CARE IN CUSTODY

CARE IN CUSTODY: AN ETHNOGRAPHY OF ILLNESS AND END OF LIFE IN PRISON

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LAY ABSTRACT

At a time when the prison population is rapidly ageing and more people than ever are dying in custody, this thesis explores what it is like to experience serious or terminal illness in prison, the kinds of care prisoners receive and how they experience that care. Based on ethnographic fieldwork in U.S. state prisons, three themes are examined: 1) how the prison and its privatized health care system shape the illness experiences of older prisoners; 2) how prisoners mediate the experience of dying in prison through a peer-based prison hospice program; and 3) how the senses and especially touch elicit new ways of knowing and understanding end of life in prison. Taken together, the three papers shed light on forms of care in prison, the mutability of relations and life, and points of friction between care and custody.

ABSTRACT

This thesis presents an ethnographic study of the experiences of men living with and dying from serious illness in prison, with a particular focus on the kinds of care they receive and the ways in which they experience that care. The dissertation draws on extensive ethnographic fieldwork conducted over two years in U.S. state prisons in Maine, presented in three standalone papers. The first paper outlines how the prison and its health care system shape the illness experiences of older and ageing prisoners and asks, what does it mean when the lives of prisoners collide with contracted for-profit medical care and how might their lives be constituted as unworthy of care? The stakes lie in applied policy and practical solutions for custodial services. The second paper explores the experience of caring and being cared for in the context of a prison hospice program, in which incarcerated men provide care to peers who are ill or dying. Through tracing one man's end of life journey, this chapter considers how hospice caring makes and remakes death *and* life in prison, and the ways in which this "nefarious" form of escape from disciplinary power translates in the repressive penal regime. The final paper has its roots in sensory ethnography and the emerging field of sensory penality. This is a reflexive piece in which I probe my sensorial subjectivity and particularly touch as a medium of inquiry to explore the sensations of life, death, and dis/connection experienced in a prison infirmary. The observed *feel* of life and death illuminates new ways of understanding care in custody as a space of simultaneous brutality, beauty, indignity and intimacy. Taken together, the papers shed light on constellations of care in prison, the contingency of relations and personhood, and points of friction between care and custody.

Keywords: *prison, ageing in prison, terminal illness, end of life, prison health care, prison hospice, medical anthropology, prison ethnography*

DEDICATION

For the Maine State Prison hospice volunteers and their patients.

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CONTENTS

LIST OF FIGURES

LIST OF ABBREVIATIONS

BCF – Bolduc Correctional Facility (The Farm)
CO – Correctional Officer
DCF – Downeast Correctional Facility
HSA – Health Service Administrator
IMHU – Intensive Mental Health Unit
MCC – Maine Correctional Center
MDOC – Maine Department of Corrections
MHC – Maine Hospice Council and Center for End of Life Care
MVCF – Mountain View Correctional Facility
MSP – Maine State Prison
pADL – Prison Activities of Daily Living
pALU – Prison Assisted Living Unit
PSS – Personal Support Specialist
SMU – Special Management Unit

DEFINITIONS

Chow: Meal time typically in a dining hall (chow hall) or in-unit (in medical units, meals are brought directly to the unit/pod).

Code: Often used in the literature to refer to the "convict code". However, in the everyday context of the prison, "code" referred most often to an emergency situation (i.e. "A code was called"; also referred to as "ICS").

Co-pay: A fee charged to prisoners for medical and dental visits, medications and prosthetic devices. Unless exempted by policy, each medical or dental visit is assessed at a fee of $5.00; each prescription, non-prescription medication or prosthetic device is assessed at a fee of $3.00. Prisoners who are receiving health care services initiated by staff are typically exempt from co-pay fees.

Count: Institutional headcounts conducted at specific times each day or in the instance of a major emergency.

Determinate sentencing: A prison sentence with a fixed term of imprisonment that can be reduced by good-time or earned-time credits.

Indeterminate sentencing: A prison sentence whose maximum or minimum term is established at the time of sentencing – but not a fixed term. Parole boards determine when to release individuals from prison.

Disciplinary Segregation (D-Time): Out of cell time for one hour per day, five days a week, outdoors weather permitting; three shower times per week; designated orange uniform and footwear is issued; up to three items of "general reading material" at any one time acquired through library (personal books and other reading materials are not permitted).

Discretionary release: Release from prison to community supervision that is decided by a parole board. Discretionary release was abolished in Maine in the 1970s.

General population (Gen. pop.): Prisoners housed in "usual" housing (such as medium and close custody housing units, as opposed to medical units or administrative segregation).

Good Time: Time earned that can be applied to reduce time on sentence (in the same way it can be "earned" it can also be revoked as a disciplinary consequence).

Grievance: Formal written complaint submitted by a prisoner.

House: A prison cell.

Movement: Designated by mass movement times or with a movement pass authorized by correctional staff.

Property: Personal property and state-issued clothing or effects (e.g. books).

Pod: A self-contained housing unit that typically has a secure door, living area, and yard e.g. A-pod, B-pod); housing is designated according to custody level unit and pod (e.g. Medium A).

Rec: Designated recreational/exercise time.

Sick call slip: A medical request form submitted to Medical and/or Mental Health services.

Special Management Unit: A high security controlled housing unit including Administrative Segregation (often referred to as "AdSeg").

Yard: Outdoor enclosures (typically with high cement walls) attached to housing units and/or pods, used for "rec" purposes.

DECLARATION OF ACADEMIC ACHIEVEMENT

I, Daina Stanley, am responsible for this program of research and thesis in its entirety. I conducted all parts of the ethnographic study and am the sole author of each chapter in this dissertation. My thesis supervisors, Dr. Ellen Badone and Dr. Kathryn Goldfarb, and committee member, Dr. Saara Greene, supported my analysis and writing through guidance on earlier versions of the thesis. The dissertation takes the form of a sandwich thesis; it is constituted by three body chapters and an interlude between each.

To briefly describe each chapter, Chapter Two "Privatized Health Care in the Lives of Older Prisoners" has been prepared for submission to *Human Organization: Journal of the Society for Applied Anthropology*.[1] In this chapter, I explore how "older prisoners" experience privatized correctional health care and unpack some of the ways in which this type of care is harmful to their health and well-being. This chapter makes an important contribution to the field of prison ethnography through extensive participant observation in custodial spaces typically inaccessible to researchers (for instance see Herbert, 2019) and draws out some of the applied stakes of my doctoral research through practical recommendations for corrections services and health care providers. This chapter sets the stage for the larger dissertation, including how peer caregiving makes and remakes life and death in prison – the focus of Chapter Three.

"Prison Hospice: Making and Escaping Life and Power in Prison" constitutes the third chapter of this dissertation. I have prepared this chapter for submission to *Ethos: Journal of the Society of Psychological Anthropology.* This chapter examines the

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[1] Each chapter has been prepared for the respective journal or book. For the purpose of the dissertation, I have adjusted each chapter to reflect one consistent style of citation and referencing throughout (i.e. APA).

experiences of caring and being cared for in the context of a peer-centric prison hospice program. The paper argues hospice caring opens up possibilities for reconstituting life and death at the end of life in prison and considers how this cultivation translates into the repressive penal regime. This paper contributes to the broad body of anthropology of care literature, as well as the field of prison ethnography and makes a critical contribution to the limited scholarship that examines "custody" and "care". This paper further provides the necessary context for the subsequent chapter and introduces the reader to the Maine State Prison infirmary (the setting of Chapter Four) and the prison hospice program (the focus of the fourth chapter).

Chapter Four is entitled "Touching Life, Death and Dis/connection in a State Prison Infirmary". In this chapter, I present a single-authored peer-reviewed paper that is in press. This chapter will be published in the forthcoming work "Sensory Penalities: Exploring the Senses in Spaces of Punishment and Social Control" edited by Kate Herrity, Bethany E. Schmidt and Jason Warr (Emerald Publishing Limited; https://books.emeraldinsight.com/page/detail/Sensory-Penalities/?k=9781839097270). In this chapter I focus on my bodily engagement within the prison infirmary with a specific emphasis on tactile sensations and how touch intersected with peculiar prison deathscapes. The chapter contributes to the emerging body of work that pushes the artistry of anthropological craft into the field of criminology and criminological research. The book itself is part of a larger series, Emerald Studies in Culture, Criminal Justice and the Arts (edited by Yvonne Jewkes, Sarah Moore and Travis Linnemann). This dissertation will be embargoed (unpublished) until at least March 2021 at which point the licence agreement will take effect and I retain copyright of the paper.

