 2020).

Currently at the forefront of this vital plight are advocates of the Humane Prison Hospice Project (HPHP), a California-based non-profit organization dedicated to delivering a humanitarian, cost-effective and restorative justice solution to ensure that those aging and dying in corrections receive compassionate care. Founded in 2015 by Sandra Fish, co-chair for San Francisco End-of-Life Network, and Ladybird Morgan, social worker and registered nurse specializing in hospice and end-of-life care, these advocates sought the collaboration of Marvin Mutch, current associate director of the HPHP and director of advocacy at the Prisoner Reentry Network. Mutch was imprisoned at San Quentin State Prison (California) for 41 years after a wrongful conviction in 1975 and was released in 2016. The amalgamation of Fish's and Morgan's advocacy and clinical skills, paired with Mutch's knowledge of legal processes and daunting experiences with loss and grief while imprisoned, the values and mission of the HPHP surfaced to provoke much warranted change. Today, the team at the HPHP strive for a world where incarcerated populations are regarded with dignity and respect, baring the basic human right to receive compassionate care at the end of life. The curriculum developed by the HPHP trains incarcerated volunteers in end-of-life care and grief support, as well as modes of crisis intervention that prepares them to support their peers who are suffering from depression, suicidal ideation, and/or the effects of trauma and violence within correctional settings. The HPHP's model benefits not only the terminally ill, yet the peer-caregivers who deliver the care, in addition to the correctional staff as they witness how transformative experiences emerge as end-of-life care volunteers learn to care for their dying peers. The outcome is a therapeutic community within concrete walls, resulting in a cultural shift toward compassionate care, empathy and support that sets the foundation for restorative justice practices; thus the correctional environment becomes a setting for rehabilitation and support opposed to conflict and punishment.

The prolific advocacy of the HPHP is unlikely to have emerged if it was not for the perpetual injustices and trauma endured by Mutch. As a survivor of childhood abuse and juvenile confinement, Mutch then endured 41 years of false imprisonment. During these decades of harrowing conditions within San Quentin State Prison, Mutch observed an absence of compassion for the dying and survivors. As he explains, “there were many times when guys died on their cell floor. If you die in your cell, your cellmate goes to segregation until the autopsy is completed. Most of these guys have lived together as lifers for years, [and] now their grief process must start in total isolation" (Coyle, 2020). To summarize, should an incarcerated individual die of natural causes, the surviving cellmate will be sent to solitary confinement until a medical examiner can absolve the survivor of the death, thus prosecuting the bereaved under the jurisdiction of guilty until proven innocent.

The HPHP is largely influenced by the mission and success of the Brothers’ Keepers Peer Support Program at San Quentin State Prison; an existing curriculum developed and utilized by HPHP staff to train hospice volunteers, in addition to implementing materials utilized in training peer hospice volunteers at California Medical Facility, home of the only prison hospice program in the state. Since 2017, the HPHP team has trained volunteers who have graduated from Brother’s Keepers training; training which entails how to be at the bedside of their dying peers and provide empathetic and compassionate comfort care. The fruition of the Brother’s Keepers program was in response to the distressing rate at which incarcerated individuals were taking their own lives at San Quentin. In 2005, San Quentin State Prison had a suicide rate six times the national average and presently, it is zero due to the peer intercessors who permit this effective program to flourish (The Coalition to Transform Advanced Care, 2022). Undoubtedly, this model of care is transformative for the dying, for the peer-caregiver providing the care, and for the correctional staff who witness this act of compassion and love. As one of the Brother's Keepers shared of his experience sitting along a dying peer, "His dying made me start to change. He was my friend. The person who took care of him, that was a good part of me" (The Coalition to Transform Advanced Care, 2022).

Simultaneous to the grassroots efforts in training incarcerated volunteers to be caregivers to the dying, the HPHP advocacy adopts a top-down approach to increase public awareness, change attitudes, and promote policy reform that supports the vision of dignified deaths for all. The team at HPHP participates in conferences and forums, speaks before legislators and key policymakers, in the hopes that legislation reflects mandates in which hospice care is a basic right for each individual dying while incarcerated. The HPHP aim to implement their model of care to other correctional facilities in California and across the nation, to assist in training a cadre of incarcerated individuals to provide end-of-life care and to develop integrated hospice programs. As reflective of the HPHP team, as well as members of the National Prison Hospice Association, a network designed to assist corrections and hospice professionals in their continuing efforts to develop high quality patient care procedures and management programs, correctional end-of-life care advocates have historically championed that no being should be excluded when dying with dignity. Therefore, dignity must be viewed as an essential component of one's humanity and must be extended into the shadows of society, particularly for those who will die in isolation (Coyle, 2020).

Limitations of Reviewed Studies

Despite the valuable insights the aforementioned studies provide, they are derived from very few studies. Although a majority of the literature reviewed was conceptual and theoretical, there was a limited number of empirical studies. In regard to methodology, the limited empirical studies were cross-sectional and utilized small sample sizes. Additionally, a significant limitation of this evidence are the limited studies that address and/or disclose the direct outcomes from the perspective of dying incarcerated individuals. As this imperative voice is silenced within the majority of prison health studies, the true outcomes of their experiences at the end-of-life, related to other facets outside of pain, such as existential quality of life and social support, are difficult to ascertain. In fact, there has been limited research, in general, on the perceptions and attitudes of those who work with terminally ill incarcerated individuals (Cloyes et al., 2016; Penrod et al., 2016; Wright & Bronstein, 2007). Consequently, the scarcity of literature and significant gaps regarding correctional end-of-life care and indispensable advocacy regarding this human rights' issue merely amplifies the imperative need for this qualitative study. Advocates who have close connections to peer-volunteers through training and supporting them in their roles as caregivers, can provide a voice and glimpse into the veiled world of end-of-life correctional care.

Gaps in Current Literature

Despite considerable research aimed at identifying the needs of individuals at the end-of-life, only limited discussions regarding the specific needs of incarcerated populations and the systems which deliver their end-of-life care exist. With access to terminally ill individuals in corrections often restricted, it is thus the insights of those campaigning for integral correctional health care reform that emerge as integral. Caregiving for dying imprisoned persons is an under-researched area, despite the growing importance of this advocacy (Klock & Liantonio, 2018). Studies have suggested that supportive end-of-life interventions that entail compassionate understanding, intimate relationships, and autonomy have effectively supported dying individuals as they navigate the physical, emotional, and spiritual challenges at the end-of-life; aspects of care which correctional health care advocates tirelessly promote (Hoffman & Dickinson, 2010). With a comparative literature review of prison palliative care determining that "limited available literature on prison hospices may suggest an attitude of less value being placed on end-of-life care for incarcerated individuals" (Stone et al., 2011, p. 970), advocates thrive to shed a vital light on this marginalized population. Therefore, utilizing advocates to further an investigation into the unique needs of aging and dying imprisoned persons should be prioritized, as this permits a better understanding into the supportive interventions that are sensitive to correctional end-of-life care concerns.

Longitudinal research is additionally required in regard to correctional end-of-life care advocacy. Research dedicated to showcasing the processes and dedication necessary to implement end-of-life models of care in corrections will allot a vital understanding in why such advocacy is crucial for dying imprisoned persons. The implementation of longitudinal studies allows for a more profound understanding of the dynamic motivations to implement end-of-life care, bonding opportunities, gaps in care, and the critical reform crucial to advance care for the dying. Documenting the evolution of peer-caregivers' attitudes towards end-of-life care via the narratives and experiences of advocates could provide noteworthy insight and knowledge of caregivers values, beliefs, and perceptions of end-of-life care. This is vital since the perspectives of the imprisoned have been marginalized and undervalued due to a lack of social status and the vulnerability they face. With the voice of advocates, the ability to identify and relate events to particular exposures would support a deeper understanding of the barriers related to end-of-life care in corrections. Due to the lack of longitudinal studies, there is minimal understanding and support related to evolving needs over time, the precursors of increased needs, proper timing of interventions, and the potential consequences of failing to meet these needs (Stewart & Edmond, 2017). Therefore, the views and perceptions of correctional end-of-life care advocates should be examined over time to attain a truthful, holistic comprehension of their transformative experiences.

An absence of theoretical foundations currently exists in empirical research that pertains to correctional end-of-life care advocacy. The phenomenon of end-of-life advocacy is an important aspect of the death and dying experience for imprisoned human beings. The complexity and variability that characterizes end-of-life advocacy provides a an often veiled picture of the dying process and related needs of incarcerated individuals. End-of-life care advocates play an integral role in helping the incarcerated navigate this complex experience, as they are well-situated to deliver tools and education pertaining to caring for the dying, in addition to observing alarming gaps in care (Norton & Talerico, 2000). Therefore, end-of-life care advocates can aid in a further understanding of the requisites to delivering dignified and optimal care for dying incarcerated individuals.

Summary of Literature

Current evidence suggests that whilst there has been a growing discourse regarding the provision of compassionate end-of-life care to incarcerated individuals, as demonstrated by the gradual increase of prison-based end-of-life programs, there still remains ongoing challenges in effectively implementing these indispensable and humane interventions to an isolated population. Advocates have highlighted correctional facilities as lacking end-of-life care services, with the justifications for imprisonment are often in conflict with or impede the provision of quality care to imprisoned populations. Given the various barriers that limit imprisoned people access to proper health care, the prospect of dying well in corrections is severely questioned. Thus, a pressing need to further research and explore end-of-life care in correctional settings utilizing the transformative insights and experiences of advocates is evident for both policy and practice implications.

CHAPTER 3 – THEORETICAL FRAMEWORKS

Introduction

Various theoretical frameworks were utilized in providing a foundation for understanding the influence of correctional end-of-life care advocacy on participants' meaning-making experiences. This chapter presents theories pertaining to the provision of end-of-life care for incarcerated individuals and guidance of how correctional end-of-life care advocacy illuminates participants meaning-making experiences. Additionally, the theoretical perspectives will support the revelation of how advocates, when challenged with the trials and tribulations of their advocacy, find an existential understanding of their role and responsibilities as a correctional end-of-life care advocate.

Existential Theory

Contrary to the deterministic view of human nature, *existential theory* emphasizes the freedom that individuals must create meaning from their experiences (Sartre, 1938; Wilkes & Milton, 2006). A primary goal that existentialists embrace is encouraging human beings to connect with their real selves (comprised of authentic feelings and emotions) and make choices that reflect with the real self and its wants, thus preventing other individuals or events from determining their behaviour (Fernando, 2007). Human beings are susceptible to becoming distracted by superficial relationships, thus losing focus on their own potential to express their unique existence; however, existential theory demonstrates that when individuals are able to recognize their own feelings and emotions, they have the ability to embrace the potential for growth and improvement (Moustakas, 2004; Satre, 1938). Further, this approach promotes individuals' capacity to make choices for themselves with an awareness of their role in the family and community (Fernando, 2007). The roots of existential theory lie in 1800s philosophy and were greatly influenced by philosophers whose interests centered on human existence (Gingerich & Eisengart, 2000). Søren Kierkegaard proposed that human discontent could only be conquered through internal wisdom, while Friedrich Nietzsche presented the idea of free will and personal responsibility (Fernando, 2007). By the 1900s, the exploration of role interpretation and investigation flourished and contributed to the existential approach presently known. The four premises, or "givens" of existential theory, *death, freedom, isolation,* and *meaninglessness*, were subsequently established to assist with the complex aspects of an individual's existence (Yalom, 1980). An awareness of death, or the concept of "nonbeing", can create paralyzing thoughts that can inhibit an individual's ability to live a life worth living, whereas freedom refers to individuals creating their own world and related life stories (Fernando, 2007). Isolation addresses the fundamental separateness individuals possess and how this aloneness of the human condition occurs despite the connections that may exist with others (Gingerich & Eisengart, 2000). Lastly, meaninglessness suggests the absence of any apparent meaning or sense to one's life, therefore inspiring individuals to create reality and their own meaning in life, thus providing direction and structure (Krueger & Hanna, 1997).

To investigate end-of-life care advocacy in correctional settings, issues related to existentialism can serve as an effective central concept. Cassel (2004) defined existentialism at the end-of-life as hopelessness, futility, meaninglessness, disappointment, remorse, death anxiety, and disruption of personal identity. In congruence with the aforementioned "givens" of existential theory, these different concepts relate to individual, end-of-life situational experiences through the experience of dependency (inability and restrictions on freedom), the experience of meaning (or lack of meaning), thoughts about the dying process, as well as thoughts about faith and personal suffering (Dobrikova, et al., 2016, p.48). More specifically, an existential approach to end-of-life research recognizes that the subject (ie. the advocate) is one's own being. In these instances, the concept of freedom is essential, as a lack of freedom can diminish the awareness of one's possibilities (Feldman, 2002). Further, existential theory in this particular area of study adopts the position that one cannot separate what an individual does from who the individual is, indicating that advocates must question who they are as champions for end-of-life care in order for research in this area to be effective (Cooper, 2008). Greene (1989) suggests existential-driven research has the ability to attend to a situation that differs from other forms of research, as it possesses "a certain mode of human attending, active attending and active interpretation, not the blank passivity of powerlessness (p. 36). Similarly, it can lead to aspects related to decision-making, and the power to act, thus providing a fundamental search for freedom through critical understanding (Feldman, 2002).

Jean Watson's Theory of Human Caring

Jean Watson's theory of human caring is a novel approach to the caregiving process based on the idea of lived phenomena and subjective experiences. This theory outlines various caring factors associated with the caregiving process. With advocates in positions of inter-caregiving roles in supporting dying imprisoned people, such as social workers, nurses, and chaplains, this theory can serve as a motivating influence in promoting humane and dignified care. Ten "carative" factors were used in the theoretical framework of this theory, which sought to define nursing as a unique profession based on distinct nursing-specific caring practices. This theory acknowledges that "carative" factors were developed based on Watson's own philosophical, intellectual, and practical experiences in nursing (Watson, 2007). The following 10 original "carative" factors were outlined in 1979 by Watson:

> *formation of humanistic-altruistic system of values; instillation of hope; cultivation of sensitivity to oneself and others; development of helping-trusting (human caring) relationship; promotion and acceptance of the expression of positive and negative feelings; systematic use of the scientific problem-solving method of decision-making; promotion of interpersonal teaching-learning; provision for a supportive, protective, and/or corrective mental, physical, sociocultural, and spiritual environment; assistance with gratification of human needs; allowance for existential-phenomenological forces. (Watson, 2007, pp. 131–132)*

The core guiding concepts of the theory are grounded in the idea of "relational caring for self and others" (Wagner, 2010, p. 1) with carative factors based on a moral, ethical, or philosophical foundation of "love and values" (Wagner, 2010, p. 1). The caring relationship that emerges is supported by genuine presence of both the advocate for care and the dying population. Watson states there are "multiple ways of knowing," and this knowledge is attained through many means including science, art, intuition, personal, culture, and spirituality (Wagner, 2010, p.1). Meditation and reflection are also important in this theory, which are used to increase awareness of the humanism of both individuals involved in the caring relationship. Watson explained that caring involves caring for oneself, others, the environment, and the universe and has the potential to change each. Watson's theory encourages an understanding of the trajectory of caregiving advocacy and thus can provide an awareness of the experiences of advocates, leading towards enhanced, proactive supportive care for dying incarcerated populations.

A small but growing literature is developing on existentialism and end-of-life care; however, published literature revealed no studies pertaining to correctional end-of-life care and more specifically, advocates of this care. Existential distress is a common phenomenon in end-of-life care; patients, nurses, and researchers have illustrated the reciprocal nature of suffering among patients and those who care for them (Funk et al., 2014). Correctional end-of-life care advocates are not immune to the reciprocal nature of suffering impacts them and those they support, which may result in psychological and emotional distress, depression, loneliness, and suppression of social activities (Wittenberg-Lyles et al., 2011).

Watson's theory provides end-of-life care advocacy research with a nursing approach that is holistic and acknowledges the subjective experience of the advocate and individuals they champion for. Watson's theory provides an evolved approach to defining caregiving and related advocacy, providing a theory fundamentally rooted in postmodern thought. With a postmodernist approach, advocates can consider the delivery of end-of-life care as a contextually driven and meaning-laden experience. Further, Aghaei et al., (2020) reports Watson's Theory as a theory of care and guidance for providing dignified, end-of-life care. This framework can be utilized by advocates in different conditions and places and analyzes the incarcerated in their cultural context, family, and society, allowing the advocate to get adapted and provide unique support. Moreover, utilizing the core theory concepts can assist advocates in promoting a common language for all health care providers in care and intervention planning for dying incarcerated persons. With the advocacy of and provision of compassionate care at the end-of-life, the humanistic relationship framework and strategies such as paying attention to the spiritual aspects of terminally ill incarcerated individuals, meeting their unique needs through purposeful care, effective presence, and practice of love and kindness can be used to enhance trust and provide effective services to the dying.

Critical Race Theory

Critical race theory (CRT) originally emerged in academic legal scholarship in the United States as a means to characterize the social construction of racial categories as a method of oppression and the systemic existence of racism in society (Bell, 2022). Though this theory does not serve as a framework to underlie this study, this theory illustrates the societal power that permits one dominant socially constructed racial group to marginalize others. Moreover, this theory illustrates why Black, Indigenous, and people of colour (BIPOC) are disproportionately harmed by the corrections system and are therefore at higher risk of an inhumane end-of-life experience. Despite CRT originally developed within a legal framework, scholars in the health sciences seek to make connections between this theory and health outcomes (Roberson, 2022). In the context of incarceration, the racial and ethnic disparities bourgeoning within state prisons across the U.S. are unmistakable. At present, Black Americans are incarcerated at a rate five times the rate of White Americans. In addition to the individual-level consequences of imprisonment, including barriers to employment and acquiring stable housing, societal level consequences are equally prevalent, as high levels of incarceration in communities create high levels of crime and neighbourhood corrosion, thus fueling greater disparities (Dutil, 2020; McCarter, 2016). It is evident that this harrowing outcome of mass incarceration is not due to any coincidence; instead, this has been designed as a result of policies created by a dominant White culture that promotes the suppression of BIPOC individuals (Dutil, 2020). Therefore CRT is an appropriate framework to incorporate in a study concerning incarcerated populations, as this theory thoroughly examines the concepts of racism, power, and policy within the criminal justice field (Dutil, 2020; Delgado & Stefancic, 2017).

The deplorable lack of medical care for human beings in carceral institutions particularly affects Black, Latinx, and Indigenous individuals due to the higher rates of incarceration of these populations (Farr, 2022; Sohn, 2017; Binswager et al., 2012). The inability to acquire medical care while in custody places a greater number of risks for more vulnerable and minority populations, as reflected in the general population where fewer BIPOC people have health insurance (Sohn, 2017). Thus, due to the lack of access to health care for BIPOC individuals, those in custody who identify as such have disparate outcomes for chronic and terminal diseases (Farr, 2022; Binswager et al., 2012). The majority of incarcerated individuals are age 55 or older and have high health risks for chronic and terminal diseases (Li & Lewis, 2020). The older age of this population specifically affects Black, Latinx, and Indigenous people who are more likely to have significant health risks (Hawks et al., 2020). As reflective in the general population, Black, Latinx, and Indigenous people in corrections are at a higher risk for chronic and terminal illnesses largely due to the unequal income and social conditions in the U.S. (Hawks et al., 2020; Binswager et al., 2012).

Chapter Summary

In summary, the prevalent characteristics of existential theory, Watson's theory of human caring, and critical race theory each address relevant aspects of correctional end-of-life care advocates meaning-making experiences. Motivational factors guiding participants to advocate in the field of correctional end-of-life care may also derive from the aforementioned theories; however, further research is necessary to study the distinctive connection between theory and meaning-making within advocacy work.

CHAPTER 4 – METHODOLOGY

Introduction

The objective of this qualitative study is to explore the meaning-making experiences of individuals advocating for the implementation of prison-based end-of-life programs. A semi-structured interview guide (see Appendix A) was designed consisting of 15 questions; questions influenced by existentialism and Jean Watson's theory of human caring, as well as current literature focused on correctional end-of-life care and my own professional experience working within the field of death and dying. More specifically, the questions addressed advocates' motivations, knowledge of end-of-life philosophy, and the personal challenges and triumphs associated with advocating for dignified care for terminally ill incarcerated individuals.

Phenomenology is grounded in early-20th-century continental philosophy, with particular emphasis on the works of Heidegger (1962) and Husserl (1913). The beginning and end point of phenomenological research is lived experience and encompasses a temporal structure; it can never be grasped in its immediate manifestation but only reflectively as past presence. The interpretive assumption of lived experience treats experience as a text, understanding the meaning of the whole, and vice versa (Smith & Shinebourne, 2012). Thus, a meaningful interpretation consists of back-and-forth movement between parts and whole. Understanding cannot be pursued in the absence of context and interpretive framework. In hermeneutic perspective, human experience is context-bound and there can be no context-free or neutral scientific language with which to express what happens in the social world (Eatough & Smith, 2008).

Interpretative phenomenological analysis (IPA) is a qualitative research approach that examines the essence of the lived experiences of an individual, exploring how the individual understands their personal and social worlds and how they give meaning to particular experiences and events (Eatough & Smith, 2008). Through the utilization of semi-structured interview questions, the goal of this study is to increase the understanding of the essence of the lived experience of those advocating for end-of-life care for incarcerated populations by exploring their motivational factors, perceived benefits of end-of-life care prison programs, potential unmet needs in delivering care, and their own personal struggles and successes in advocating for compassionate support to dying incarcerated individuals.

Interpretative phenomenology analysis is a prevalent methodology in exploring the transformative experiences of caregivers. Interpretative phenomenology has assisted researchers in examining caregivers who support individuals with varying diagnoses, including (but not limited to) mental health (Park, 2012), dementia (Quinn et al., 2015) and cancer (Githaiga, 2016), Moreover, this analysis has been employed to explore advocates and caregivers of diverse populations, from adolescence (Virat & Dubreil, 2020) to older adults (Williams et al., 2013). In regard to end-of-life care, interpretative phenomenology has identified various essences which permit a deeper understanding of advocates and caregivers' lived experiences. In Tan-Ho et al.'s (2020) study of end-of-life caregiving among Asian family members, numerous themes emerged to highlight the motivating factors related to caregiving, such as cultural influences, blessings, burdens, and self-determination. As a result of this analysis, the researchers suggested interventions which should be offered to family caregivers in a culturally-relatable manner, emphasizing how these advocates will assist family caregivers in enhancing their practical caregiving with heightened competence and a sense of meaning-making.

An interpretative phenomenological study of the lived experiences of family advocates and caregivers for individuals with advanced dementia (Peacock et al., 2013) identified two essential aspects embedded in this end-of-life care: being-with and being-there. Further findings examined advocates and caregivers' existential life worlds, demonstrating that
1) *spatiality* provided a sense or lack of feeling welcome to provide end-of-life care;
2) *temporality* was an eternity or time melting away quickly, or the right or wrong time to die;
3) *corporeality* revealed feelings of exhaustion; and 4) *relationality* was felt as a closeness to others or in tension-filled relationships. Subsequently, the authors encouraged that a deeper understanding from bereaved caregivers' perspectives will assist health care advocates and practitioners in better supporting and empathizing with family caregivers. Moreover, further research is warranted that focuses on other places of death and differences in experience based on the relationship to the care receiver.

Overall, IPA provides the opportunity to "thicken" (Geertz, 1973) the description of what is proven effective for correctional end-of-life care advocacy. With a focus on an identifiable phenomenon, IPA can lead to the identification of the actual processes that resulted in a specific outcome in a particular context (Maxwell, 2012). Moreover, IPA permits the inclusion of context-specific aspects such as therapeutic approach, setting, or presenting issue (Pawson, 2006). Lastly, IPA seeks to incorporate different epistemological and ontological approaches to the understanding of clinical research and allows for the inclusion of meaning and values (Sayer, 1992).

Utilizing interpretative phenomenology provides participants with the ability to share their own perspectives and freedom to share what is of interest to them. Interpretative phenomenology additionally encourages showcasing participants' verbatim narratives to illustrate their genuine and authentic responses. The semi-structured questions permit participants to guide how they prefer to answer the questions, enabling flexibility and participant control. Further, advocates are provided with very rare opportunities to share their personal and transformative experiences in an incredibly unique field of care. These individuals are essential members of their community and it is imperative that all populations, from health care workers, to researchers, to the general public, are aware of end-of-life support in correctional settings and the positive outcomes that are produced.

The purpose of this study is to capture the meaning-making narratives of correctional end-of-life care advocates. The study included five main exploratory aims to: (1) explore advocates' understanding of end-of-life philosophy; (2) motivating factors of advocates that promote end-of-life caregiving opportunities; (3) barriers to the provision of end-of-life care; (4) how personal, social, and political influences related to correctional end-of-life care shape advocates' meaning-making experiences and; (5) to better inform the general public of this integral need and humane service to combat the stigma related to accessing end-of-life care for incarcerated individuals. Throughout the data collection and analysis, I adhered to the following research question: "How do these participants find and/or make meaning from their correctional end-of-life care advocacy?"

Research Sample

I chose to focus on advocates in the field of correctional end-of-life care for several reasons: (1) advocates possess knowledge and information regarding care for terminally ill incarcerated individuals regarding clinical practice, policy trends, or both; (2) correctional end-of-life care is an under-researched area prompting a need to gather systemic insights from various correctional health care professionals; (3) advocates have a deep understanding of public perceptions; and (4) to provide an outlet for advocates, such as myself, to find and reflect upon the intrinsic value in the work they do.

The study's inclusion criteria consisted of English-speaking individuals who identify as a correctional end-of-life care advocate (ie. social worker, chaplain, peer-caregiver program directors), who are over the age of 18, reside in the United States and are English speaking. The exclusion of advocates outside of the U.S. was purposeful as knowledge of and/or experiences with the U.S. carceral system maintains focus on this specific population. Despite differences in life circumstances such as education and career, the narratives of correctional end-of-life care advocates created comparable meaning-making experiences.

The final sample for the study consisted of 12 advocate participants; however 14 consented to participate in the study. Two individuals did not follow-up with the PI to be interviewed. Of those 12 interviewed, 11 participated in a video and audio recorded Zoom interview; one participant could not accommodate this platform due to carceral restrictions, thus the interview was audio recorded over the telephone. The study included a fairly diverse sample of advocates as professions included chaplaincy, social work, and nursing. Participants resided in California, Missouri, or Colorado, and had an average of 15 years of experience in correctional end-of-life care advocacy. Table 1 presents the participants demographic characteristics.

Table 1

Participant Demographics

Profession	U.S. State	Years of Advocacy Work
Chaplain	CA	28
Filmmaker	CA	24
Non-Profit Co-Founder	CA	16
Non-Profit Outreach Manager	CA	1
Non-Profit Program Director	CA	35
Non-Profit Program Director	CA	38
Registered Nurse	CA	12

Table 1 (continued).

Lawyer	CO	2
Registered Nurse	CO	9
Social Worker	CO	7
Chaplain	MO	6
Social Worker	MO	6

Participant Recruitment

Participants were recruited through the generous efforts of The Humane Prison Hospice Project, the Social Work Hospice and Palliative Care Network (SWHPN) and Christa Burke, LCSW, ACHP-SW. Personal identifiers, including names, were excluded from the interview transcripts and overall study. The Principal Investigator (PI) sought advocates' consent to reflect participants understanding of the aims and purpose of the study. The link to the study's consent form was delivered via email and consent was recorded utilizing Qualtrics software. Participants were asked for their first/preferred name and were provided with the option of being contacted via email or telephone. This consent also addresses the right of the participant to leave the study at any point. All research materials were identified with a unique de-identified study number that was not affixed to the participant.

Study Design

This qualitative design employed interpretive phenomenology to examine the narratives of correctional end-of-life care advocates. Interpretative phenomenological analysis (IPA) is a qualitative research approach that examines the essence of the lived experiences of an individual, exploring how the individual understands their personal and social worlds and how they give meaning to particular experiences and events (Eatough & Smith, 2008).