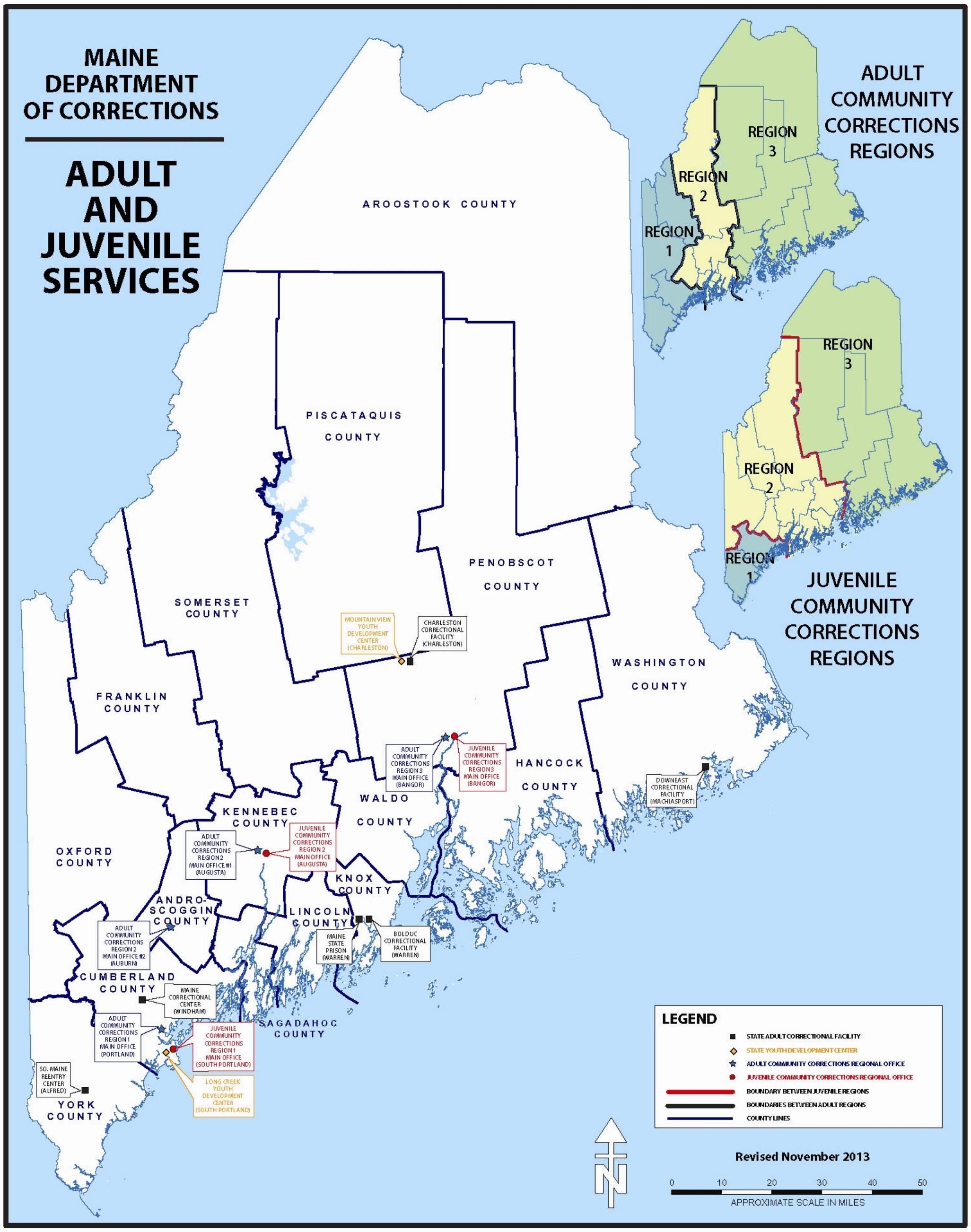

Figure 1. Maine Department of Corrections Facilities Map

Figure 2. Maine State Prison Infirmary
*Not to scale

Night Dreams

The sun is sinking and fading fast,
In a few more days I'll be home at last;
After many long years in a prison cell,
The curse of the wicked, draws me closer to hell.

The mind drifts back to the years gone by,
The reason I'm here I know not why;
The nights bring on great spells of fear,
The night dreams make it plain and clear,
Why many men perish year after year.

The mind goes suddenly when the spirit falls,
And those gray stone rocks that cover the walls;
The bugle still sounding its frightful sound,
That will keep on sounding when I'm not around.

\- Gray

One

Introduction

At the heart of this dissertation is a peer-based prison hospice program, in which incarcerated men provide palliative and end of life care for their peers who are dying. A fateful Google search and generous invitation from the program's longtime director, Kandyce, ultimately led me to the program and the inspiring group of men, who invited me to take an intimate look at care in custody.

This dissertation takes place primarily in a state prison infirmary in Maine. The Maine State Prison (MSP) infirmary, a small five-cell acute care medical unit, can be found in the state's highest security prison for men. The correctional system in Maine operates at the state level,[1] the five men's prisons,[2] one women's prison, one youth

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[1] In other words, there are no federal prisons or private prisons in the state.

[2] During my fieldwork, Maine Governor Lepage secretly closed one of the men's minimum-security prisons, Downeast Correctional Facility (DCF). The move took place in the early morning hours, with Maine State Police and several buses showing up to transport prisoners, in a move that surprised correctional authorities and prisoners. Lepage's motivation for closing the prison was far from concern for those who were housed there, and was connected to fiscal interests. Like most of Maine's prisons, DCF was a key source of income for many local families. It also provided prisoners with the rare opportunity for day release where they could work in local businesses for more lucrative pay. Though the Maine Department of Corrections deducted 20 percent of prisoners' income for "room and board", pay earned in the community typically was much higher than menial prison pay and allowed prisoners the opportunity to earn money before release. Prisoners relied on these jobs as much as local businesses relied on their labour and staff their "union-protected wages" (Rhodes, 2004, p. 9). County officials presented a legal challenge

facility and two re-entry facilities (one for men, one for women) fall under the jurisdiction of the Maine Department of Corrections (MDOC). Maine makes up one of the smallest custodial[3] states in the U.S. 2,600 state-level beds, seven of which belong to the state's sole prison infirmary, all of which are usually full. This dissertation is an ethnographic exploration of the lived experiences of the people who occupied these beds, and some of Maine's other prison medical units, with a focus on their lived care realities. I further narrow my analytic lens to experiences of men who lived the end of their lives behind the walls of Maine State Prison, and in the care of peer caregivers. Given that more people than ever are ageing and dying in custody – the lethal legacy of mass incarceration – this study is tragically timely and necessary.

Local Biologies and the Deadly Legacy of Mass Incarceration in the United States

Douglas Rooks (2020) writes, "Today's 'mass incarceration,' giving the United States the highest per capita rate in the world, began here [in Maine]." Rooks is referring to the state's move to abolish discretionary parole in 1976, making it the first U.S. state to use modern determinate sentencing[4] (National Research Council [NRC], 2014). The new "truth-in-sentencing" model increased the length of sentences (Shaler, 2014) and reflected the increasingly punitive criminal justice agenda that marked the last decades of

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to the move and a judge ruled several months later that LePage had overstepped his constitutional authority, ordering the return of prisoners to the facility. The facility has since been re-closed.

[3] Rhodes' (2004) definition of custody may be applied to the paramilitary structure of the MDOC "organization" whereby "centralized management overlays a second organizational hierarchy, the older paramilitary structure – called 'custody' – composed of officers and the sergeants….and captains who make up their 'chain of command' in each [MDOC] prison" (p. 11).

[4] Under a determinate sentencing scheme, the length of time an individual will serve is determined at the time a sentence is imposed.

the twentieth century across the United States.[5] Two decades later, Maine introduced new legislation (*Maine S 201, 1995*) that reduced "statutory meritorious good time" (referred to as "good time"), from ten days a month to five, with the purported purpose of ensuring "that the term of imprisonment imposed closely approximates that which will be served" (Lyons & Yee, 1995). Joseph Jackson, the coordinator of the Maine Prisoner Advocacy Coalition, served 19 years in Maine prisons. He describes the shifting landscape of penality in Maine:

> As the population of prisoners of color [sic] rose, tough-on-crime rhetoric started to dominate the public conversation, and led to the introduction of truth-in-sentencing legislation…The philosophy of punishment in Maine seemed to change overnight. The Maine state prison branch of the NAACP was disbanded and prisoner organizing became a Class A offense. The good time policy was revised and good time reduced from 10 to five days a month. The position of prisoner advocate was abolished, the correction staff took over the disciplinary and grievance proceedings, and the three-member panel was disbanded. Grievances and write-ups began to soar. Suddenly, Maine's most dangerous prisoners were those who'd failed urine tests and been found guilty of tattooing, smiling at the wrong time, staring at an officer too long, or fighting. The supermax was filled to capacity, and there was a year-long waiting list. (Jackson, 2018, n.p.)

Like other parts of the U.S., Maine's prison population grew exponentially as a result of multiple interrelated racialized and minoritized forces, including "tough on crime" approaches, harsh policy changes, and a rise in life without parole sentencing (Nellis, 2010). In 1983, Maine confined approximately 1500 people to its prisons and jails. By

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[5] Spelman (2009) explains, "Truth-in-sentencing laws have little immediate effect but a substantial long-run effect" (p. 59). The NRC (2014) describes this as a "sleeper effect" whereby for many years new prison admissions accumulate and the numbers are not offset by prison releases (p. 82). In other words, determinate sentencing schemes consequently increase time served and reduce the number of individuals released in future years.

2015 the state saw a 163 percent growth in the number of people incarcerated, with just under 4000 people in the custody of its local jails and prisons (Vera Institute of Justice [VERA], 2019).[6] [7] Intimately tied to mass incarceration is the closure and downsizing of psychiatric and mental health hospitals (i.e. "deinstitutionalization" movement) (Parsons, 2018), the rise of neoliberalism and "the waning of the public safety net" (see Sufrin, 2017, p. 43).[8] These interrelated processes are deeply embedded in economic and racialized exclusion with the state governing marginalized bodies through imprisonment as opposed to investment in "robust and effective" social welfare services (Sufrin, 2017, p. 42).

The people who make up Maine's prison population largely represent the most marginalized and disadvantaged segments of the population, their lives typically embedded in contexts of social and material inequality. Medical anthropologist Margaret Lock (1993) proposes the notion of "local biologies" to highlight the contingency and entanglements of the material and the social and the need to examine health and illness

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[6] In Maine anyone sentenced to nine months or less will typically be sentenced to jail, while nine months or more usually means an individual will serve their sentence in prison. In the course of my fieldwork, I encountered a man at the prison who was neither convicted nor sentenced of a crime. Ernest was transferred to the prison after the state's only psychiatric facility determined they could not care for him.

[7] In 2014, 1,888 men and 142 women were incarcerated in Maine prisons (Carson, 2015), as of 2020, 1,535 men and 133 women were incarcerated at the state-level (MDOC, 2020).

[8] A large body of research examines the history of U.S. penology and mass incarceration over the last four decades. See for example Brett Story (2019) "Prison Land: Mapping Carceral Power across Neoliberal America"; Ruth Wilson Gilmore (2007) "Golden Gulag: Prisons, Surplus, Crisis, and Opposition in Globalizing California"; and David Garland (editor; 2001) "Mass Imprisonment: Social Causes and Consequences". In "From Asylum to Prison: Deinstitutionalization and the Rise of Mass Incarceration after 1945" Anne E. Parsons (2018) also offers critical insight into the linked phenomena of mass incarceration and deinstitutionalization, and the Maine Advisory Committee to the U.S. Commission on Civil Rights (2019) reports that presently "Maine incarcerates more individuals with severe mental illnesses than it hospitalizes (p. 4).

experiences in particular local contexts (Lock & Kaufert, 2001; Lock & Nguyen, 2010). Under this framework, the trajectory of health (and ageing) may be influenced by biological, psychological, social and cultural factors (Goldfarb, 2019; Lock & Kaufert, 2001). In a recent article Lock (2020) notes:

> In 2004, epidemiologists Nancy and George Davey-Smith cited the classic 1854 Engels text on this matter: 'common observation shows how the sufferings of childhood are indelibly stamped on the adults' (Kreiger & Davey-Smith, 2004, p. 2)…These findings demand that bodies be situated in context to account for the vagaries of disease. (p. 29)

Lock's concept of local biologies therefore offers a critical tool to understand the significance of exposure to consequences of inequity, including adverse biospsychosocial, political, and environmental conditions, such as violence, neglect, poverty, substance use, homelessness, incarceration, and poor access to health and social care across the life course, for prisoner biology and later life health (e.g., Johnson, Bazargan & Cherpitel, 2001; Lock, 2020; Murray et al., 2012; Riem & Karreman, 2019; Scott et al., 2013). In other words, legacies of social exclusion and violence manifest as adverse health and illness. As Professor of Criminal Justice Studies, Martha Hurley (2010), recently put it, "Prisoners grow old faster and become sick earlier."[9] What does it mean when local biologies are tethered to mass incarceration? 70-year-old Gray, who was nearly 50 years into a life sentence when I met him, offered the tragic consequence, "You grow old and you die here."

A growing body of work articulates the ways in which the local biologies of incarcerated people might contribute to poor health (Bedard, Metzger & Williams, 2016;

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[9] For a global discussion about ageing in prison see Maschi, Viola and Sun (2013).

Binswanger, Krueger & Steiner, 2009) and “disadvantaged health profiles” (Nowotny, 2017). Public health and epidemiological research indicate high rates of illness and disease in prisons (e.g., Bedard et al., 2016, Bedard & Pelleg, 2019; Binswanger et al., 2009; Cloyes et al., 2015; de Viggiani, 2007; Fazel & Baillargeon, 2011; Nowotny et al., 2016; Simon, 2014). The social world in which individuals are enmeshed may also shape the course and outcome of illness (Desjarlais et al., 1995). Rosen, Wohl and Schoenback (2011) compared North Carolina Prison records with state death records over a ten-year period (1995 to 2005), concluding that there were more deaths among prisoners from viral hepatitis, liver disease, cancer, HIV/AIDS and chronic lower respiratory disease, than non-incarcerated communities. Two years later, sociologist Evelyn Patterson (2013) suggested that for every year of incarceration, a person’s life expectancy may be reduced by an average of two years. Patterson’s findings are startling: in the parole cohort examined, five years in prison increased the chance of death by 78 percent and reduced the expected life expectancy at age 30 by ten years.

Researchers have also theorized a process by which people in prison may experience biological changes typically associated with later in the life course. In the U.S., poor health is strongly associated with “frailty”, “oldness” and old age (Coupland & Coupland, 1993); therefore scholars have framed the prison process as “rapid ageing” whereby the physiological and cognitive health age of an older prisoner is imagined to be akin to that of someone, in the outside community, who is ten to 15 years older (Aday, 2003; Dubler, 1998; Falter, 2006; Gates et al., 2018; Maschi et al., 2013; Williams et al., 2012).[10] Compounding this, 40 years of hyperincarceration has led to a large number of ageing and older persons in U.S. prisons and jails. Older adults are now the fastest growing group in the U.S. justice system. Prisoners aged 55 years or older accounted for most of the growth (106 percent) in the American prison population from 2003 to 2013 (Kitt-Lewis et al., 2018). In state prisons, this age cohort increased from three percent in 1993 to ten percent by 2013 (Carson & Sabol, 2016; Psick et al., 2017); Human Rights Watch (2012) estimates that between 2007 to 2010, the number of prisoners aged 65 years or older increased 94 times faster than the total sentenced prisoner population.[11]

Maine's own unforgiving criminal justice system has played a key role in its ageing and older prison population, a critical public health issue further exacerbated by an increase in later-in-life convictions for historical offences and state demographic changes. Specifically, Maine is considered to be the "oldest" U.S. state. Its median age is rising faster than the national average and the state population is growing older at one of the fastest rates in the U.S. The Baby Boomer cohort aged 52-70 years old in 2017 accounted for 28 percent of Maine's total population. The 65 and older age group is anticipated to increase by 37 percent from 2016 to 2026 as the Baby Boomers age into this cohort (Maine State Economist, 2018). As Maine's largest generation cohort ages, it is likely that the state's prison population will follow this trend unless urgent action is taken. According to a 2013 study, prisoners over the age of 50 represented 15.2 percent

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[10] The American Civil Liberties Union (ACLU) (2012) estimates that in just over ten years, by 2030, the "geriatric prison population" will exceed 400,000 across the United States, many of whom will die before they are ever released.

[11] The definition of "older prisoner" varies by correctional service ranging from 50 to 70 chronological years old. For some justice systems, no official age is designated.

of the total state prison population, compared to 11.9 percent in 2005 (Shaler, 2014), and Ahalt et al. (2013) indicate that the number of older prisoners increased by 287 percent between 1990 to 2009. "As the correctional population ages," Rikers Island jail gerontologist, Rachel Bedard, and correctional health colleagues (2016) explain, "an increasing number of incarcerated individuals are at risk of developing serious, life-limiting illnesses and dying while incarcerated" (p. 932). This elicits pressing questions: how are people who are experiencing serious or terminal illness cared for in prison? What does this mean for their lives? And what of their deaths? These are questions I take up in this thesis.