The stages of interpretative phenomenological analysis include:

(1) *Reading and re-reading the interview transcription*

Highlighting or “chunking” significant responses from the individual, statements, sentences, or quotes in the transcript (open coding)

(2) *Identifying meaning units (themes)*

Identification of and labelling of major and minor meaning units

(3) *Structuring the analysis*

Clustering the meaning units are labelled in a way to capture their essence

(4) *Production of a summary table of the meaning units*

Quotations selected that illustrate meaning units and abandon meaning units that are not well-represented

(5) *Construction of a cohesive narrative*

The narrative is based on the summary table; direct quotes from participants are included to add depth and richness

Data Collection

Advocates responses were captured via Zoom through audio and video recordings or through a recorded telephone conversation. Utilizing the interview guide, I sought to collect advocates’ narratives pertaining to their experiences as correctional end-of-life care advocates. The following variables serve as key foci of the interview guide:

- correctional end-of-life care advocates’ understanding of end-of-life care philosophy
- motivating factors that promote caregiving and advocacy opportunities
- barriers to the provision of end-of-life care
- how the personal, social, and cultural influences related to end-of-life care shape advocates’ meaning-making experiences

The duration of each interview ranged from 60 to 90 minutes. Sociodemographic data collected pertained to advocates' current profession, with their U.S. state of residence and years of service as a correctional end-of-life care advocate also being noted. Once the interview was completed, I transcribed the responses and saved the transcriptions by the participants' de-identified study number as a word document on Colorado State University Microsoft Teams folder only accessible to the PI and Dr. Currin-McCulloch. These files will be permanently deleted from Colorado State University's Microsoft Teams folder (within 1 year of the participant's completing their interview). The transcription documents are stored on CSU's Microsoft Teams folder until transferred to MAXQDA for qualitative analysis. All study files will be saved on a password protected computer with MAXQDA software. These files will be stored in the Colorado State University Microsoft TEAMS folder only accessible to the PI and Dr. Currin-McCulloch. MAXQDA files will be permanently deleted from the Microsoft Teams folder three years after completion of the study. These software files will be stored on a password protected computer that is only accessible to myself and Dr. Currin-McCulloch.

Ethical Considerations

Prior to the initiation of data collection, I received approval from the Institutional Review Board at Colorado State University. Participants were not provided an incentive to contribute to this study; however, participants were encouraged that their narratives would aid in the plight of raising awareness of this integral topic and they may find great intrinsic value in sharing their insights and experiences. Moreover, as a health care provider, I have a deep understanding of how sharing personal narratives can invoke latent trauma and distressing thoughts. Therefore, vital respect for participant's emotional well-being was prioritized for each interview, along with a kind reminder that participants were allowed to leave the study at any time.

Data Analysis

Analysis of the data employed a constructivist framework to enable multiple interpretations of data (Brooks & King, 2014). Employing interpretative phenomenological analysis (IPA) encouraged the researcher to investigate and interpret the impact of the phenomenon on the ‘lived experiences’ of the research participants. This approach is interpretative, interpersonal, and interactive in nature; endowed with many features that assist researchers with rich abundance of data insight and holistic flavor of the narratives being explored (Alase, 2017). The essence of this approach is to understand and amplify the ‘lived experiences’ of the research participants, by exploring and maximizing the potential opportunities and possibility that the tradition/approach affords them. Moreover, IPA affords participants the opportunity to share their ‘lived experience’ narratives without fear of distortions and/or prosecutions. This study, however, will explicitly share with potential participants (via the consent form) that their responses may be viewed by correctional staff, as per the correctional facility’s correspondence policy.

Through the application of interpretive phenomenology, practical acts of living, accessed via narratives, assist to reveal deeper meanings. Additionally, it increases sensitivity to humans’ ways of being-in-the-world, as opposed to providing theory for generalization or prediction of the phenomena. Within this methodology, participants are considered to be valuable team members as they are the individuals experiencing the phenomena. Interviews were transcribed verbatim to provide a full and accurate account of participant experiences. Further, interpretative phenomenology encourages researchers to bracket themselves away from the issue being researched and set aside prejudgments, biases, and preconceived ideas about a subject we are trying to understand (Moustakas, 2004). Thus, the PI acknowledged any assumptions that could influence the investigator's conduct during the interviews and the team's interpretation of the narratives. Moreover, interpretive phenomenology relies on an inductive process: the procedure is exploratory, and no research hypotheses are formulated before starting; rather, they emerge from participants' narratives, designed to penetrate as far as possible into the participants' lived experience. Thus, variables will evolve based on the participants' descriptions of their experiences.

The key variables will be measured utilizing interpretive phenomenology methods (Smythe et al., 2008). An integral aspect of this methodology is providing participants with the opportunity to share their narration of their own 'lived experiences' (Alase, 2017). To best capture these lived experiences, the following data coding procedure and process were utilized (Alase, 2017):

(1) I transcribed all interview responses and convert responses into a MAXQDA analysis file. I read through all participants' response transcripts as an iterative process to identify common themes; searched for words/phrases that are repeated in the participants' responses to narrow down (condense) the words/sentences in the transcript. My advisor (Dr. Currin-McCulloch) reviewed the codebook after my initial analysis to ensure the codes were appropriate and accurate. I also consulted with my advisor throughout the coding process and within the final data analysis phase to garner an accurate reflection of advocates' meaning-making experiences.

(2) A further condensation process to reduce the first generic chunky statements/sentences into fewer words to approach the 'core essence' (emerging themes) of what participants are actually conveying. This process permitted another opportunity to extrapolate in very few tangible words the true 'core essence' of what the phenomenon (correctional end-of-life advocacy) has meant to the 'lived experiences' of the participants.

(3) This category stage (subordinate themes) entailed narrowing down participants' responses to a very few words to encapsulate the 'core essence' of the central meaning (meaning unit) of the participants' 'lived experiences' in one or two words.

(4) A similar process from the category stage was utilized to develop research themes (superordinate themes), to capture and represent the 'core essence' of the 'lived experiences' of the participants without distorting or misrepresenting the 'core essence' of what the participants have experienced.

The resulting emerging, subordinate, and superordinate themes, with verbatim quotes, were utilized to construct a table to represent each theme (see Appendix B), which guided the data analysis write-up. Additionally, the process of this theme analysis incorporated the support of Dr. Currin-McCulloch.

Researcher Assumptions

Throughout my post-secondary education, I have gained extensive knowledge, experience, and expertise regarding the needs of an aging population, specifically those at the end-of-life. Upon graduating with a Masters of Science in Social Work, I worked as a medical social worker for ten years, supporting diverse populations, from intensive care settings to community hospices. As a result, I have had the incredible opportunity to witness various forms and degrees of caregiving at the end of an individual's life. I have had the utmost pleasure in participating and supporting individuals at the end-of-life, as they are surrounded by loved ones and means to access adequate medical care; therefore, I have been a spectator to dying well. As we are all incredibly unique beings and thus require our own unique needs as we die, there is simply no "one size fits all" solution to end-of-life care. Undoubtedly, when faced with the anticipated demise of a human being, including our own self, the ability to predict our actions and feelings is unrealistic. Pairing unpredictable feelings with the provision of practical assistance and emotional support to the dying is an incredible balancing act to achieve. However, with the presence of compassion and dignity, the loss of human life has the potential of being a beautiful process. Thus, the mere fact that individuals in this world advocate for marginalized and isolated populations to receive such dignified end-of-life care is a bright example of restoring faith in humanity.

Although my professional career has provided invaluable knowledge and experiences, it’s the opportunities to advocate that bring the most insight and joy. As an individual drawn to root for the underdog, it is the lack of respect and abysmal access to care that incarcerated populations endure that motivates my actions and provides a deep sense of purpose. I only know these stories through research and the media, however. I am incredibly grateful to be given the opportunity to provide a platform for advocates like myself and give voice not to the voiceless, but to those who have been purposely silenced. Thus, one of the most effective avenues to gain a genuine understanding of dying in corrections come from those who advocate for compassionate care at the end-of-life.

Due to previous research findings (Burles et al., 2015; Depner et al., 2018) and this author’s own professional experience as a palliative care social worker, it was anticipated that the following aspects may arise during my bracketing processes:

(a) advocates’ understanding of end-of-life care will be dependent on previous experiences with end-of-life care, in addition to the education provided within any end-of-life training they may have received. I believe that a concrete and deep understanding of end-of-life care philosophy (mission, values, and ethics) provides a foundation for advocates to effectively demand for end-of-life care.

(b) a belief that the motivating factors of advocates will vary from personal experiences with end-of-life care, a firm belief in end-of-life care philosophy (to minimalize the pain and suffering of others), engaging in opportunities to support the dying to provide compassionate support.

(c) barriers to providing end-of-life care may include financial constraints, lack of education/training for correctional staff and volunteers, difficulty with staff retention, poor communication and/or mistrust between imprisoned persons and staff, and social stigma influencing administrators' decision-making.

(d) the personal, social, and political influences may shape advocates' meaning-making experiences related to end-of-life care; the intrapersonal components of the advocates' self, their involvement in social groups and the socially constructed learnings they possess will play an integral role in how advocates convey and find meaning in the end-of-life care they advocate for.

(e) the findings from this study will serve as a significant contribution to correctional health care literature to better inform scholars, policymakers, and the general public of the essential provision of compassionate care and comforting measures to elderly and terminally ill incarcerated individuals, thus eradicating the promotion of punitive practices at the end-of-life.

Rigor and Trustworthiness

To enhance rigor, the PI engaged several strategies throughout the study design and data analysis (Padgett, 2017; Tong et al., 2007). The COREQ (Consolidated criteria for Reporting Qualitative research) checklist was utilized to ensure qualitative research guidelines are appropriately followed. This 32-item checklist for interviews mandates the researcher to report the research team's personal characteristics, relationship to participants, theoretical framework, participant selection, setting, data collection, data analysis, and reporting (Tong et al., 2007). As these guidelines call for explicit and comprehensive reporting on behalf of the researcher, the checklist aided me in reporting imperative aspects of the research team, study methods, context of the study, findings, analysis, and interpretations. The COREQ initiative is designed to incite improvement in the quality of reporting of qualitative studies, indirectly leading to improved conduct. Moreover, COREQ guidelines allow for a greater recognition of qualitative research as an integral scientific endeavor that is utilized to assess the quality and safety of health care (Tong et al., 2007).

To further support rigor throughout the study, my advisor (Dr. Currin-McCulloch) was utilized as a second coder to aid in the verification of this study's processes and formulation of the findings by reviewing participant transcripts, providing suggestions for new codes, appraising the codebook after my initial analysis to ensure codes were appropriate and accurate, engaging in thorough discussions regarding code and meaning saturation, and also assisted in the final data analysis phase. All interviews were conducted and transcribed by myself, in addition to validating the transcription by viewing and/or listening to the audio or recording. In-vivo coding processes also permitted participants' verbatim narratives to emerge and portray the true essence of their lived experiences. Although many qualtitive methods have historically utilized member checking, it is not required for expressing rigor in phenomenology as it contradicts many of the underpinning philosophies (McConnell-Henry et al., 2011). Thus, the traditional context of member checking was not utilized; however, I integrated my clinical interviewing skills to seek clarity and verification during the interview to ensure I was remaining true to participants' narratives.

Due to the large corpus of data, an audit trail supported the management of reflexive and analytic memos. The memos traced decisions made regarding code definitions, emerging meaning units, essences, barriers, and personal feelings discovered through the interpretative phenomenological analysis. The research team utilized MAXQDA software (VERBI, 2018) to assist with data analysis and management. With IPA, researchers must bracket themselves away from the issue being researched and set aside prejudgments, biases, and preconceived ideas about a subject we are trying to understand (Moustakas, 2004). Bracketing was achieved via three avenues: (1) Dialogue: discuss, explore, and document with my co-investigator, Dr. Currin-McCulloch, the personal biases, experiences, and past knowledge regarding my research topic prior to beginning the project. (2) Maintain a bracketing journal: journal entries were documented during data collection, analysis, and while reporting the final research project. If I sensed a bias or if a preconceived notion arose, I ensured to take note of it. This is a process I engaged in throughout the research process. (3) Final report: I documented and shared all biases and preconceived notions that surfaced in my final research project, as it is imperative that my audience is aware of my biases as they read the results and interpret the research data.

Having worked as medical social worker of ten years, with six years dedicated specifically to end-of-life care, it was necessary to separate my professional experiences from participants' narratives. To practice this reflexivity, I often journaled and reflected internally on the research process, evaluating myself by prioritizing opportunities to reflect on potential biases and preconceptions to prevent biased interpretations about the qualitative data I collected. While reflexivity allots me the ability to evaluate myself, the preliminary act of bracketing will encourage the actual process of setting aside my personal experiences, biases, and preconceived notions regarding peer-caregiving for those at the end-of-life. Being reflexive during the process of bracketing in qualitative research is vital as I am aiming to understand the genuine views and perspectives of the participants, the advocates who call for vital care to dying incarcerated individuals. Bracketing will additionally incite the need to set aside knowledge of previous research findings and theories (however limited) regarding correctional end-of-life care and advocacy.

Chapter Summary

This phenomenological study permitted the exploration of correctional end-of-life care advocates meaning-making experiences. More specifically, this study demonstrated a dynamic process of accessing a participant's experience and how, through interpretative activity, they make sense of the their personal world. The analytical process is a dual interpretation process as initially participants make meaning of their world and then the researcher attempts to decode that meaning to make sense of the participants' meaning-making (Smith & Shinebourne, 2012). Consequently, this study aimed to understand what the lived experiences of correctional end-of-life care advocates entail from the participant's perspective and how personal, social, and cultural meanings related to advocates of correctional end-of-life care meaning-making experiences.

Limitations

Despite IPA specifically offering a flexible and versatile approach to understanding people's experiences, criticisms have been raised as to whether IPA can accurately capture the experiences and meanings of experiences rather than opinions of it (Tuffour, 2017). Therefore, researchers must take extra attentiveness to collect rich and exhaustive data from participants and are advised to take active steps to give voice to the experiences of the participants, followed by sufficient interpretation of their narratives.

CHAPTER 5 – RESULTS: ADVOCATES' MEANING-MAKING EXPERIENCES

Introduction

The purpose of this qualitative, phenomenological study was to gain an intrinsic understanding of the meaning-making experiences of correctional end-of-life care advocates. The presentation of this study's findings appears in this chapter, accentuating participants' meaningful experiences within their advocacy for dignified care for the dying. The final analysis revealed four superordinate themes: *daunting work as motivation; the people are the joy; this is what I'm meant to do;* and *being a mirror to their humanity*. Each superordinate theme encompasses multiple subordinate and emerging themes to permit greater detail to support the analysis. These sections showcase advocates' unique experiences, in addition to highlighting how the four superordinate themes were common components of advocates' meaning-making experiences despite their unique roles and experiences within their correctional advocacy work. Superordinate and subordinate themes with corresponding quotations of the interpretative phenomenological analysis of advocates appear in Table 2.

Table 2

Interpretative Phenomenological Analysis of Advocates' Narratives

Superordinate Theme	Subordinate Theme	Quotations
Daunting Work as Motivation	No One Seems to Care It's Not Fair They Are Being Punished Again	[Incarcerated individuals] did get their punishment. They lost their freedom. But it's not a part of the punishment [that] you die without compassion. No one seems to care what really happens to [the dying]. (P09) Everyone deserves to die well no matter what the crime. The punishment is the loss of freedom. (P05)

Table 2 (continued).

The People Are the Joy	End-Of-Life Care Is a Gift They Are Like Family Couldn't Do This Without Them	There are so many things that [being at the dying's bedside] meant to me. For me, not only was it a privilege in a sense, but also a gift to be able to be with the patient. (P08) So for me the joy in it is the people that are in it. To see these people making it happen. I am so grateful for them. (P07)
This Is What I'm Meant to Do	Educate to Empower Wanting to Make a Change Always Been a Fighter	Education going in was a way of empowering people. And so I guess helping them help others was probably the biggest part for me. (P04) I've always been like this. I've always been a fighter, but in a good way. I never back down and I really believe in humane [end-of-life] care for [the incarcerated]. (P10)
Being a Mirror to Their Humanity	They Are Remarkable They Are Remorseful They Are Strong	[W]e brought a mirror so that [volunteers] could see that [they] all have this, this it's [their] humanity and compassion that [they're] looking at. It's not ours. (P01) Mostly [volunteers wanted to participate because they] want to do something for somebody else [to make up for the past]. (P06)

Daunting Work as Motivation

The disheartening and overwhelming nature of correctional health care advocacy was omnipresent amongst the narratives within this study. Outside of the integral care provided by peer-caregivers, compassion and dignity emerged as a rarity within prison walls. Chronic pain and suffering materialized as an unjust mean to punish a population that has already been punished with their carceral sentence. In addition to physical pain, the emotional suffering of imprisoned persons and isolation from loved ones is rampant. With advocates cultivating ideals related to humanity, the certainty of an incarcerated individual enduring some type of torment until their last breath causes them great anguish; however, advocates choose to pivot these daunting feelings into motivating factors.

No One Seems to Care

For advocates, compassionate care serves as the crux of appropriate end-of-life care, as this practice promotes humane interactions which place great value into the needs of the dying. Due to the stigmatization of imprisoned populations, however, the absence of this integral type of care for incarcerated individuals appears to be justified amongst administrators and societal members. Reflecting on this disregard for compassion and its impact on their advocacy, a participant conveyed:

> [Incarcerated individuals] did get their punishment. They lost their freedom. But it's not a part of the punishment [that] you die without compassion. That you die alone, chained to a bed. Nobody wrote that down. Nobody put that in their sentence. But we, society, we just agree with it. It's like an unspoken rule that we just followed. No one seems to care what really happens to [dying incarcerated individuals] (P03).

Advocates expressed that the absence of compassion within corrections, often perpetuated by judgement and apathy, provided vigor and motivation to uncompromisingly champion for more empathetic understanding towards the imprisoned.

Despite the purported crimes which lead these individuals to a world of imprisonment, advocates expressed an urgency to view the dying and those who care for them as human beings. Failing to acknowledge incarcerated persons as “real people with thoughts and feelings and who are capable of good" (P11) impedes the critical care they are entitled to, particularly at the end of life. Advocates stressed the prevalence of inhumane attitudes within and out of corrections and its subsequent harm by explaining:

> [There is] punitive versus actual rehabilitation, and we're not making a shift away from that punishment piece. It's really black and white for people. You did something bad, now you go away. And even a part of the dying, it's also a part of the punishment. That you don't get compassion because of what you may or may not have done. Trying to shift that sort of perception especially in the world that we find ourselves in today is difficult. It's needed more than ever, but there's still a lot of hesitancy (P02).

Advocates argued that a lack of compassion at the end of life further dehumanizes incarcerated individuals' existence. Thus, their narratives embraced an ideal for empathy over punitive ideals, viewing compassion as a necessity for humane care.

The absence of compassion enforced feelings of loneliness, as advocates recalled the detrimental effects that isolation had on incarcerated individuals dying and grief experiences.

> I think [end-of-life care] is so necessary, [it's] an obvious fact that it's a human right. And I think that absolutely everyone is owed the opportunity to die with dignity and with care and compassion. It should also be a right to have help. I know firsthand what it's like to feel how isolating death and grief are [...] going through that process. Not enough people [in prison] care. No one is really talking to you about dying. There's a lot of loneliness attached to it, and I say that as somebody who is not incarcerated (P03).

Processing loss and grief is a tremendous undertaking for any human being; however, advocates were swift to note how these processes within corrections are magnified due to the innate isolating nature of correctional facilities. Therefore, advocates often acknowledged their privilege through the solitary experiences of incarcerated individuals.

It's Not Fair

Patient dignity at the end-of-life is often equated with the provision of honour and respect. While it is unlikely for one to dispute that dignity during this time is an essential concept, advocates highlight that dignity often serves as an imaginary concept within corrections. For older adults specifically, correctional facilities were "certainly not built for an aging population" (P01) and often utilize "dreary infirmaries" (P11) to hoard imprisoned persons in their final days. This "unfairness [...] of dying people in prison being written off" (P08) exuded from advocates stories, as they appealed for dignified care for incarcerated populations.

Though correctional settings are not synonymous with equality, advocates were still unwavering in their support for dignified care and proper access to health care rights. Instances where family members are permitted to be at a dying individual's bedside within corrections is an exemplary example of delivering dignity. The ability to provide an iota of autonomy and respect via the presence of loved ones at the end of life functioned as a source of content and hope for advocates considering the vital civil liberties stripped from individuals once they are imprisoned.

> I can't imagine anything more noble for a dying person then to allow them to say who they want, if anyone, to be with them as they die. That you allow them to choose who they feel safest with, next to, to leave this life. I mean, the rest of us gets to do that. If that is the only thing we can do for [dying incarcerated people] then we really need to do that. It also means so much to the families. Especially if we don't let them go home to die. It gives them a bit of closure after being away from [the dying] for so long. They didn't do

> anything wrong, so why punish them? What's to gain by preventing that final [goodbye]? (P08)

Advocates' participation in championing loved ones to visit the dying provided significant meaning as this dignified practice is not only reflective of community hospice guidelines, yet it also has the potential to provide imperative resolution to both the dying and their loved ones after many years of estrangement. Moreover, advocates were steadfast supporters of compassionate release policies as an outlet for dignified deaths and to alleviate overcrowding in corrections.

They Are Being Punished Again

The tolerance for inhumane practices in corrections and subsequent ongoing suffering of incarcerated persons horrified advocates, raising vital concern of the unwarranted harm perpetuated against imprisoned persons. This deficiency of compassionate care was intolerable for advocates, as they stressed the need for reform to purge such continuous, excruciating treatment.

> [T]hey knew that the [incarcerated male] had a longstanding liver cancer to been treated in the prison. He died of that on the cell floor. And his cellmate went into solitary confinement, grieving the death of his best friend who was a cellmate. [The correctional officers put him in solitary for] between six and nine months, until the prison [could determine or not if] he had murdered [his friend]. And so here you have a person who's grieving. So imagine somebody who their biggest supporter possibly for the last 10 years dies right there in front of you [...] the horrible death and pain that's out of control. And then you go and you're put in solitary confinement to navigate that grief for six to nine months. That's unnecessary pain. So there's better ways to do this (P01).

In recollecting harrowing accounts of perpetual punishment in corrections, advocates acknowledged how dehumanizing practices at the end of life invigorates them to mitigate the inhumanity flourishing within prison walls.

Advocates' reflections of the inhumane conduct towards incarcerated persons were often supported by sentiments to eliminate punitive ideals, as these callous practices are devoid of any constructive purposes. Instead, they pervade correctional institutions as merited actions towards the incarcerated and dying, with one advocate stressing:

> Everyone deserves to die well no matter what the crime. The punishment is the loss of freedom. It shouldn't be continued torture and bad health care and horrible food and, you know, everything else we all know about correctional life. So I mean, it's not just the way they're dying. It's the way they're living too (P05).

Conceding that incarcerated individuals are susceptible to punishment until their last breath, advocates choose to employ this demoralizing fact to add more purpose to their cause to eradicate brutal and gratuitous behaviours.

Despite the prevalence of retribution within the carceral system, hope that compassion would supersede punishment within correctional settings appeared within advocates' narratives. With meaningful consideration, advocates reflected on the indispensable factors required to alleviate the pain and suffering permeating within corrections, with one advocate advising:

> I just think [it's] love, you know? The idea that you see people as worthy, that their comfort is catered to. Not just their physical comfort but with their soul comfort, their spirit. Who they really are as a person. That human being. That they don't have to be punished out of this life. That is doing more harm than any good (P02).

Advocates consistently conveyed that suffering at the end-of-life should never be an acceptable consequence of any crime. Advocates believed that by endorsing suffering, the correctional system was merely adding an unnecessary layer of moral suffering for the incarcerated and doing grave harm in the process.

The People Are the Joy

Participants of this study all shared a mutual desire and pride in building genuine bonds with the dying, caregiver volunteers, and their fellow peers championing for adequate correctional health care. Advocates' narratives highlighted the prevalent loneliness endured by the majority of incarcerated individuals, thus generating a hope in fostering meaningful connections with those they support and educate. Moreover, advocates frequently seek guidance and inspiration from their colleagues who are crusading for the same vital cause.

End-Of-Life Care Is a Gift

Those advocates who had direct interactions with dying incarcerated persons lamented sage meanings within their encounters, often referring to those interactions as "special gifts" (P05, P07). The opportunity to be at the bedside of a dying person, who are limited to no visitors outside of medical personnel, surfaced as a momentous occasion within participants' advocacy work. The prospect of filling an emotional void for terminally ill individuals shined within advocates narratives, with one articulating:

> There are so many things that [being at the dying's bedside] meant to me. Not everybody is able to be a part of a situation like that. For me, not only was it a privilege in a sense, but also a gift to be able to be with the patient, the person, you know, that's suffering at the end of life. To be a part of that and to feel all of those emotions, it's life changing. It's

> hard to put into words, but yeah, it's a gift really to be able to be there to help in any way you can to support [the dying] (P08).

The privilege and honour attached to being alongside a person in their final days was echoed amongst those fortunate enough to participate in those moments, producing gracious meanings for advocates' and their provision of direct care.

With their interactions with terminally ill persons limited, many advocates explained how they discovered meaning through the vicarious experiences of the peer-caregiver volunteers they were training to deliver care. Despite this separation from the dying, advocates disclosed how their guidance enabled volunteers to "reach and connect with the dying" (P10). One such advocate who provided end-of-life care resources to peer caregivers disclosed:

> No, I didn't get to visit with [the dying]. Oddly enough, I don't think many of us who train volunteers [to be caregivers] actually visit with them [...] but that doesn't mean we don't get to play a part in that bond they are making. I had a volunteer tell me once that if it wasn't for the tools we gave him, about holding space for that [dying] person, he didn't think he could keep visiting. So yeah, it makes me feel good to be a part of that gift even though I didn't know the patient (P10).

As conduits to care for an inaccessible population, advocates were able to discover purpose and meaning via the teachings and knowledge they imparted to volunteers.

They Are Like Family

If time and circumstance permitted, advocates were afforded the opportunity to build meaningful rapports with volunteers. Advocates who trained caregiver volunteers expressed appreciation for the instances when they sensed a genuine bond with volunteers. Embracing their educators as familial support was a customary act from volunteers, with advocates expressing how these unions conjured “a lot of joy” (P07). Emotional bonds are not uncommon between advocates and volunteers in corrections, as one participant vividly recollected:

> [The volunteers] told me about their childhood. I would just sit in there with those guys and ask them questions about their family and this and that. And eventually they'd asked me stuff too. I mean, we all ended up bonding. My point is that we ended up like blabbing about everything. They know me, they know my [partner], they know about my mom. I mean, prison is all about talking too, and it's a bunch of gossip. Everyone's a gossip and everyone listens <laughs>. Everyone wants to tell a story. So I mean, yeah, we just bonded while we were in there. And for me to just suddenly leave and not talk to them ever again was just... it wouldn't even occur to me. So, thank God we wrote a lot [of letters] at the beginning [and now] we can use email to stay in touch. Yeah, I consider them family (P05).

An appreciation and exuberance emitted from advocates as they shared instances of fostering genuine bonds with volunteers, as these intimate experiences provided familial comfort for all involved.

Volunteers seeking compassion and security from surrogate family members was a common anecdote for advocates, as their provision of empathy spurred feelings of support to deliver care, with one seasoned care provider noting:

> I have a team of volunteers and they become family, along with myself. I become like their [parent], I guess because of my [role here]. We all do our best to make sure everyone is doing ok, because we don’t want anyone to die alone. When I know my team, my family, is doing well, it gives me, all of us, reassurance that they are caring for their friends the best they can (P12).

Advocates explained that volunteers' mutual admiration for an end-of-life care philosophy not only endorsed a resilient sense of teamwork yet provided caregivers with a satisfaction that they were fulfilling care mandates.

Couldn't Do This Without Them

The plight of implementing compassionate end-of-life care in corrections was described as "lonely" (P05), "frustrating" (P06), "heartbreaking" (P07), as well as "really essential work" (P12). Due to the multifaceted feelings and emotions which accompany this type of advocacy, participants shared a resounding sentiment related to the importance of providing and receiving encouragement to and from fellow advocates. Without fail, advocates assigned profound value in creating and sustaining a community consisting of correctional health care advocates. This small, yet growing group reliably served as an appreciated and vital source of comfort and inspiration for participants.

Building supportive bridges between advocates and relevant organizations who are championing for humane care for dying incarcerated individuals resonated as a meaningful experience for advocates. Reflecting on the gratitude for this unique community and the respite they provide, an advocate expressed:

> So for me the joy in it is the people that are in it. I mean [my fellow advocates] are a Godsend. [They] are unbelievable. To see these people making it happen. I can't tell you the relief I have. I am so grateful for them (P07).

Meaningful connections with fellow advocates emerged as not only a source of comfort for participants, yet continuously served as an outlet for the varying consequential emotions which arise within correctional end-of-life care advocacy.

Moreover, advocates shared that the quality of compassion possessed by those delivering care within corrections must be considered when creating and implementing end-of-life care programs for the dying and their caregivers. Those allies who demonstrated compassion and commitment to humane care served as profound inspiration as one advocate emphasized:

> I am in awe of the nurse who started the program at the prison I visited. Not everyone in the facility was supporting the program. They think [incarcerated individuals] don’t deserve compassion, but that nurse said, “okay, if you don't want to support this hospice program, then don't, but don't talk badly about it, just shut up.” Programs don’t get far without people like her (P05)

As uncovered by advocates, the sustainability of end-of-life programs often depends on the presence of compassion. Consequently, advocates discovered honour in possessing this seemingly atypical trait as well as the ability to compensate for others’ lack of support.