Medical anthropologist and obstetrician-gynecologist Carolyn Sufrin (2017) asks, "What is the state's responsibility to care for its citizens, and which subjects are constructed as unworthy of care?" (pp. 43-44). In the same year parole was abolished in Maine, there was a landmark legal case. The *Estelle v. Gamble, 429 U.S. 97* (1976) established a constitutional mandate for custodial agencies to provide incarcerated persons with access to care for serious health conditions. According to the Supreme Court ruling, under the Eight Amendment:

> Deliberate indifference to serious medical needs of prisoners constitutes the 'unnecessary and wanton infliction of pain'…This is true whether the indifference is manifested by prison doctors in their response to the prisoner's needs or by prison guards intentionally denying or delaying access to medical care or intentionally interfering with the treatment once prescribed. (pp. 104-105)

Despite the ruling, prison health researchers and advocates suggest prisoners often do not receive appropriate access to care (Kitt-Lewis et al., 2018; Novisky, 2018; Nowotny et al., 2016; Wilper et al., 2009). In fact correctional health researcher Kathryn Nowotny (2017) describes prison health services as at best "episodic care". As Aday and Krabill (2011) explain, "[M]edical services tend to lag behind mainstream medicine in terms of offering necessary treatment" (Deaton, Aday & Wahidin, 2009; Vaughn & Collins, 2004; Watson, Simpson & Hostick, 2004; as referenced in Aday & Krabill, 2011, p. 207). Criminology scholar Meghan Novisky (2018) reports that older prisoners in federal custody wait 114 days on average to see cardiology and pulmonology specialists. Consistently throughout my fieldwork, I witnessed scenes of deplorable health care; the stories I heard were even worse. I unpack this situation in Chapter Two.

I share Simon's (2014) contention that this indefensible situation reflects the crisis of mass incarceration and the normalization of medical neglect of prisoners, but extend his point further, suggesting that ageist and "criminal" stereotypes are deeply embedded into the social fabric of the U.S. When these factors intersect with the local biologies of prisoners, it is detrimental to their lives. Jefferson and Jalloh (2019) make the dire point that:

> We have seen how under compromised circumstances the prisoner's body becomes a site that illustrates the way that some people matter more than others. In many prison situations, in experiential terms, the prisoner is not equal, does not have dignity, does not have their rights respected and so on…Tragically, sickness does not necessarily invoke care and compassion and may even serve as an invitation to brutalize, exploit and exacerbate suffering…To not be cared for, to not have one's wounds or infections, aches and pains tended to can become an extension of punishment, an exacerbation of pre-existing deprivation. The ill-health of the prisoner can be an opportunity to passively punish, by allowing nature to simply take its course to the prisoner's detriment. (p. 585)

The exceptional growth of the penal system and the hyperincarceration of marginalized bodies contribute to *mass death* behind prison walls, a term used by Chavez (2015) to denote the "massive number of elderly and terminally ill prisoners who are dying inside" (p. 2).

This is part of a disturbing trend that reflects a steady rise in state prison deaths, despite a decrease in the number of people in state custody (Carson & Cowhig, 2020). Between 2006 to 2016, more than 53,000 people died of "natural" causes in state prisons, reflecting a 15 percent increase in prisoners' deaths. In 2013, approximately 3,800 people died in U.S. prisons (Bedard et al., 2016), and, by 2016, more than 4,100 people died in state or federal custody (Carson & Cowhig, 2020). To quote Patterson (2013), death "cannot be reversed. It is this lack of reversal that makes this area of study so consequential" (p. 527).

The Study

On an otherwise non-eventful September Sunday, I typed `prison hospice` into my browser search bar. Though I had done this many times over the past two years, this search proved to be the "fateful" one. I noticed a website called "Hospice Analytics" and a few clicks later and I found myself staring at a list of correctional hospices in the United States. The next day, I excitedly shared my discovery with my advisor. After that, everything seemed to unfold rather quickly. An email was sent to Dr. Cordt Kassner, the executive director of Hospice Analytics, who was incredibly supportive and to whom I will forever be eternally grateful. Dr. Kassner and I spoke by phone, which set off another flurry of emails including one to Kandyce Powell, the director of the Maine State Prison Hospice program and executive director of the Maine Hospice Council and Center for End of Life Care. Two weeks later I was on a call with Kandyce and not long after, sitting face-to-face with Kandyce in a small restaurant in Augusta, Maine – the next morning I would join her for the prison hospice class she had held every Wednesday for nearly ten years. That Wednesday, I woke at 4 a.m. and carefully picked out my outfit – a cream wool sweater, green corduroys, ballet flats and (as I learned the night before) the ever-important underwire-less bra to avoid setting off the prison metal detectors. As I drove my rental car along Maine's famous coastal Route 1, the sun only just beginning to rise, I was a mixture of nerves and excitement. Two hours later, I sat in a large classroom alongside the fourteen men who volunteered their time to care for fellow prisoners and who invited me to visit again. A few weeks later, I returned to Maine and the prison to visit with Kandyce and the hospice volunteers. And again a few weeks after that. My usual three-day visits and stays in hotels extended to three weeks and a cosy room in Kandyce's home. Relationships grew alongside my project and less than a year after I first walked into the Maine State Prison, I moved into Kandyce's welcoming house in a quaint coastal town.

Over two years (including fourteen consecutive months) I conducted ethnographic fieldwork in state prisons in Maine. As the "science of intimacy" (Myers, 2015, p. 10) that involves deep engagement (Jewkes, 2013) and investigation over time, anthropology's ethnographic method was best-suited to draw out complexities of dying and care in prison. Indeed, Nancy Scheper-Hughes (2007) makes the point:

> Our craft requires engage[ment] in long and intense periods of living among strangers and bearing witness to human lives and events lived in less well-lit, certainly less visible, and often marginalized spaces of the world…Anthropology attends to the minutia of everyday life and to 'small things forgotten' and 'no account' people…whose lives and deaths go unnoticed. (p. 159)

Long-term engagement and close participant observation enabled me to learn a great deal about the experience of terminal illness and dying in prison by tracing people's experiences over time and across space via their illness trajectory (see Sue, 2019). Such ethnographic explorations have largely remained outside of ethnographic possibility due to the "opacity" of prisons (Bandyopadhyay, 2015; Herbert, 2019; Rhodes, 2004; Waldram, 2009), and prison medical units are especially impenetrable spaces for ethnographers.[12] Researchers are often permitted only highly controlled access to prison populations or blocked out of these prison spaces altogether (see Herbert, 2019; Novisky, 2018 for example). Yet, the Maine Department of Corrections[13] administration was supportive of the embedded-nature of my ethnographic endeavour.

I imagine the MDOC supported my project in part because of Kandyce's endorsement, and the support of the prison's warden whom I had come to know in the course of my preliminary fieldwork. I met with the prison administration early in my fieldwork to develop a research schedule and negotiate access. To my surprise, I was offered unescorted daily access and an ID badge and pass that would open the prison's

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[12] Sanders, Stensland and Juraco (2018) observed advance care planning discussions between people "preparing to die" in prison and prison staff, however as they modestly acknowledge, their findings offer only "a glimpse into [the dying] experience for inmates" (p. 235).

[13] Consistent with the work of other penal anthropologists, I do not name prison staff or administrators unless they are a public figure or invoked as an authority (see Sue, 2019) or if they requested to be identified.

various steel barriers, on the condition that I participate in the MDOC's training for medical staff and interns. The weeklong training was an exercise in frustration and I struggled through the dehumanizing undertones and persistent narrative of "manipulative offenders".[14]

Having "earned" my badge, I was authorized to visit the prison between 7 a.m. to 6 p.m. – "regular hours of operation" – and spend my days in the infirmary, where the state's most critically ill prisoners were housed. The self-contained unit had its own recreation yard and a segregation unit with two cells (though it was rarely used as such). Unit "security" was overseen by a single officer, its care by a nurse; each had their own desk from which to conduct their respective jobs. The infirmary was attached to the prison's larger medical clinic, though separated by a steel slider that cut it off from the wider prison. Within a matter of weeks, my "access" was extended to 24-hours at the suggestion of a long-time prison administrator. "We can talk about changing this during a hospice vigil, I think she'll need to see that," he'd said to his colleagues who nodded in agreement, an offer they extended after Daniel (Chapter Four) was placed on "vigil", a status assigned when death is determined to be imminent. On vigil, peer caregivers attend a patient's bedside around the clock until they die.

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[14] This narrative persisted beyond training and penetrated daily life in my fieldwork [Rhodes (2004) also describes how custodial staff are trained to assume prisoners are manipulative]. I was often cautioned against overfamiliarity and the dangers of becoming a "duck". The term is used to refer to a staff member who is perceived as vulnerable to being manipulated (usually through persuasion by a prisoner to break some level of rule or policy and which is then used against them for blackmail purposes). The process is referred to as "downing the duck". The process is described in detail in a short story "Downing a Duck – An Inmate's Version", which was often mentioned by custodial staff [see Lindhal (2011) "Intimacy, Manipulation, and the Maintenance of Social Boundaries at San Quentin Prison" for a detailed description of "Downing the Duck" – both the story and the process (pp. 18-20)].