Likewise, instances that allowed advocates to reciprocate support with their peers also enriched advocates meaning-making experiences. Opportunities to thoughtfully collaborate with like-minded individuals radiated throughout advocates’ narratives, as one participant articulated:

> [Another advocate] and I, who I’d never met, shared these really heartfelt emails back and forth because I think we were both feeling really discouraged about our work in our own different ways. But one day, we found ourselves in the same place at the same time and we'd kind of heard each other from across an entire prison. Eventually we built our new partnership, our collaboration and that is so important [...] these connections are so important because sometimes it feels like there aren't many of us and if only we could kind of just stumble upon each other and give each other just a little bit of hope, a little

> bit of support and encouragement. For two strangers to [come together] and do that for each other – that meant the world (P03).

Finding occasions to share ideas, hopes, and even frustrations which emerge from promoting dignified deaths, with a comrade of dedicated individuals, proved to be a vital outlet for advocates especially given the rarity of locating this unique type of support system.

This Is What I'm Meant to Do

Though the personal and professional experiences which led participants to their advocacy work varied, an underlying drive and enthusiasm to enhance equality and improve individual's overall well-being stemmed from an intrinsic ambition to help others. Regardless of their expertise, advocates embraced their roles as educators, promoters of vital change, and "being the 'fighter' [they] always were" (P06). As correctional health care advocates, participants relished in opportunities to showcase their allyship towards a terribly disregarded population in the hopes of enriching the quality of and access to humane end-of-life care.

Educate to Empower

Affording knowledge and tools related to the delivery of compassionate end-of-life care resonated greatly with advocates, as these occasions permitted them, as educators, to enhance volunteers' skillset and confidence. These authentic and elevating interactions not only provided budding caregivers with the practical tools necessary to support dying populations, yet the opportunity to feel empowered through their scholarship and delivery of care. Moreover, witnessing volunteers' transformative experiences as learners upheld advocates' belief that utilizing education to galvanize imprisoned person's latent talents was effective.

As volunteers' understandings of concepts related to death and dying cultivated, advocates discovered immense meaning as advisors to care. Despite advocates' inability to amend imprisoned person's living environments, this did not deter them from employing knowledge as a means to support volunteers.

> Education going in was a way of empowering people. Maybe not to change their status or their situation, but maybe change their perspective and affirm them on their already abundant choices of helping somebody else. And so I guess helping them help others was probably the biggest part for me (P04).

Advocates cautioned emerging allies within the field of correctional health care to avoid "getting stuck in the pitfalls" (P12) of this crusade and instead find "the pockets of joy" (P11) which complement the opportunities to enlighten a dedicated and motivated group of students.

Wanting to Make a Change

Advocates' aspirations to encourage and educate was not exclusive to incarcerated populations, as participants shared their eagerness to inspire change amongst societal members as well. Narratives reflected an urgency to "inform a horribly misinformed society" (P05) regarding the cruel realities of dying in corrections. More specifically, calling for more civilized and empathetic care unceasingly weaved into participants' narratives when reflecting upon their role and responsibilities as advocates.

With dated and unjust policies sentencing individuals to endless years of incarceration, advocates underlined a need to inform society that compassion should not be sacrificed in corrections, as a lengthy imprisonment is punishment enough. As one advocate illustrated:

> A person who was in the correctional facility has had a different life experience than I've had and if I had their life experience, I probably made the same choices, or I probably would've done the same thing, but I didn't so I will suspend judgment and I'll say, "I don't know." Consequences are consequences. And for everybody, there are consequences for

> actions. And they need to be mitigated. They need to stop, and they need to learn from those experiences. But at what point do people learn from the experiences? I don't know. Is it after five years or after 20 years, or one year? I don't know. But at some point, let's hope that people can learn from their experience if they had their mental capacity to do so. Even if they don't, let's just give compassion where compassion's needed and deserved, and not worry about the right or wrongness of it all (P04).

Many advocates shared the sentiment that it was not their position to judge the actions of the incarcerated individuals; however, affording compassion, especially to an individual who may have lacked such care in the past, was reiterated as a fundamental responsibility.

Though advocates revealed that the correctional end-of-life programs they engage with have not encountered challenges related to cost, many conveyed a disdain for how their (and others) taxpayer dollars were funding degrading actions toward incarcerated individuals, as these are not reflective of the humane and rehabilitative practices correctional facilities are obligated to adhere to. Combating this falseness, one advocate articulated:

> The reality of prison is that people... their humanity is [being] stripped away, layer by layer and that is why prisons survive, mostly because people on the outside don't know what's going on in there, but if I'm paying for the experience people are having in prison with my tax dollars, what I want is for people to be trained to treat it as dignified and with as much humanity as possible, because that is the only real antidote. It's clear that more punishment does not prevent crime. [T]here's nothing, there's no research, there [are] no numbers where those things align. It's extraordinarily expensive as a taxpayer to pay for people to be incarcerated when there's no need for them to be incarcerated. (P01).

Advocates questioned the backwards nature of the carceral system, pondering how high tax contributions from the public were not equating to decarceration or at the very least, more constructive and rehabilitative efforts within corrections.

Always Been a Fighter

The commitment of bringing awareness to and reforming great injustices was a deep-rooted purpose for advocates. From their earliest recollections, advocates spoke of "sticking up for others" (P09) and "showing the wrongdoings of the world" (P12) with the intent of amending vast inequalities. Though advocates described their journey to promoting correctional end-of-life care as "happenstance" (P05) or "stars align[ing]" (P03), defending those who voices have been ignored served as a significant motivator to their work.

Emerging from years or even decades of advocacy work in end-of-life care, participants revealed an organic gravitation towards correctional health care rights. From childhood experiences to more recent encounters with injustice, advocates maintain a keen eye on society's prejudice. With imprisoned persons being historically marginalized and isolated, advocates shared their tenacity for supporting a condemned population. Reflecting upon their own character and history of advocacy, one participant explained:

> I've always been like this. I've always been a fighter, but in a good way. I always root for the underdog, the forgotten. When I believe in something, I never back down and I really believe in humane [end-of-life] care for [the incarcerated] (P10).

Participants consistently reflected a belief that all individuals are natural born advocates, with those in privileged positions bearing a responsibility to meet the critical needs of overlooked populations.

Witnessing the discriminatory actions during the AIDS epidemic to more recent acts of police brutality, advocates shared a perseverance to eradicate racist systems and social detriments to health. For many advocates, these two incentives also function as the greatest conduits to mass incarceration in the United States. Highlighting the systemic racism widespread within the U.S. judicial system, one advocate opined:

> When you look at the prison demographics and then you look at the demographics through the rest of the United States, they don't match up at all. I think one in 81 Black people in the U.S. is serving time in state prison and so these are the people who are dying terrible deaths. Black and brown people. People who are dying terrible deaths here in this country. People that are in prison and people who are not (P01).

Advocates argued that significant consideration must be allotted to racial discrimination and power dynamics that influence incarceration through policies and practices.

Withstanding emotional distress is archetypal of end-of-life work and advocacy. To maneuver the affecting challenges paired with supporting the dying often results in mental and spiritual upheaval. Speaking of the anguish related to their advocacy, a participant unveiled:

> [The work] can actually be painful. Sometimes very, very painful. I remember just weeping and thinking, I can't do this if I'm going to get this intensely upset by it... but then it passes. The joy is a good reason to keep going (P07).

Despite the upsetting intricacies linked to working within the field of end-of-life care, advocates similarly highlighted the benefits to their work and how this bliss would often offset any unpleasantries.

Valuing human rights, specifically rights related to accessing adequate health care, resonated deeply among advocates. One advocate stressed that "disease causes the most deaths in prison" (P10), due to the foreseeable consequences of "overcrowding, disgusting living areas, and lack of medical care" (P09). With conditions grossly violating incarcerated persons rights and barriers to accessing appropriate health care pervasive, advocates showcased their persistence to ameliorate this demoralizing reality, with one participant affirming:

> Everyone deserves good health care. Good end-of-life care. I know, we know, what that looks like and everyone should have that right. I've told people that I would drop this like a hot rock if I could but I just can't. It's one of those things. As long as I'm needed, and it feels very satisfying and I can go, you know, I can still keep doing this, I'm going to always be involved. I can't really see myself walking away (P07).

With many working within and/or having competent knowledge of the U.S. health care system, advocates are well versed with the standard of care that "free" persons are entitled to, thus their vigor to demand optimal health care for all.

Being a Mirror to Their Humanity

Moments which allowed volunteers to reflect upon and comprehend their integral and compassionate skillset were frequently celebrated, as advocates sought opportunities to showcase the productivity of incarcerated individuals to those in and outside of prison walls. From documentary films to news articles, showcasing volunteer caregivers as valuable members of society and as essential team members was embedded within advocates' experiences. Having long been dismissed by society as inept and heartless, advocates cherished occasions to applaud the immeasurable contributions to care by peer volunteers.

They Are Remarkable

Advocates continuously addressed the misconception that imprisoned people were not capable of exhibiting compassionate endeavours. Advocates illustrated that incarcerated persons are not irredeemably inhumane people; however, humanity has been historically deprived of them as retribution for crimes they may or may have not committed.

> I think most people would be shocked if they went into a prison and [saw] there was a group of people that were interested in providing end-of-life care, the amount of really good care and compassion that [incarcerated] people have for each other and their situation in prison is pretty remarkable (P02).

The opportunity to diminish perceptions which depict incarcerated individuals as ruthless criminals revealed advocates' gratification in proving incarcerated individuals as extraordinary sources of comfort and goodwill.

Advocates voiced their pride in observing how caregiver volunteers' appreciation for and understanding of the end-of-life care philosophy directly assisted in alleviating suffering for their dying peers. For the dying, "most of their physical, emotional, and spiritual suffering is relieved through their interactions with the volunteers" (P09). Whether supporting the dying's emotional needs through communicating or spiritual wishes via sitting vigil (this may include the act of sitting in silence, praying, talking, and performing rituals for the actively dying), advocates were adamant of how the multifaceted roles of volunteers merit powerful accolade.

In sharing their accounts of volunteers providing hands-on assistance to lessen the dying's physical pain, advocates relished in bestowing caregivers with "overdue praise" (P04) for delivering practical, humane support. As vital care team members, volunteers were relied upon by medical staff to compensate for the alarming gaps in care.

> I think a lot of the [volunteers] found the hands-on care very, very meaningful. I think they were also giving that care because they were seeing that it was being neglected. If they weren't doing it, then [the dying] weren't getting the care that they were supposed to

> get. So you need the ground support they provide and really, they are the best ones to provide it. No one can do it as well as them (P06).

In addition to maintaining the skillset necessary to provide practical end-of-life care, volunteers offer their peers a sense of safety and comfort. This relationship, similar to familial support, assists in eradicating mistrust between the provider and patient, thus allowing the patient to be more trusting of and receptive to care.

Recalling volunteers' appreciation and pride for their fellow team members afforded advocates with an understanding of incarcerated people's yearning to feel included. Therefore, promoting a sense of belonging for volunteers emerged as a noteworthy aspect of participants' advocacy work. Aiding the inclusion of isolated individuals into a community where they are treated as equals and viewed as essential care members, one advocate conveyed:

> I had one volunteer tell me how much he loved that we called him and [the] other volunteers or referred to them as being a 'team'. Being a part of this compassionate team to help their dying friends. Yeah, they loved that. And I get it. For some of them, they've never been on a team or on a team that means this much to them. I remember shedding a few tears at their graduation [from training] because I knew how hard they worked to get there (P10).

Given how imprisoned persons are often dismissed by greater society and even their own family members, the opportunity to form lasting friendships with and gain support from fellow team members reflected an organic need to feel connected and included.

They Are Remorseful

Atonement, regret, and finding forgiveness were revealed by advocates as prevalent motivators for volunteers' participation in an end-of-life care program. Caregivers appeared stricken with guilt, as the humane care they provided to their dying peers and the sensitivity attached to end-of-life care work, changed their harsh perspective on death. According to advocates, volunteers whose convictions were related to taking an individual's life appeared to have the deepest feelings of remorse and regret as their awareness regarding the consequences of loss and grief matured.

In an effort to alleviate their emotional and spiritual suffering, volunteers disclosed to advocates that their participation in an end-of-life care program was motivated to atone for their crime(s) and separation from loved ones:

> It was their way of not only being involved in hospice, but their way of apologizing. It's their way of giving back after they feel like they've taken, taken and taken and taken. So it's their way of giving back and doing their best to make up for what they took away from others, including their own families (P05).

Advocates frequently highlighted that volunteers considered their past behaviour and its consequences, rather than feeling compelled to defend their actions.

Caregiver volunteers acknowledged their inability to change their past actions and behaviours; however, this did not deter volunteers from viewing their future with optimism and opportunities to be valuable members of their community.

> Mostly [volunteers wanted to participate because they] want to do something for somebody else. It was giving back for what, almost in remorse for what they had done. Like, 'I have done something terrible in my previous life, and now I'm doing something good.' So I think in that place it was a little bit of 'I'm giving back to the community and more like I'm making up for what I'd done in the past' (P06).

With volunteers placing meaningful value in their community and their contributions to it, advocates emphasized how this dedication provided vital passion for the program's success and sustainability.

Contrary to more accepted perceptions of incarcerated populations as indifferent villains, advocates were staunch in their opinions that imprisoned people are more invested in doing well than wrong:

> I think it's harder [for volunteers] to deal with doing harm to someone than being harmed. And I think you see that on them, as that horrible remorse, and to live with that and then to care so much and want to serve for the rest of their lives in order to feel better so that that [their crime] isn't plaguing them and haunting them (P07).

With guilt, individuals are inclined to ruminate over their misdeeds, wishing they had behaved differently; however, volunteers were instead opting to redirect burdening thoughts into more productive measures.

The aspiration for volunteers to "give back" surfaced in advocates' stories, with peer caregivers discovering their role and meaning in delivering essential end-of-life care:

> A lot of [volunteers] were able to talk about the value of giving back and having not been able to be there for their loved ones who were dying out in the community, not been able to be there for a grandmother or for a parent but being able to then be there for somebody else who didn't have someone else, to be able to care for them. And so that it really brought meaning and purpose to their time (P06).

The provision of care to their peers allowed volunteers to discover vicarious opportunities to support their loved ones from afar, affording an indispensable meaning to condemned individuals who struggle to find purpose in a confined setting. Witnessing and playing a role to support volunteers' meaning-making experiences provided advocates with a profound sense of peace, as it permitted incarcerated individuals to comprehend their value in an incredibly dismissive environment.