I conducted thousands of hours of participant observation in the prison infirmary and several more hundreds of hours in the MDOC's other prisons.[15] I primarily observed prison medical spaces but extended my observation to other prison spaces including housing units (e.g., close custody and medium custody, Administrative Segregation, Intensive Mental Health Unit) and conducted observation from different vantage points including as an engaged participant observer in the units themselves and more distant and unobtrusive observation from the view of control rooms or "bubbles". I observed prison activities including weekly prison hospice classes, prison hospice conferences and workshops, memorial services held at the prison, and non-hospice related events (e.g., talent shows, prisoner barbecues).

For the most part, this dissertation chronicles events that took place at the Maine State Prison and in the infirmary. Additionally, Chapter Two traverses several penal medical spaces, including the MSP infirmary and a prison Assisted Living Unit (pALU) at a multi-level security institution several hours from the higher security prison. I first visited the pALU several months into my fieldwork after Gray – whose poems are scattered throughout this dissertation – was transferred to the pALU. I had spent several weeks chatting with him as he dealt with pneumonia, his third bout and so severe that all those around him anticipated he would die. Gray recovered, much to everyone's surprise including his own, and was transferred to the pALU – he no longer required the more intensive medical care the infirmary afforded. Gray and I had bonded quite a bit over the few weeks he'd been in the infirmary and he suggested I visit the pALU (and him). "You

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[15] I visited and toured all of the state's prisons, except for the Downeast Correctional Facility.

might learn something for that book you're working on," he'd said in his signature growl, waving his hand in the direction of my notebook, "Plus, I can teach you some chess."

To Gray's dismay and despite his best efforts, I was a rather terrible student of chess. But I am indebted to him for many other reasons, including his wise encouragement to broaden my gaze to the pALU. At the time of data collection, the pALU was a newer initiative by the MDOC and emerged in direct response to the management of older prisoners who required regular access to health and medical services, or assistance with prison Activities of Daily Living (pADLs). The pALU was located in a former youth prison that had been converted to a correctional treatment facility that included one young offender's unit, two units dedicated to individuals convicted of a sex offence, and the pALU. It was in this 19-bed unit that I encountered a group of older men who under the state's tight grip, were left to languish in prison. The cells in the pALU were small and windowless with heavy metal doors. The unit's former purpose as a segregation unit was undeniable, largely due to the lack of structural changes when it was "converted" to a housing unit for older adults.

After my first visit to the pALU, I adjusted my research schedule and began to make the two-hour drive to MVCF each week. I would typically arrive early on a Thursday morning, stay over in a hotel in the nearest city 40 minutes away, and return for another full day of observation on the Friday. Like Gray and Cat (who the reader will meet in the coming pages), several of the men I followed over time repeatedly moved to and from the pALU and the MSP infirmary. Sometimes our paths first crossed at the pALU and after a bad fall, stroke, or cancer treatment they would be moved to the infirmary, other times I traced them from an initial encounter in the infirmary and to the pALU – and often back again.

I constantly questioned the ethics of my research and was hyper aware of the position of power and privilege I occupied, including my freedom to leave the confines of prison whenever I pleased. I often questioned my presence and felt intrusion in people's lives and checked in regularly with hospice caregivers and Kandyce, as well as administration, to ensure my being there continued to be welcome. On many occasions I opted to forgo rich ethnographic moments or opportunities. When I kept coming up against gatekeepers (i.e. correctional officers or "COs") who hindered my ability to do interviews, I was offered a space in the Visits room but opted to forgo this as participants would have been subjected to strip searches before and after each interview and their participation widely known. I took care to slowly foster relationships and figure out the social landscape of the different spaces, to learn which staff perceived me as a "liability" and which officers were comfortable with my unconventional presence. I never entered a cell without first having been invited and placed the expressed wishes of patients before my "data". An older man named Bill, for example, repeatedly expressed a desire to die on his own. His death was particularly harrowing and painful and he wanted to shield others, including the caregivers, from the horrors of his decaying body. Listening to Bill's wishes was far more important than any amount of ethnographic data I could have gleaned from witnessing the brutality of his death and so I did not probe his end of life, until I was invited in.

To complement my ethnographic fieldnotes, informal conversations and observations, I conducted in-depth interviews with hospice volunteers, patients, on occasion patients' family members, men housed in the pALU, as well as some security staff, members of prison administration, and medical administrators. Interviews were unstructured and were guided by the participants and entailed listening reflexively in order to ask follow-up probes and foster rich discussion. I conducted all recruitment independently and did not report participation to correctional administration or staff. Given the small number of individuals in the pALU (as well as hospice patients), in order to protect anonymity and confidentiality of participants, I do not disclose the time period of data collection. All interviews were held one-on-one in private, the most common location being the participant's cell or a private room in the adjoining clinics. I regularly visited with prisoners in their medical cells, which helped to further conceal interview participation. All interviews were audio-recorded, with the exception of one that was recorded by hand at the participant's request. Interviews ranged from 60 minutes to as long as two and a half hours, and took place over one to three periods of time, based on a participant's request or if the interview had to be stopped due to an institutional emergency (e.g. a code or ICS) which turned out to be quite common.

Nearly all of the men I encountered as "patients" in the various medical units were white. Less than a handful of men self-identified as Native and I encountered only one patient who self-identified as Black.[16] This was surprising to me as racial disparities

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[16] At the time I conducted my study, approximately half of the volunteers were white and half self-identified as Black or Brown. I do not refer to race when speaking about the individual caregivers as this information would make participants easily identifiable.

in Maine's prison system are striking – as of 2019, Black people constituted two percent of the state population but represented nine percent of the state's prison system (VERA, 2019). It is possible that the absence of Black men in my study reflects the subpopulation I was studying and the broader phenomena of racialized incarceration in Maine, of which we are only now starting to see unfold. Most of the older men in the prison were white, many of whom were sentenced to long sentences in the in the 1970s, `80s and `90s or convicted of an offence for the first-time later in life. Most of the Black men in the prison were younger – the Maine criminal justice system especially criminalizes young Black men and since 1990, the Black incarceration rate has increased by 139 percent (VERA, 2019). I imagine if I conducted this study some years from now, I would encounter more Black men who have grown up, grown older, and grown sick in the state's carceral grip. But, might the absence of Black men from the prison care units also signal the racialization of these spaces of care and a further form of marginality and exclusion in their lives?

When I wasn't in the prison, I could usually be found with Kandyce, so much so that on more than one occasion a colleague or friend lightheartedly referred to me as her "appendage". I attended weekend hospice retreats in the community, palliative and hospice care trainings, and tagged along to many lunches and meetings between Kandyce and other end of life care providers in Maine. To amplify my ethnographic research, I spent many days sitting on the floor of Kandyce's office pouring over box after box of MSP hospice documents that Kandyce had collected over the past 17 years.

Despite the significant support I received from various administrators, fieldwork was complex and challenging. As anthropologist Paul Brodwin (2013) explains, "For obvious methodological reasons, the researcher can gain the trust and (relative) acceptance of only one group of people at a time" (p. 2). While my choice of "sides" was simple, navigating the terrain was tricky. As a petite young woman with vibrant purple hair, the researcher and ethnographer who spent her days "hanging around with prisoners," I was often regarded as highly suspect by staff. I was in a perpetual struggle to give the illusion of distance while engaging in close and meaningful relations with the men I studied. I was constantly reminded to be "professional", chastised for "getting too close to prisoners," and harshly informed by a medical administrator that I had "no business being in cells." A longtime officer warned me early on in my fieldwork, "Watch your back and I'm not talking about the inmates." By the time I finished my study, I knew all too well what he meant. In order to protect the well-being of my interlocutors, I have chosen not to disclose further detail. For those of you who have spent time in prisons, I imagine you will understand.

The Structure

I initially intended to write a monograph, however as I waded through disordered and very human data, I began to question my determination to carefully craft a clear and ordered picture. As anthropologists we are often guilty of seeking to impose some kind of order onto uncertainty, to control and neatly package our data, perhaps without realizing the consequence of our actions. At times, I couldn't help but feel that I was coopting the stories of people's lives (or silencing them) manipulating lives and deaths into a deceptively coherent narrative, a tidied narrative that was not, in its tidiness, a true depiction of their experiences. Instead I embraced the "analytic noise" (Biehl, Good & Kleinman, 2007) finding inspiration in the work of Elizabeth Povinelli (2011), Anne Lovell and Lorna Rhodes (2014), Yvonne Jewkes (2012; 2013) and Sandra Hyde and Laurie Willis (2020). I read Hyde and Willis' (2020) article at a time when I was struggling to make sense of and "pace" each chapter and the thesis more broadly. As they explain:

> Trying pace to both precarity and care, we suggest, opens up a space for novel contributions showing how and why we tell the stories we do, what we expect a story to do in the world, and how our ethnographic practice can shift in critical ways if we pace ourselves and our stories differently. (p. 297)

I shifted the structure of the thesis and instead of a monograph, I present a sandwich thesis composed of three papers, with an interlude between each. No interlude is the same and each paper is distinct; I have tried to minimize overlap between papers. In each I provide a methodological description and engage with extant literature, though do so carefully. I place the voices of participants at the centre of my dissertation as I argue against the traditional research practice that works to marginalize the voices of communities. The eloquent work of Sharon Kaufman (1986, 2005) and Paul Brodwin (2013) resonates; in each chapter I seek to subtly engage scholars in ways that do not overwhelm my text and the stories of the men. In Kandyce's words, prison generates an "invisibleness of the people that reside there",[17] therefore I hope to amplify the voices of the men I met and "introduce them into debates where they are typically absent" (Brodwin, 2013, p. 20).[18] While each chapter is written to stand on its own, they share a story of custody and care.