They Are Strong

With corrections suffering from a famine of humanity, it was unsurprisingly the resilient nature of volunteers that frequently arose as a revered trait amongst advocates. For caregiver volunteers especially, their ability to maneuver their own personal challenges while caring for others requires incredible emotional concentration and robust compassion for others and themselves. With a proficient awareness of the difficulties attached to delivering suitable end-of-life care in the "free" community, advocates consistently recognized the unique barriers imprisoned persons endure to effectively support their dying peers and the resiliency required to prosper.

Advocates expressed immense gratification in playing a role for volunteers to comprehend their compassionate qualities and abilities. Conceding the limited opportunities for incarcerated individuals to receive positive feedback, one advocate exquisitely shared their experiences in commending volunteers' talents:

> Maybe [advocates are] compassionate and appreciate humanity, but we brought a mirror so that [volunteers] could see that [they] all have this, that it's [their] humanity and compassion that [they're] looking at. It's not ours. And [their] own humanity and [their] ability to be compassionate in the face of suffering (P01).

Generating dialogue that encouraged volunteers to reflect upon their own innate empathy and responsiveness to the needs of the dying gifted advocates with joyous opportunities to shine light on volunteers' resiliency.

Despite the mercilessness rife within corrections, the vitality of volunteers delivering care to their peers emerged in advocates' insightful narratives. Acknowledging incarcerated persons as "strong human beings" (P06) and adept to acts of compassion was a collective sentiment amongst participants, with one advocate disclosing:

> I really can see how horrible it is for [the incarcerated] and how they're getting punished and saw how good [they are at] taking care of someone in prison at the end of their life, even when they're estranged from their family, and I saw how much that meant to them. To be able to show that kind of compassion [...] that people didn't think they were capable of is so amazing" (P07).

In addition to surviving an incredibly isolating and retributive environment, providing varying forms of support to the dying can be an intimidating task, therefore those who understand the deep nuances of end-of-life care work and deliver such integral care deserve considerable accolade.

The vulnerability of volunteer caregivers was frequently observed by advocates, with those in program facilitating roles illustrating how volunteers "let their guard down" (P12) to form bonds after a long existence of solitude.

> I would describe them as 'brothers'. I can't think of a better word to describe their bond, their friendship. Some of these [volunteers] didn't even have these types of relationships on the outside. I've had a volunteer tell me that he had to go all the way to prison and be in this program just to find family. He was crying when he told me that, but they were tears of joy. It's great to be a part of that (P12).

Witnessing and being a facilitator to the comradery between volunteers surfaced as a reminder to advocates of the significant implications their work and advocacy was producing, for both the incarcerated and themselves.

Humanity unfailingly triumphed over vengeance for caregiver volunteers, with advocates lamenting the value incarcerated individuals bestowed on altruistic efforts over acts and/or thoughts of retaliation. Regardless of the hardened atmosphere often embedded within corrections, volunteers sought avenues to showcase compassionate endeavours. Speaking to this unknown phenomena, one advocate professed:

> [Volunteers] want to respond to suffering in a positive way. Like that's huge. Most people turn away and run from that. And to do it in a prison environment where [there] is already so much suffering that is about you having a depth of humanity and compassion that is rarely found anywhere else (P01).

By reflecting volunteers' humanity back onto themselves, advocates empowered volunteers' to acknowledge their resiliency and determination in delivering dignified care to their peers. In doing so, advocates shared were able to comprehend how the presence of end-of-life services and its devoted caregivers bring humanity and compassion into the stony confines of prison, casting vital care into the shadows of society where many individuals will die alone.

Chapter Summary

The meaningful, yet complex lived experiences of correctional end-of-life care advocates centered on findings related to compassion, connection, purpose, and humanity. These extraordinary principles guided advocates in their motivation to empower a long-neglected group of individuals who, despite their genuine and compassionate efforts, continue to be subjected to perpetual suffering. Advocates' deep understanding of dignified care and the transformative experiences via interactions with peer-caregivers played fundamental roles in their perseverance to ameliorate current end-of-life practices within corrections. As staunch proponents of humane care, advocates maintained that utilizing trained, volunteer caregivers to deliver integral support to their dying peers as the most viable and beneficial intervention. Advocates revealed that opportunities to advocate for compassionate care provided both them and volunteers with the resiliency to dismantle current injustices related to end-of-life care for terminally ill incarcerated individuals.

CHAPTER 6 – DISCUSSION

Introduction

Findings from this novel study reveal the passionate, yet multifarious nature of correctional end-of-life care advocates' meaning-making experiences. Harrowing stories of torment and dying without dignity enhanced advocates' understanding of the dire scarcity of compassion and empathy for imprisoned persons. To offset the staggering lack of benevolence within corrections, advocates celebrated opportunities to build meaningful bonds with those championing for dignified care. Despite the emotional despair which emerged from the continuous punishment endured by the incarcerated, advocates reflected on their personal character and thus acknowledged their sense of purpose to enrich incarcerated individuals' final stage of life. Undoubtedly, the culmination of their advocacy efforts was to demonstrate imprisoned beings as human beings; individuals who possess integral skills and boundless abilities to contribute goodness to society. Prior studies have explored aspects of compassion and resiliency regarding end-of-life care in corrections via the perspectives of correctional staff and medical providers; however, this study delves into the unique essence and lived experiences of advocates, providing unheard and dynamic insights on this vital human rights issue.

The discussion chapter begins by assimilating findings from advocates' meaning-making experiences and comparing these results to existing literature on end-of-life care in corrections and this study's theoretical frameworks. This chapter will additionally address the strengths and limitations to this study.

The Victory of Punitive Ideals

The data suggests that the overarching theme for advocates' meaning-making experiences was dedicated to the provision of compassionate care to all individuals, regardless of their criminal history. Showcasing compassion as abandoned tool within corrections, advocates reflected on how punitive ideals and unjust negligence have been perpetually favoured by constituents, including policymakers, correctional administrators, and members of society. Mirroring findings in prior studies (Crewe et al., 2019; Friedman, 2021), punishment within corrections merely functions as a means to disregard humanity, abandoning imprisoned individuals to battle unfair conditions related to their health and wellness. With dignity, empathy, and understanding serving as the nucleus of end-of-life care, advocates emphasized that proper care for the dying is conditional on these acts of compassion. The incessant need to punish those who have already been sentenced, and who will likely endure ongoing prejudice and hardships even upon release, has proven to be fruitless according to advocates' narratives. Participants' continuously echoed a sentiment reflecting how the inhumane treatment of imprisoned persons does not lead to decarceration. Instead, actions imposed on incarcerated individuals which are deficient of understanding and empathy perpetuate feelings of indifference, thus highlighting the contradictory outcomes of true rehabilitation; rehabilitation in which corrections is intended to facilitate.

Though imprisonment is often depicted as rehabilitative discipline, advocates reflected previous studies' sentiment in which the U.S. criminal justice system essentially criminalizes individuals not only by inflicting punitive and exclusionary disciplinary actions at distressing rates, but also by restricting their access to vital health care, including compassionate care at the end of life (Cloyes et al., 2017; Mitchell & Williams, 2017). Further, for many advocates, the absence of compassion was deemed permissible by those in authority due to systemic racism and imprisoned populations consisting mostly of BIPOC individuals. Regrettably, these individuals have historically endured similar racist and systemic barriers to access quality health care in "free" communities. Utilizing critical race theory to dismantle the racial and health inequities that thrive in correctional settings, there needs to be an increased awareness that rising incarceration rates, prison discipline, and the disparities in health care outcomes for racial minorities are interconnected (Dutil, 2020; Gregory & Fergus, 2017). Employing retaliatory and exclusionary discipline policies may be rationalized as a means to maintain order in corrections; however, critical race theorists assert that correctional policy functions as social control and oppression (Gillborn, 2013). Moreover, individuals are further penalized by losing the right to vote following felony incarceration (Delgado & Stefancic, 2017). The perpetual traumatization and oppression of individuals, families, and communities of colour can be viewed as a mechanism for those in power to remain in power and profit financially by maintaining a prison population of historically marginalized individuals (Dutil, 2020).

The Endless Gift of Peer-Caregiving

Benefits of peer-caregiving revealed by this study were congruent with the findings from Cloyes et al. (2015, 2017), Evans et al.(2000) , and Tillman (2000). Echoing the vital role of peer-caregivers exposed in these prior studies, participants disclosed how peer-caregivers are best-situated to deliver essential care to their dying contemporaries, as they ease mistrust and provide a unique empathy in which those in positions of authority are unable to afford. With bonding playing a critical role in the provision of end-of-life care, advocates highlighted how peer-caregivers build enduring relationships with the dying and a level of trust required to meet end-of-life needs due to the mutual understandings evolved from shared experiences. Advocates comparably expressed concern for an aging crisis within corrections and escalating illnesses amongst imprisoned persons, resulting in an increase of individuals requiring end-of-life care. Resultingly, advocates stress that utilizing peer-caregivers can positively impact models of correctional end-of-life care by exercising their acquired hands-on skills and assist facilities in meeting care mandates, emulating findings of Depner et al.'s (2018) study which revealed multifaceted benefits of prison-based peer-caregiving programs.

Advocates' provided vivid insight into the death experiences of imprisoned persons and the vital role of their peer-caregivers. Reflecting Watson's 'carative' factors, including developing help-trusting relationships and promoting supportive environments (Aghaei et al, 2020), advocates assisted peer-caregivers in facilitating comfortable deaths by reducing the suffering of the dying and providing dignified assistance in a setting often devoid of humanity. Though end-of-life care is often perceived as delivering practical care, providing paths to alleviate emotional suffering is equally fundamental. As a result, peer-caregivers often built genuine bonds with the dying and often served as surrogate family to ameliorate this suffering. Advocates revealed these roles were of particular importance due to the institutional and geographic barriers imposed on the dying to access their loved ones. Acknowledging the isolation in which their peers experienced in their final days enhanced volunteers' understanding of how their presence filled a poignant, emotional gap in delivering quality end-of-life care. Therefore, the training delivered by advocates provided meaning embedded in empowerment and enhancing end-of-life care through teachings which promote compassion and connection.

Atonement as a motivating factor emerged as a surprising prominent influence for volunteers' participation. The expiating nature of these peer-caregiver volunteers weaved throughout advocates' narratives, underscoring the penitence and forgiveness often sought by imprisoned people. Correcting public perceptions which view incarcerated persons as unapologetic and shameless, this study's data suggests peer-caregivers valued the opportunity to compensate for prior offenses. Given the rarity of such experiences being afforded in correctional settings, peer-caregivers expressed gratitude for the end-of-life program and found purpose within their own humanity. Therefore, the utilization of peer-caregiving programs can contribute to good behaviour amongst volunteers due to their strong aspiration to remain in their caregiver role and as productive members of their community. Advocates acknowledged the transformative journey of peer-caregivers and how bearing witness to these experiences contributed to their meaning-making experiences of aiding volunteers in their self-discovery.

Individuals who deliver end-of-life care in the "free" community are often touted as resilient heroes, as they endlessly navigate the potential burn-out and burden that accompanies such care. Participants, however, indicated that although incarcerated persons deliver similar care in more dire settings, they were not recipients of the same accolade as their "free" counterparts. Consequently, advocates' were determined to utilize their narratives to emphasize the benefits of peer-caregiving models, focusing on the integral role of peer volunteers and how their tireless efforts contribute to enhancing end-of-life care, profiting numerous individuals from the dying to taxpayers.

The Hope for Autonomy at the End of Life

For advocates, the opportunity to enhance autonomy at the end of life was critical. Participants continuously emphasized the importance of allotting a population already robbed of their civil liberties with the opportunity to make one final decision for their own health and well-being. For instance, in "free" communities, individuals are encouraged to complete advance directives and do-not-resuscitate orders, which affords their dying wishes to come to fruition. This pertinent documentation, however, is elusive within correctional settings, depriving dying imprisoned people the justified right to direct their own care in their final days. Further, the option for terminally ill incarcerated individuals to be eligible for compassionate release (early/medical parole) afforded advocates with the prospect of hope in a setting that is susceptible to great hopelessness. Regardless of low rates of recidivism demonstrated in this particular population, older adults and those with terminal illness are still perceived for their potential to break the law, thus contributing to the under-utilization of this policy (James et al., 2022; Kaushik & Currin-McCulloch, 2022).

Existential theory, rooted in the philosophical idea that human beings have free choice, materialized within participants' narrative as they addressed terminally ill imprisoned people right to convey their wishes at the end of life. To provide this fully autonomous opportunity to the dying, advocates revealed their staunch belief that humans, despite their supposed crimes, must be given the freedom to make end-of-life decisions for themselves. Though incarcerated populations are deprived of their civil liberties, advocates stressed that this should not be extended to the needs and wants of one's own health at the end of life. Health care professionals working within corrections must provide an evaluative judgement regarding the best medical course of action, they need to restrict themselves to support patients to make their own decisions rather than accepting the choices presented to them (Madder, 1997).

Recognizing the familial bonds forged between volunteers and patients, advocates' conveyed confidence that the dying were recipients of dignified care; however, advocates still acknowledged the equally fundamental role of loved ones outside of correctional walls. Advocates expressed that discounting the significant role of family and community members outside of corrections is a destructive practice which merely punishes both the condemned and their loved ones. Despite the compassion and dignity allotted to the dying from peer-caregivers, advocates stressed that the dying should be permitted to select their own support system at the end of life. To deny a dying individual the opportunity to reconnect with estranged loved ones and potentially make amends for past wrongdoings creates undeserved emotional and spiritual despair, thus perpetuating the carceral cycle of unnecessary torment and suffering.

Advocates as Essential Caregivers

Despite participants' narratives showcasing their limited, direct interactions with dying incarcerated persons, this distance did not preclude advocates from contributing as central caregivers. Delivering end-of-life care education to peer volunteers served as a principal role for advocates, affording caregivers with the confidence and skills to provide essential support. Due to the complex nature of assisting those at the end of life, direct caregivers benefit from the comprehensive knowledge and emotional support afforded by advocates. Advocates lamented that peer-caregivers experiencing the serial death of their peers; therefore it is essential their overall well-being is cultivated to prevent compassion fatigue and burnout (Cloyes et al., 2017; Loeb et al., 2013). Without the presence and expertise of advocates within corrections, the majority of the imprisoned with continue to endure agonizing lives and deaths.