The first paper, entitled "Privatized Health Care in the Lives of Older Prisoners", outlines how the prison and its health care system shape the illness experiences of older prisoners. In this chapter, I move back and forth between scenes I witnessed and the voices of imprisoned men to explore how health care systems interact with the local biologies of "medically ill" older prisoners. What has been less explored in the literature are the ways in which custodial health care takes shape as violent or harmful. Therefore I ask, what does it mean when the lives of older prisoners collide with contracted for-profit medical care and how might their lives be constituted as "undeserving" of care (Jefferson

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[17] Scholars have also been critical of prison research that marginalizes or silences the voices of the individuals and communities we study. For instance, David Garland (1992) is critical of literature that tends "to silence the human beings who fall under its gaze" (p. 419) and Yvonne Jewkes (2013) writes, "[I]n an age of mass incarceration, the temptation is to focus on the big numbers" but "if prison researchers embrace the 'reflexive turn' in qualitative sociology and acknowledge the emotion and humanity inherent in the ethnographic research process we can enrich our work and deepen our understanding of the people and contexts we study without compromising our ability to effectively critique penal systems" (p. 14).

[18] It was once suggested to me that I "pseudonnimize" my fieldsites, as well as interlocutors. I chose to identify my research sites, first and foremost, to respect the requests of the men I encountered. Ignoring their wishes felt to me like another form of silencing their voices. There are contextual details that are also necessary to disclose, and omitting these details would have altered the integrity of my account (Sue, 2019). Given the necessity to include contextual and historical information, the program and the prisons would have been easily identifiable, even if I had taken the additional step to anonymize the state. Moreover, the purpose of anonymity is to protect participants from possible repercussions. However, in the case of my study, and as many of us who work or live in prisons would argue, the individuals who pose the greatest risk to interlocutors are those who control their custody and care. In an institution like a prison, where every movement is regulated and logged, and human eyes and cameras constantly surveil, participant anonymity cannot be guaranteed. Anonymizing the public institutions would do little to protect the interests of those we hold captive within them. Rather, to protect participants, I have chosen to omit or alter potentially "risky" or "threatening" details.

& Jalloh, 2019, p. 586)? In this chapter, I present the narratives of three older men I encountered in prison medical units to show how the lives of older prisoners are devalued and dehumanized and the ways that the market-based health care system within the prison threatens the dignity and well-being of older prisoners. I conclude the chapter with policy and practice recommendations for those providing care to older and ill people in custody.

The second paper is entitled "Prison Hospice: Making and Escaping Life and Power in Prison". In this paper, I share the story of a patient and his caregivers to consider how hospice caring reconsitutes death *and* life in prison. I draw on the work of Jefferson and colleagues (2018) who explore how life is lived in and across sites of confinement "by focusing on the tactics of everyday life and hope while being mindful of … ever-present forms of abjection" (p. 1). This chapter also finds inspiration in the anthropology of care work of Janelle Taylor (2008, 2010), Aaron Seaman (2020), and Arthur Kleinman (2010), to understand care as an intimate relational practice that shapes and reshapes personhood and sense of self. I argue that as such, caring in the prison hospice usurps power over experience away from the prison apparatus. Yet, as a "nefarious" form of escape from disciplinary efforts over life, hospice care inevitably provokes the prison and its actors to reassert control.

The final paper, entitled "Touching Life, Death and Dis/connection in a State Prison Infirmary", has its roots in sensory ethnography and the emerging field of sensory penality. This is a reflexive piece in which I present a thickly descriptive (Geertz, 1973) account of my experiences as a "subjective sensory explorer" engaged "bodily in and with" (Blake, 2011, p. 3) end of life in the prison infirmary.[19] This chapter is inspired by philosopher Michel Serres' (2008) "The Five Senses: A Philosophy of Mingled Bodies" and the sensorial works of Paul Stoller (1989, 1997) and David Howes (2010). Martin Buber's "I/Thou" also ripples through this chapter. Sensory penologist Kate Herrity (2020) presents a compelling case for sensory ethnography:

> Dwelling on the emotional labour of navigating the traumatic and intimate spaces of prison alongside those who live and work there runs the risk of lapsing into self-indulgence. What these embodied aspects of social experience have to tell us about life in carceral spaces, however, warrants further exploration.

I probe my sensorial subjectivity and particularly touch as a medium of inquiry to explore the sensations of life, death, and dis/connection experienced in the rooms of the prison infirmary. More specifically, I present the dissonant spaces and sensations of disciplinary segregation and the prison hospice cell, reflecting on the ways in which the *feel* of a man's life and death illuminate new ways of knowing and understanding of the prison infirmary as a space simultaneously of brutality and beauty and indignity and intimacy. I conclude the chapter by asking, what embodied subjectivity enables for ethnographic ways of knowing custodial life and death? And, in the spirit of Ruth Behar's (1997) eloquent text "The Vulnerable Observer: Anthropology that Breaks Your Heart" which gently pushes, "What happens within the observer must be made known…if the nature of what has been observed is to be understood" (p. 97), I reflect on my sensorial subjectivity

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[19] I understand reflexivity as a "recognition that the researcher is not separate from but exists in a relationship with what [they are] trying to understand…in other words, the researcher is a part of, rather than separate from, the research" (Fernandez, 2009; as referenced in Strega and Brown, 2015, p. 8).

and how I learned to *be* as an ethnographer. As a whole, the three papers shed light on constellations of care in prison, the contingency of relations and personhood, and points of friction between care and custody.

My encounters with death and the brutality that punctuated daily life in the prison inspire my approach for the conclusion of this thesis, which lends to the emotional experience of this ethnographic work and a call for change to care and custody.

Infected Foot Bound

I had barely set foot into the infirmary when Billy, a recently admitted patient, stepped out of his cell, “You shoulda seen when they took him to PenBay [hospital]!” There was a hint of disgust in his voice. “They had him in three-points [restraints] and shackles. They cuffed him up real good,” he said, shaking his head as he recalled Cat being taken to the hospital by two “COs”. The officer assigned to the medical unit overheard the exchange and approached us.

“I wouldn’t have, but not up…” he began to say but Billy cut him off.

“I asked ‘em why they were doing it, couldn’t believe it!” his anger was palpable. “He was crying out in pain when they put those damn things on him. Makes no sense if you ask me. I’m missing half my organs and have tubes sticking out of my stomach,” he lifted his shirt to show me the tubes and drain that were sewn into his stomach and the nasty, still-fresh eight-inch incision, “I get why they’d do it to me, even with all this, but that dude? Doesn’t sit right with me. Shackling an old man like that.”

Later that same day, Cat returned from the hospital. The distinct click of a heavy metal latch alerted me to the opening infirmary door. As I tried to quickly finish a note before I looked up, shoes of an unusual crimson colour rolled into my line of sight. My gaze fixed on the shoes, the red screaming at me as I absorbed the scene before me. I had recently finished reading “Doing Time With Charlie,” a deeply moving memoir written by Kay Page whose husband Charlie had died in this same prison infirmary several years earlier. In it, Kay described Charlie’s painful journey navigating a serious illness while in the clutches of custody. “I walked in to still another hospital room reserved for my husband. I happened to glance at the bed before I greeted Charlie. At first I thought I was seeing things. I actually touched it before I was sure. To my shock, I saw his infected foot bound with a cuff and a chain secured to the edge of the bed," Kay writes (2013, p. 216). This shocking image from Kay's memoir returned to my mind vividly, as the officer pushed Cat's wheelchair closer, and I could see his ankles. The sickening realization hit me. "Infected foot bound."

I tore my eyes from the blood that painted Cat's formerly white sneakers. He was hunched over in the wheelchair; his frail hands were docile, handcuffed in his lap. His face was pale. He emitted slight moans and his head lulled to one side. "Cat, you okay buddy?" I asked rising from my chair, feeling disturbed in that moment yet trying to appear composed. Another resident of the infirmary, Brady, emerged from his cell and began to roll his wheelchair towards Cat. They were the only two long-term residents of the infirmary, and spent most of their time together. Despite living with stage 3 multiple myeloma cancer that ravaged his body, Brady took on the role of informal carer for Cat.

"What's up Cat Cat? You get some puddin' at the hospital?" Brady tried unsuccessfully to rally some type of reaction from Cat.

The officer continued to push Cat to his cell as Brady and I looked on helplessly. Once inside, the two large officers unshackled him, removed his bloodied shoes, and stripped him of his urine-soaked clothes. Another indignity awaited Cat: strip searches were policy-mandated after any visit to the "outside."

Cat's shackled ankles represent a stark, but not unusual, illustration of the ways in which prison security policies and the custodial logic of care (Dubler, 1998) collide – and clash – with well-being. Prisons and the disciplinary logic that informs their policies and "mandates" their practices, were designed to punish young, able bodies; such violent policies and practices, however, have long posed a threat to people in prison, one that increases exponentially with the interplay of older age and illness.

Two

Privatized Health Care in the Lives of Older Prisoners

For submission to *Human Organization,* Journal of the Society for Applied Anthropology

> My celly, he's doing life. Well he's not doing life, but his sentence
> will be longer than his life; he'd be 112 if he made it.
> - Nicholas, Maine State Prison

> So I know that unless the laws change, a lot of us have a long ways to go.
> We have a release date, but it's not for a long time out.
> - Mamba, Maine State Prison

The United States has the highest rate of incarceration in the world (Fazel & Baillargeon, 2011) with more than two million people currently housed in its prisons or jails (Walmsley, 2018). This reflects a growth of over 500 percent in the past four decades (The Sentencing Project, 2019), and is a direct consequence of a more punitive turn in so-called justice systems (Caverley, 2006; Hoffman & Dickinson, 2011). Harsh sentencing schemes have increased the rate and length of incarceration in the U.S.[1] including longer average prison sentences and a significant increase in the number of individuals serving life sentences without the possibility of parole (Nellis, 2010). Research suggests that

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[1] The "Maine Crime and Justice Data Book" (Shaler, 2014) indicates that the number of persons under the jurisdiction of state correctional authorities grew by nearly 13 percent across a ten-year period (2003 to 2012).

consequently, ageing in U.S. prisons and jails is outpacing the general population (Bedard & Pelleg, 2019) and, while state prison populations numbers are falling, the same cannot be said of the "older" prison population. Today, "older prisoners" represent the fastest growing group in the U.S. penal system.[2] Projections suggest that approximately one in three people in prison will be aged 55 years or older by 2030 (Enders, Paterniti & Meyers, 2005; Williams et al., 2006), representing a 4,400 percent increase from 1980 to 2030 (American Civil Liberties Union [ACLU], 2012; Herbert, 2019).

In this chapter, I add depth and provide a human context to this statistical picture presented above, by exploring the lived realities of older men entangled in a prison health care system. Penologist Yvonne Jewkes (2013) argues "the bald statistics conceal complex lives and important stories" and encourages researchers to "go beyond abstraction and describe the lived experience of imprisonment, the felt effects of which can only be understood ethnographically" (p. 14). I draw on ethnographic data from my larger study on end of life and care in prison to focus my analysis on the illness experiences of the older men I encountered in prison medical units. As I traced the journeys of prisoners through observation and interviews, their health care experiences emerged as a key concern. Nearly all of the men I encountered shared accounts of inadequate or poor care experiences, some of which had serious consequences for their health and well-being.

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[2] The definition of "older prisoner" is determined by specific age ranges, though these vary by state and custodial system. The age range understood to constitute "older" ranges from 50 years and over to 65 years of age and over. For the purpose of my study, I focus on the experiences of adults aged 50 years and over.

In what follows, I present the narratives of Nikolai, Cat and Cliff, all older men living with chronic illness in prison. Their narratives bring to light a number of common themes that emerged across the stories of the many older men I encountered in prison medical units. Based on the experiences they shared with me and allowed me to witness, in this article I raise concern about the state of being older and living with illness in prison, with particular attention to the prison health care structure and delivery. More specifically, through these stories, I show how the lives of older prisoners are devalued and dehumanized and the ways that the health care system within the prison threatens the dignity and well-being of older prisoners. I hope that my research on the lived realities of older prisoners might result in informing humane and compassionate policy and practice recommendations for those providing care to older people in custody.

Local Biologies and Prison Health Care

> A lot of us are here [medical unit] because of an illness.
> Prison, it's rough on us.
> - Gray

In 1976 a legal mandate established the right to health care for prisoners across the U.S. as per Estelle v. Gamble (see Venters, 2019). The landmark ruling ostensibly guaranteed that prisoners were entitled to, and *should* receive, community-standards of care. However, prison health researchers indicate that, despite this ruling, prisoners often do not receive adequate medical care (Kitt-Lewis et al., 2018). Aday and Farney (2014) explain that penal harm thus extends "beyond the custody and control of inmates and into the inmates' health care treatment" (p. 360), and research suggests that "when people are sentenced to prison, they lose not only their freedom but also all too often lose their health and quality of life" (Haney, 2001; Maschi et al., 2012, p. 444).

I argue that older prisoners are especially vulnerable to experiencing multiple levels of disadvantage and marginalization (Galli et al., 2019; Fazel et al., 2004) due to the stigmatizing social constructions of the (un)worthiness of older people *and* prisoners that are embedded in society and its health care structures. Ageist and "criminal" stereotypes are woven into the social fabric of the U.S.; prejudice and discrimination intersect with the "local biologies" (Lock, 1993) of older prisoners, creating barriers to health equality and care that are detrimental to their lives. Specifically older prisoners experience a disproportionate burden of adverse health consequences compared to both non-incarcerated communities and younger prisoners (Binswanger, Krueger & Steiner, 2009; Pro & Marzell, 2017; Skarupski et al., 2018) due to local biologies, whereby the trajectory of health and ageing may be influenced by biological, psychological, social and cultural factors (Goldfarb, 2019; Lock & Kaufert, 2001). Exposure to adverse biopsychosocial, political, and environmental conditions, such as violence, neglect, poverty, substance use, homelessness, incarceration, and poor access to health and social care, across the life course, may impact human biology and later life health (e.g., Johnson, Bazargan & Cherpitel, 2001; Lock, 2020; Murray et al., 2012; Riem & Karreman, 2019; Scott et al., 2013). Researchers have theorized a process in which people in prison may experience biological changes typically associated with later stages in the life course. In the U.S., poor health is strongly associated with "oldness" and old age (Coupland & Coupland, 1993); therefore scholars have framed this process as "rapid ageing”. Maschi, Viola and Sun (2013) argue, “Older adults in prison have unique individual and social developmental needs that result from life course exposure to cumulative risk factors compounded by prison conditions that accelerate their ageing” (p. 543).[3]

The inequities to which older prisoners are subjected have become particularly clear in the current COVID-19 pandemic. Despite facing the greatest risks for infection and death, older prisoners largely continue to be housed in high-risk custodial settings. Older prisoners are confronted with the widespread social narrative that “elders are dying anyways and tend to blame old age itself for their deaths” (Aronson, 2020) and with prisoner health as a “matter of public disinterest” (Jefferson & Jalloh, 2019, p. 574). Older prisoners, and especially those living with chronic health conditions, are arguably the most vulnerable to disadvantage when they encounter prison health care systems. What are the implications and potential consequences when older men living with illness confront the prison medical system? What does it mean when they are embedded in a world of for-profit health care?

In the pages that follow, I foreground the experiences and voices of Nikolai, Cat and Cliff, some of the older men I encountered in prison medical units, to explore the following questions: how does the prison and its health care system shape the illness experiences of older men in custody, and how do older men in prison live and experience

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[3] More specifically, researchers suggest the physiological and cognitive health age of an older prisoner may be more similar to that of someone, in the outside community, who is ten to 15 years older (Aday, 2003; Dubler, 1998; Falter, 2006; Maschi et al., 2012; Williams et al., 2012). In a study of incarcerated men age 50 and over, Gates et al. (2018) found the onset of geriatric conditions appeared to occur earlier than in community-dwelling peers.

illness? In what ways do health care systems interact with the local biologies of "medically ill" older prisoners? What does it mean when the lives of older prisoners collide with contracted for-profit medical care?[4] How might their lives be constituted as "unworthy of care" (Jefferson & Jalloh, 2019, p. 586)?