Participants' narratives disclosed how their advocacy impacted their own sense of purpose. In bringing awareness to a neglected human rights issue, advocates created meaning from their advocacy efforts, reflecting an existential concept in which individuals must create meaning from their personal experiences (Wilkes & Milton, 2006). Further, a primary goal of existentialism is encouraging human beings to connect with their authentic feelings and emotions, and thusly make choices which reflect the true self (Fernando, 2007). With an understanding that all beings are entitled to compassion and support, advocates channeled these beliefs though the provision of education and tools to enhance volunteers' skill-set. By enabling this knowledge, advocates demonstrated their true self as facilitators to care. Moreover, participants were cognizant of their role in building and sustaining peer-caregiving programs and how this model of care can positively impact the dying, thus echoing existentialism's approach of promoting individuals' capacity to make choices for themselves with an awareness of their role in the community (Fernando, 2007). Advocates did not describe their work as a burden; instead, they embraced the responsibilities of their activism as it contributed to the promotion of humane care for imprisoned persons. Undoubtedly, the crusade to implement dignified end-of-life care in corrections stimulated advocates to strengthen their knowledge and resilience to bring attention to the long-neglected violation of human rights, reflecting an existentialist belief that when individuals are able to recognize their own feelings and emotions, they have the ability to embrace the potential for growth and improvement (Moustakas, 2004).

Advocates struggled to comprehend why compassionate acts (acts in which they asserted most individuals were capable of exercising) should be seized from imprisoned people. Creating a safe and comforting setting for the dying was essential for advocates, in addition to promoting a model of care which enhances relationships rooted in dignity and respect. Therefore, the data suggests that advocates find motivation in their advocacy work which are reflective of the 'carative' tenets embedded in Watson's theory of human caring (Aghaei et al, 2020). Cultivating ones sensitivity to others, providing a supportive mental, physical, and spiritual environment, in addition to the gratification of human needs, resounded throughout advocates' narratives as they defended the dyings' right to humane care in their final days. Similarly, the suffering endured by the terminally ill served as motivating factors for participants' advocacy work, with the restriction of pain management serving as a primary example of the unnecessary torture endured by dying incarcerated people. As discussed by Howe (2012) and Tillman (2000) in their respective studies, the provision of pain management to imprisoned people, commonly in the form of medication, is sacrificed to justify the needs of those in authoritative positions. To prevent the risk of narcotics filtering through to the general prison population, correctional facilities hesitate to provide pain relief medication, thus impeding an individual's right to access warranted treatment at the end of life. Consequently, advocates yearned to unveil the gross negligence and mistreatment of people who are sentenced to die inhumanely within the confines of a concrete container.

Though finances were an anticipated barrier to care, advocates rarely mentioned cost as a challenge. Instead, advocates illuminated how the sustainability of end-of-life care programs rely significantly on the vision, guidance, and perseverance of the initial program director. This role, often fulfilled by registered nurses with community-hospice experience, must transcend their knowledge of dying well in the "free" community to the restrains of correctional settings. As such, advocates' narratives exposed an abiding credit to those individuals who championed for correctional end-of-life care prior to their own advocacy journey. Maneuvering systemic challenges and authoritative positions who favour punitive ideals, the pioneers of correctional end-of-life care were herald as courageous individuals who recognized a need to implement humane care for an incessantly disregarded population. Regrettably, this warranted appreciation for past and present correctional end-of-life care advocates has been perpetually absent from current literature.

While advocates often shared sentiments regarding the magnificence and bravery of caregiver volunteers and fellow peers in the field of correctional end-of-life care, participants were extremely reluctant to provide themselves with the same high regard. Their modesty was omnipresent and highlighted the need to best support and celebrate those in the frontline of correctional health care advocacy. Just as those delivering end-of-life care in the "free" world, correctional advocates must also be praised for their ability to maneuver the emotional and systemic challenges associated with the provision of correctional end-of-life care. Relying on their utmost resiliency and perseverance to enhance humane treatment of imprisoned persons, advocates are determined to thoughtfully engage with caregiver volunteers to provide the tools, skills, and confidence necessary to deliver vital care to their dying peers. More specifically, advocates play an integral role in permitting imprisoned persons to acknowledge their own humanity and compassionate nature. Due to these enduring interactions, advocates are well positioned to espouse integral guidance and emotional support to peer-caregiver volunteers. Therefore, one must support the plight of advocates, as this unique group of champions are ideally positioned to forge meaningful relationships with and provide care to a neglected population, to essentially shine a glimmer of light amongst those who have been cast in the shadows.

Strengths

Findings from this study offer novel insights into the meaning-making experiences of correctional end-of-life care advocates, including motivating factors, barriers to care, and the various benefits of supporting this unique population. The study draws from a diverse sample of advocates regarding professions and years of advocacy. The study additionally provides integral insight into the productivity and compassion imprisoned persons are eager to showcase. The findings of this study provide tangible examples of the humane support for the dying delivered by peer-caregivers and the positive ripple effect resulting from such compassionate care. From the knowledge derived from this study, correctional health care providers can implement adequate models of care that appropriately support terminally ill incarcerated persons. By addressing the gaps in care and further unveiling the advantages of utilizing peer-caregivers, advocates play an integral role in enhancing correctional end-of-life care practice and research.

Finally, a genuine appreciation echoed throughout advocates' narratives for their ability to participate in this study. Their earnest gratitude for the opportunity to share their experiences, insights, and feelings resonated with each interview. Despite the absence of monetary incentive, participants were eager to contribute and trusted their story would have an impact on the lives of incarcerated individuals, as well as those who support them. Therefore, a continued need exists to include the voices of advocates in correctional health care research, as their narratives gives warranted attention to those who have been silenced.

Limitations

Generalizability is a significant limitation to this study as the majority of research participants reside in California. Although recruitment strategies aimed to gather experiences of advocates across the U.S., the majority of participants resided in California. California, Colorado, and Missouri currently utilize peer-caregiving programs within corrections and are well-positioned to speak to the value of this model of care; however, it is equally integral to capture the experiences of facilities who are unable to, or who refuse to, utilize volunteer caregivers. Moreover, the majority of narratives exposed the nuances of supporting a male, dying population. Future research would greatly benefit from the investigation of the experiences of advocates working alongside females who provide end-of-life care in all-female facilities and programs which support transgender populations. Additionally, this study relied on cross-sectional data.

A critical limitation to this study was the inability to connect with incarcerated individuals for whom end-of-life interventions are most essential to. The initial aim of this study was to capture the meaning-making experiences of the fundamental volunteers who deliver end-of-life care to their dying peers within corrections. However, after two fiscal years of providing the necessary documentation to conduct research in corrections, due to bureaucratic reasonings, this study never came to fruition. Historically, conducting research within corrections has proven to be quite challenging, as incarcerated individuals are regarded as a vulnerable population for research study purposes. Consequently, researchers who want to conduct correctional research encounter heightened scrutiny from institutional review boards and endure longer timelines.

As standard with research pertaining to corrections, this study lacks the direct voice of incarcerated individuals. Regrettably, this scarcity is merely reflective of broader social constructs which aim to silence the marginalized. Though advocates were considerate and passionate in sharing the experiences of peer-caregivers and the dying, the absence of their voices creates a void and mystique of the death experience within correctional facilities. Therefore, future research must be dedicated to capturing the significant narratives of imprisoned persons, as these individuals are primarily impacted by the drought of compassionate end-of-life care.

CHAPTER 7 – CONCLUSIONS

The meaning-making experiences derived from correctional end-of-life care advocacy demonstrated itself as both versatile and earnest. The multi-layered narratives of advocates exposed motivations for advocacy as well as the numerous gaps in correctional end-of-life care and thus the vast room for improvement and reform. Despite the extraordinary progress following decades of indispensable advocacy, the plight to implement adequate end-of-life care interventions remains continuous. The involvement and advocacy of health care providers aiding the movement of access to essential health care within correctional settings is instrumental; however, the integral insights of advocates and their suggestions for reform are alarming absent from current literature. This omission thus showcases an obligation to include these significant perspectives to enhance the accessibility and quality of end-of-life care in corrections. To address the amendments necessary to improve this care, this chapter will introduce social work practice, pedagogy, policy, and research implications derived from this study.

Practice Implications

Advocates bring imperative awareness to the scarcity of clinical and practical knowledge regarding the state of end-of-life care for incarcerated individuals in the United States. More concentrated efforts, in particular, should be considered to monitor the quality of existing health care provided in correctional settings, as this continues to be under-represented (Burles, et al., 2015). Likewise, increased consideration should be given to how correctional staff and health care providers navigate issues related to end-of-life care, equity and the integration of community and prison-based palliative care interventions (Cipolletta & Oprandi, 2014). Furthermore, improved integration of community specialist end-of-life care services is required to provide education and practical support to the care team in correctional settings (Loeb, 2013). As the provision of compassionate and humane care is fundamental, advocates further highlight the systemic obstacles of delivering adequate end-of-life care and the subsequent strategies that should be developed to alleviate mistrust and promote more empathetic connections between correctional staff, health care providers, and incarcerated individuals (Burles, et al., 2015).

The development and inclusion of health care teams to support incarcerated individuals at the end-of-life must be prioritized to effectively promote humane and dignified deaths in corrections. Compassionate medical teams composed of, but not limited to, physicians, nurses, and social workers are necessary to aid with the complex medical, emotional, and spiritual care needs of the terminally ill. Undoubtedly, it is essential for clinicians, such as social workers, who support incarcerated individuals at the end-of-life to properly identify the needs of this unique population. Without adequate care, resources, and guidance, terminally ill incarcerated individuals are left in a whirlpool of their own infinite pain and distressing thoughts. Therefore, social workers must adhere to their ethics and values to assist dying imprisoned persons in accessing various forms of support and care, as well as practical assistance for the dying individual and bereavement support for their loved ones. By providing opportunities to share, build resiliency, and foster connections with loved ones and peers, social workers can play an integral role in supporting dying incarcerated individuals coping with the complex physical, emotional, and spiritual needs at the end-of-life. Despite the heartache and feelings of hopelessness that accompany bereavement work, including the possibility of burnout and compassion fatigue, social workers have reported that the delivery of supportive interventions for terminally ill and grieving populations has been the most rewarding experience of their career (Granse, 2003).

Social workers can contribute to closing the health gap, one of the field's most prominent Grand Challenges, by ensuring access to adequate health care for imprisoned persons. For decades, the U.S. has been engaging in harrowing, penal practices that create unnecessary barriers to care for imprisoned people. Therefore, social workers must assist in meeting broad public health imperatives by employing and implementing appropriate treatment for dying incarcerated individuals. Moreover, by adopting a critical race perspective, social workers must acknowledge the horrid inequity endured by incarcerated BIPOC individuals and the racist underpinnings of the US carceral system. In order to eliminate the dire causes and consequences of these racial disparities, immediate and direct attention is necessary from the field of social work and other related disciplines.

Pedagogy Implications

Providing specific foci on aging and incarcerated populations, with an emphasis on health equity, is an emerging need in academia. Pedagogical frameworks, however, must allow humility and accountability to play prominent roles in exploring these fields to uphold dignity and respect. Regrettably, patients engaged in North America's health care system, specifically individuals from more marginalized and isolated populations, continue to endure barriers to warranted aid. Black, Indigenous and People of Colour, LGBTQIA2S+ communities, individuals with disabilities, experiencing homelessness and incarceration are incessantly degraded and dismissed by the very system that exists to sustain their livelihoods and thus necessitates a comprehension of how historical, structural barriers cause significance impairment to patients' health and trust of health care professionals. With a lack of empathy and compassion omnipresent within the health care system, it is vital to inform emerging professionals on how engaging individuals to share their unique, lived experiences can aid in bridging the gap in trust between practitioner and patient.

Social work educators must incorporate teachings which underscore not only the various health disparities that exist for imprisoned populations, but how the plight of correctional health care advocates requires vital attention. These advocates, often comprised of social workers, are essential conduits for compassion and empathy within the carceral system. Providing an understanding regarding U.S. states' varying compassionate release (early/medical parole) procedures can enrich and develop advocacy efforts to improve eligibility and expedite processes to allow the dying to be in their community. Reform to compassionate release policies, with the aid of advocates, will additionally support avenues for smart decarceration, another essential Grand Challenge for Social Work. Social work programs must implement curricula focusing on death, dying, loss, grief, and bereavement to promote the integration of end-of-life skills into clinical practice and to ensure that dying populations receive compassionate, whole-person care. Lastly, by providing field placement opportunities within correctional settings and exposing students to the vast injustices impacting this marginalized community, these emerging professionals are permitted to enhance their knowledge on best practices to support advocacy for imprisoned people.

Policy Implications

Findings from this study will encourage health care advocates to champion for incarcerated individuals' health care rights, in addition to highlighting the responsibilities of correctional facilities to provide such care. The implementation of a standardized end-of-life care model would not only permit the access to quality care for dying incarcerated individuals yet create a societal shift from providing compassion to the privileged to all dying individuals

(Exworthy et al., 2012). Social justice and correctional health care advocates should continue to play a critical role in supporting incarcerated individuals to access integral end-of-life interventions.

Participants discussed essential reforms to compassionate release policies as this was often refered to as a current, viable option for humane end-of-life care. Due to the limited applicants who are approved for this type of medical parole, policymakers are urged to reconstruct this law to ameloriate opportunities for dying in the community (Mitchell & Williams, 2017; Zunkel & Lessnick, 2023). For example, it is highly recommended that Sentencing Commissions must expand judicial discretion to identify unenumerated “extraordinary and compelling” circumstances warranting release and to reject circuit courts’ narrowing of compassionate release (Zunkel & Lessnick, 2023).

From a critical race framework, an understanding of the variation in racial and ethnic inequities regarding incarceration across states and the policies and day-to-day practices that drive these inequities is vital in order to generate true progress towards a racially just system (Nellis, 2022). With young black men often the foci of law enforcement and policymakers, policy reform regarding what the U.S. classifies as a criminal behaviour, the punishment for certain crimes, how we understand the goal of corrections, and the means in which the nation chooses to persue and prosecute suspected criminals, including the limited access to warranted health care, is essential (Neill et al., 2014). With many state and federal government policies embracing racist and punitive stances, apparent within the alarming mass incarceration of BIPOC individuals, policies which cause the disproportionate effects of mass imprisonment on minority groups are in dire need of improvement.

In addition to ethical values, including social justice, dignity, and integrity, supporters of correctional health care integrate core values to assist in their continuous efforts to address the barriers of providing adequate health care within correctional settings. Further, advocates play an essential role in influencing correctional and medical staff attitudes toward the dying by providing an education and understanding of how to effectively support this vulnerable population; to provide a comforting avenue in which terminally ill incarcerated individuals die with dignity and compassion. To promote social justice for this marginalized population, interventions need to be consistently evaluated with outcomes that improve care for imprisoned persons at the end-of-life.

Research Implications

Correctional health care advocates can participate in research which focuses on effective guidelines for correctional facilities to provide compassionate end-of-life care for incarcerated individuals. This study can assist in bridging the gap to adequate health care for marginalized populations, where we can view dignified end-of-life care for all and not just for the privileged. By ignoring the need for research on end-of-life interventions in corrections, and recognition of the barriers to care, we may be ignoring crucial aspects that teach us more on the needs of the dying, benefits of end-of-life caregiving, and even how to increase the self-efficacy of caregiver volunteers. The implications of this to the health sciences can be significant in improving the quality of end-of-life care in correctional settings. Results of this work will be disseminated through journals pertaining to social work and health care and at various health care and policy conferences such as Council for Social Work Education and National Correctional Conference on Health Care. By allowing imprisoned people to access quality care at the end-of-life, this not only aids in addressing and eradicating the health and racial disparities that exist in corrections, but to better inform society of the integral role of these caregivers, as it demonstrates that incarcerated people are vital, contributing members of society. Additionally, this research can encourage the public to champion for proper health care for imprisoned persons and not view a lack of compassion at the end-of-life as yet another appropriate form of punishment.

Conclusion

Current evidence dictates that the complexities of care, paired with a lack of funding and access to adequate resources, has created numerous challenges in delivering end-of-life care to dying incarcerated individuals (Turner et al., 2011). Despite the advocacy and recognition of health care as a right for incarcerated individuals, personal, social and political animosities related to criminality create barriers between theory and practice (Burles et al., 2015). This study, however, has the potential to validate the opportunity to advocate for and witness an individual dying well as a positive, transformative experience for both the patients, caregivers, and those who continue to champion for correctional health care rights. Supporting incarcerated persons in achieving a good death experience can decrease fear and the mistrust prevalent towards staff within a correctional setting. More specifically, this study will also provide a better understanding and evaluation of end-of-life care programs that presently exist. Exploring the end-of-life experiences of imprisoned populations would provide deep insight in how these programs can be improved. Further, this study could assist to illuminate particular personal, social and political enmities that currently exist towards the provision of end-of-life care in correctional settings. As a result, the development of initiatives to address public misconceptions and the stigma related with imprisoned populations can be appropriately challenged.

Regrettably, end-of-life care programs and research related to dying incarcerated people are inadequate within the U.S., resulting in a limited understanding of end-of-life care provision in correctional settings. This study will contribute to research that examines and documents the processes that support end-of-life care programs in corrections and resulting transformative experiences of those delivering such integral care; this is vital in addressing concerns of correctional systems that have been unwilling to consider correctional end-of-life programs led by peer-care volunteers as viable options for delivering humane, end-of-life care to the critically ill. Should an arduous process remain for those incarcerated individuals who seek approval for compassionate release, it is therefore the responsibility of correctional health care professionals to advocate for dying imprisoned people and to allow this marginalized population to live in an environment that promotes patient-centered care. Nonetheless, if the standard of care available in correctional settings remains suboptimal to a basic standard of community care, it is the essential role of advocates who will greatly contribute to the overdue reform of correctional end-of-life care.

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APPENDIX A

Interview Guide for Correctional End-of-Life Care Advocates

(a) Tell me about your current role in advocating for correctional end-of-life (EOL) care.

(b) What made you interested in advocating for this issue?

(c) What does it mean to you to advocate for correctional EOL care?

(d) How does advocating for end-of-life care give you meaning and/or purpose?

(e) Could you share with me about if and how any personal, social, or political influences play a role in your advocacy?

(f) Please share with me about exemplar EOL care programs that have worked well. What factors do you think made them stand out? Why did certain programs end?

(g) Can you describe any interactions you have had with dying incarcerated individual?

(h) Can you describe any interactions you have had with EOL care team members who work in corrections?

(i) How do you find meaning in these relationships?

(j) What do your day-to-day experiences in advocacy look like?

(k) What do you think are the benefits to EOL care in corrections?

(l) Who and/or what do you think are the challenges/barriers of implementing EOL care in corrections?

(m) What motivates you to keep advocating for this issue?

(n) What would you want others to know about end-of-life care and/or dying in corrections?

(o) What are your suggestions for correctional health care reform?

APPENDIX B

Superordinate, Subordinate, and Emerging Themes

Superordinate theme	Subordinate theme	Emerging themes	Quotes
Daunting work as motivation	No one seems to care	Absence of compassion	[Incarcerated individuals] did get their punishment. They lost their freedom. But it's not a part of the punishment [that] you die without compassion. That you die alone, chained to a bed. Nobody wrote that down. Nobody put that in their sentence. But we, society, we just agree with it. It's like an unspoken rule that we just followed. No one seems to care what really happens to [dying incarcerated individuals] (P09).
		Loneliness/isolated	I think [end-of-life care] is so necessary, [it's] an obvious fact that it's a human right. And I think that absolutely everyone is owed the opportunity to die with dignity and with care and compassion. It should also be a right to have help. I know firsthand what it's like to feel how isolating death and grief are [...] going through that process. Not enough people [in prison] care. No one is really talking to you about dying. There's a lot of loneliness attached to it, and I say

			that as somebody who is not incarcerated (P03).
		No empathy	It's working within a system that's just riddled with complexities and weirdness and almost little to no concern. It's daunting work (P05).
	It's not fair	Lack of dignity & rights	[N]ot enough people care about human beings. And it's a really sad place that we're living in... a time where everyone's so selfish. Somebody that's at end of life, they deserve to still be treated with dignity and as a human being. And I feel that a lot of the time, especially if they're old and in prison, they're just written off. And I think that's really unfair (P08).
		Lack of autonomy	I can't imagine anything more dignified for a dying person then to allow them to say who they want, if anyone, to be with them as they die. That you allow them to choose who they feel safest with, next to, to leave this life. I mean, the rest of us gets to do that. If that is the only thing we can do for [the dying] then we really need to do that. It also means so much to the families. It gives them a bit of closure after being away from [the dying] for so long.

			They didn’t do anything wrong, so why punish them? It’s not fair to anyone involved (P10)
	They are being punished again	Ongoing suffering	[T]hey knew that the [incarcerated male] had a longstanding liver cancer [that was being] treated in the prison. He died of that on [his] cell floor. And his cellmate went into solitary confinement, grieving the death of his best friend who was a cellmate. They were cellmates for, I think it was between six and nine months, until the prison determined he had murdered that person. And so here you have a person who's grieving. So imagine somebody who their biggest supporter possibly for the last 10 years dies right there in front of you [...[the horrible death and pain that's out of control. And then you go and you're put in solitary confinement to navigate that grief for six to nine months. That’s unnecessary pain. So there's better ways to do this (P01).
		Punishment	I just think [we need] love, you know? The idea that you see people as worthy, that their comfort is catered to. Not just their physical comfort but with their soul comfort, their spirit. Who they really are as a person. That

			human being. That they don't have to be punished out of this life. That is doing more harm than any good (P02).
		Inhumane practices	Everyone deserves to die well no matter what the crime. The punishment is the loss of freedom. It shouldn't be continued torture and bad health care and horrible food and, you know, everything else we all know about correctional life. So I mean, it's not just the way they're dying. It’s the way they’re living too (P05).
The people are the joy	End-of-life care is a gift	Direct care for the dying	There are so many things that [being at the dying’s bedside] meant to me. Not everybody is able to be a part of a situation like that. For me, not only was it a privilege in a sense, but also a gift to be able to be with the patient, the person, you know, that's suffering at the end of life. To be a part of that and to feel all of those emotions, it's life changing. It's hard to put into words, but yeah, it's a gift really to be able to be there to help in any way you can to support [the dying] (P08).
		Indirect bonds with the dying	I didn’t get to visit with [the dying]. I don’t think many of us who train volunteers [to be caregivers] actually

			visit with them [...] but that doesn’t mean we don’t get to play a part in that bond they are making. I had a volunteer tell me once that if it wasn’t for me, talking to him about holding space for that [dying] person, he didn’t think he could keep visiting. So yeah, it makes me feel good to be a part of that gift even if I didn’t know the patient (P10).
	They are like family	Bonds with volunteers	[The volunteers] told me about their childhood. I would just sit in there with those guys and ask them questions about their family and this and that. And eventually they'd asked me stuff too. I mean, we all ended up bonding. My point is that we ended up like blabbing about everything. They know me, they know my [partner], they know about my mom. So I mean, yeah, we just bonded while we were in there. And for me to just suddenly leave and not talk to them ever again was just... it wouldn't even occur to me. We’re still in touch today. Yeah, I consider them family (P05).
	Couldn’t do this without them	Gratitude for other advocates	So for me the joy in it is the people that are in it. I mean [my fellow advocates] are a godsend. [They] are unbelievable. To see these people making it happen. I can't tell you

			the relief I have. I am so grateful for them (P07).
		Advocates as inspiration	I am in awe of the nurse who started the program at the prison I visited. Not everyone in the facility was supporting the program. They think [incarcerated individuals] don’t deserve compassion, but that nurse said, “okay, if you don't want to support this hospice program, then don't, but don't talk badly about it, just shut up.” Programs don’t get far without people like her (P05).
		Advocates as sources of support	[Another advocate] and I, who I’d never met, shared these really heartfelt emails back and forth because I think we were both feeling really discouraged about our work in our own different ways. But one day, we found ourselves in the same place at the same time and we'd kind of heard each other from across an entire prison. Eventually we built our new partnership, our collaboration and that is so important [...] these connections are so important because sometimes it feels like there aren't many of us and if only we could kind of just stumble upon each other and

			give each other just a little bit of hope, a little bit of support and encouragement. For two strangers to [come together] and do that for each other - that meant the world (P03).
This is what I'm meant to do	Educate to empower	Providing knowledge & tools to volunteers	Education going in was a way of empowering people. Maybe not to change their status or their situation, but maybe change their perspective and affirm them on their already abundant choices of helping somebody else. And so I guess helping them help others was probably the biggest part for me (P04).
	Wanting to make a change	Erasing stigma, informing society	The reality of prison is that people... their humanity is [being] stripped away, layer by layer and that is why prisons survive, mostly because people on the outside don't know what's going on in there, but if I'm paying for the experience people are having in prison with my tax dollars, what I want is for people to be trained to treat it as dignified and with as much humanity as possible, because that is the only real antidote. It's clear that more punishment does not prevent crime. [T]here's nothing, there's no research, there [are] no numbers where those things align (P01).

	Always been a fighter	Coping with distress	[The work] can actually be painful. Sometimes very, very painful. I remember just weeping and thinking, I can't do this if I'm going to get this intensely upset by it... but then it passes (P07).
		History of advocacy	I've always been like this. I've always been a fighter, but in a good way. I always root for the underdog, the forgotten. When I believe in something, I never back down and I really believe in humane [end-of-life] care for [the incarcerated] (P10).
		Need for persistence	Everyone deserves good health care. Good end-of-life care. Everyone should have that right. I've told people that I would drop this like a hot rock if I could but I just can't. It's one of those things. As long as I'm needed, and it feels very satisfying and I can still keep doing this, I'm going to always be involved. I can't really see myself walking away (P07).
Being a mirror to their humanity	They are remarkable	Volunteers as productive members of society	I think most people would be shocked if they went into a prison and [saw] there was a group of people that were interested in providing end-of-life care, the amount of really good care and compassion that

			[incarcerated] people have for each other and their situation in prison is pretty remarkable (P02).
		Essential team members	I think a lot of the [volunteers] found the hands-on care very, very meaningful. I think they were also giving that care because they were seeing that it was being neglected. If they weren't doing it, then [the dying] weren't getting the care that they were supposed to get. So you need the ground support they provide and really, they are the best ones to provide it. No one can do it as well as them (P06).
		Pride in work/team	I had one volunteer tell me how much he loved that we called him and [the] other volunteers or referred to them as being a 'team'. Being a part of this compassionate team to help their dying friends. Yeah, they loved that. And I get it. For some of them, they've never been on a team or on a team that means this much to them. I remember shedding a few tears at their graduation [from training] because I knew how hard they worked to get there (P10).
	They are remorseful	Finding forgiveness	It was their way of not only being involved in hospice, but their way

			of apologizing. It's their way of giving back after they feel like they've taken, taken and taken. So it’s their way of giving back and doing their best to make up for what they took away from others, including their own families (P05).
		Atonement	Mostly [volunteers wanted to participate because they] want to do something for somebody else. It was giving back for what, almost in remorse for what they had done. Like, ‘I have done something terrible in my previous life, and now I'm doing something good.’ So I think in that place it was a little bit of ‘I'm giving back to the community and more like I'm making up for what I'd done in the past’ (P06).
		Regret	I think it's harder [for volunteers] to deal with doing harm to someone than being harmed. And I think you see that on them, as that horrible remorse, and to live with that and then to care so much and want to serve for the rest of their lives in order to feel better so that that isn't plaguing them and haunting them (P07).
		Giving back	A lot of [volunteers] were able to talk about

			the value of giving back and having not been able to be there for their loved ones who were dying out in the community, not been able to be there for a grandmother or for a parent but being able to then be there for somebody else who didn't have someone else, to be able to care for them. And so that it really brought meaning and purpose to their time (P06).
	They are strong	Resiliency of imprisoned persons	Maybe we're compassionate and appreciate humanity, but we brought a mirror so that [volunteers] could see that [they] all have this, this it's [their] humanity and compassion that [they're] looking at. It's not ours. And [their] own humanity and [their] ability to be compassionate in the face of suffering (P01).
		Caregiving skills	I really can see how horrible it is for [volunteers] and how they're getting punished and saw how good [they are at] taking care of someone in prison at the end of their life, even when they're estranged from their family, and I saw how much that meant to them. To be able to show that kind of compassion [...] that people didn't think they were capable of is so amazing" (P07).

		Humanity over vengeance	[Volunteers] want to respond to suffering in a positive way. Like that's huge. Most people turn away and run from that. And to do it in a prison environment where [there] is already so much suffering that is about you having a depth of humanity and compassion that is rarely found anywhere else (P01).
		Vulnerability	I would describe them as ‘brothers’. I can’t think of a better word to describe their bond, their friendship. Some of these [volunteers] didn’t even have these types of relationships on the outside. I’ve had a volunteer tell me that he had to go all the way to prison to find his family. He was crying but they were tears of joy (P09).