The voices of older prisoners are marginalized in existing literature on prisons (Di Lorito, Völlm &Dening, 2018), in favour of the perceptions and views of correctional and medical staff. Older adults housed in prison medical units are also nearly entirely excluded from research due to the inaccessibility of these spaces to prison researchers (see Novisky, 2018; Sanders & Stensland, 2010). Such approaches risk further silencing individuals whose voices historically have been marginalized, and thus contribute to dehumanizing scholarship. Moreover, the perceptions of imprisoned persons are critical to understanding their needs and lived experiences regarding health-related issues in correctional settings (Loeb & Steffenmeier, 2007). In the sections to come, I move back and forth between scenes I witnessed and sharing the voices of interlocutors and conceptualizations "that both open up the significance of [the] situation and speak to the wider analytical implications of [the] story" (Meyers, 2007, p. 207). My aim is for this paper to provide a glimpse into the complex and compelling entanglements of the experiences of ageing, illness, health care, and incarceration that is grounded by ethnographic research in U.S. prisons. By doing so, my study contributes to the limited (see Di Lorito et al., 2018) body of social science and public health literature that

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[4] I understand "older prisoner" as intersecting socially constructed identities that are characterized by marginalization and social exclusion. For a discussion about the intersections of social and relational identity and ageing in prison contexts see Aday and Farney (2014) and Herbert (2019).

examines the subjective experiences of incarcerated older adults who are living the everyday of the contemporary U.S. "correctional ageing crisis" (Bedard, Metzger & Williams, 2016).

Methods

The research was undertaken as part of a two-year ethnographic study conducted in Maine Department of Corrections (MDOC) facilities, in which my goal was to explore the end of life experiences of men in prison, as either receivers or providers of care. The study was approved by the McMaster University Research Ethics Board (#2293) and the Maine Department of Corrections Research Review Committee. The correctional system in Maine operates at state level, falling under the jurisdiction of the state government (thus, unlike other states, there are no federal prisons or private prisons in the state). As such, the five men's prisons, one women's prison, one youth facility and two re-entry facilities fall under the jurisdiction of the MDOC. Typically, all of those housed in MDOC facilities have been convicted and sentenced to nine months or more.

Over the course of two years, including fourteen consecutive months of fieldwork, I conducted thousands of hours of fieldwork in several custodial sites that I understand as "inherently entangled" (Weegels, Jefferson & Martin, 2020), including prisons of different levels of custody and a number of close custody and medium custody housing units, administrative segregation, and educational classes, and significant participant observation taken in prison medical spaces (e.g., acute-care clinics, prison infirmary, prison hospice). This study is particularly novel because of its open access to prison medical units and my ability to conduct participant observation and interviews with individuals housed in these units (see Herbert, 2019; Novisky, 2018; Rhodes, 2004). Therefore a central strength of my ethnographic study lies in the rich data made possible through participant observation.[5]

I met with men in these prison medical units and followed them as they moved in and through the prison system and its various health care settings. I witnessed and participated in the everyday lives of interlocutors and listened to their stories. I took detailed handwritten fieldnotes about everyday experience and engaged in informal conversations and formal unstructured interviews with the men I encountered. When invited, I joined in their daily activities, such as playing chess, listening to poetry readings, and watching TV, or sitting in on their case management meetings and meetings with their health care providers. Given the history of unethical research involving prisoners (Ahalt et al., 2018), and the sensitive nature of the interviews, interview recruitment began several months after regular site visits after participants were able to familiarize themselves with both myself and the study.[6] Interviews were held one-on-one in private, the most common location being the participant's cell or a private room in the adjoining clinic. I regularly visited with prisoners in these spaces, which helped to further conceal interview participation. All interview participants provided written informed consent prior to beginning the interview. All interviews were audio-recorded,

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[5] Sociologist Steve Herbert (2019), who conducted qualitative interviews with life sentenced prisoners in the U.S., notes that his study would be "richer if it included participant observation, such access was not available" (p. 8).

[6] Given the small number of individuals in the prison medical units, in order to protect anonymity and confidentiality of participants, the time period of data collection is not disclosed.

with the exception of one that was recorded by hand at the participant's request. The interviews were analyzed using thematic analysis and coded for themes. Alongside field notes, the interviews provide the primary empirical data for this paper.

The Everyday of Privatized Prison Health Care

The men incarcerated in Maine found themselves enchained within a for-profit system of prison care. Jail physician and anthropologist Carolyn Sufrin (2017) explains:

> Privatized prison health care emerged in the years immediately following *Estelle*, with classic neoliberal reasoning that the private sector could more efficiently and cheaply manage prison medical services in prisons than the government. (p. 57)

Under this model, health care services were contracted to a large out-of-state private company, which recruited, hired, and oversaw medical practitioners in the state's various prisons. The regional office was located off-site in a city several hours away, however a Health Service Administrator (HSA) was assigned to each prison and typically worked on-site. A "sick call" system was utilized, whereby prisoners were required to submit a request for an appointment (sick call) to medical and pay a $5.00 co-payment fee for non-emergency visits they self-initiated; prescriptions cost $3.00 each. The stories that medically ill older prisoners told of their encounters with the system and its actors are distressing. They reveal agonizing experiences, exacerbated health conditions and often-grievous treatment.

Nikolai's Narrative

Nikolai was in his late sixties when I first encountered him in a state prison medical unit. Nikolai had not had an easy life. He had grown up in an abusive household and later witnessed the murder of his brother. Nikolai understood himself to be a good father and shared his heartbreak that his grown adult daughters had stolen his money and abandoned him after he was sentenced to prison. When I met Nikolai, he had been in prison for six years; at the time of his arrest he had a number of serious medical issues including COPD, emphysema, and diabetes. He required use of hearing aids, a prosthetic leg and wheelchair. He reported that his physical challenges had grown more severe since entering custody. As we chatted in his cell one especially gloomy spring morning, Nikolai described his painful experience, our conversation punctuated by the pulse of his oxygen concentrator:

> *I'd never been in trouble. I stayed in [county jail] overnight…cause they didn't have oxygen, I had to bring my oxygen machine with me. And I had to bring my nebulizer. I do that four times a day. I brought my own machine, which the jail lost. Jail was horrible. Horrible. They put me in a room all by myself. That was the worst place to be. Then about a month later, they transferred me to Medium unit at the prison. That was better I guess. I had a prosthetic then, you know I walked when I came to prison. I had a cane then. See my leg, the doctor didn't do a good job, he didn't fuse the two bones together and my bones split apart. Every year or so, they change my prosthesis. I was in the [maximum] prison for 'bout three and a half years, I was in the medium unit. They threw away one of my hearing aids and they wouldn't have this one fixed. For almost three years, I couldn't hear. At all. If they talked really loud, I'd put my hand like that* [cups his hear] *and I hear...*

[My roommate] threatened to kill me one night. My concentrator made a lot of noise and every once in a while it would go 'pshewww' and it would release some air. And I was wearing that mask on my face, and they didn't have the right mask for me, and it was bothering me and in my sleep I would take it off. And the machine was making noise. My roommate took my cane and he threatened me with my own cane. I had a bunch of kids who were pickin' on me and one of the guys, he died of cancer, he threatened to kill 'em. The roommate I had in A-pod, he hung himself about a month and a half after I got here, made me feel pretty bad. And, then over here, there was one guy that died. Cause they didn't bring him to the hospital in time. He was sick. Everybody told them to bring him to the hospital. Y'know, I feel bad about stuff like that…I had guys that would come over and help me, they would make my bed and stuff like that but it was hard for me to get any help at all. Try to take a shower with one leg. My hands would be all soapy, I had to hold onto the bar to keep from falling down, and my hands were soapy. I couldn't even get a special bar. I begged them for a special bar, I begged medical, medical says, 'The guards have to get you that…'

My COPD makes things tough you know? Without a concentrator, I can't go anywhere. The prison, they have a portable concentrator but no charging unit. When I had to go out for that appointment for my leg last week, I had to use the portable concentrator but I guess they hadn't charged it full, cause it stopped working on the way there. That was real scary I'll tell you, I couldn't breathe. I didn't like that. What I've been doing while I'm here, if I go in the shower, I need oxygen 'cause the steam gets to my lungs. But they said I couldn't bring my oxygen in there, so I've been washin' up the old fashioned way. The doctor said I want to watch you do that. She told me that I did a good job. But I wash a little bit and I gotta stop due to oxygen…I can't get enough oxygen. Every time I put in a grievance for something, it doesn't go anywhere. [Nikolai paused for a moment to catch his breath, then continued.]

I've been having problems with medical because of my leg. They've been giving me problems. I begged these people for nearly a year to get a prosthetic. When I first got here, I was on three medications to make me pee that was given to me by my urologist, the guy who operated on my prostate. The doctor here [prison] took them all away and my leg went

> *WHOOP* [ballooned]*... he took the pills away.* ["Why do you think he did that?" I probed.] *Save money. Yeh. If he had spoke to me about it, I would have told him the doctor told the people at that other prison that I had to be on those three pills, the doctor here, finally, little over a week ago put me on another medication to help me pee and the swelling started to go away. See, that used to be that deep, that's how big my leg was. And with swelling, you get pain, and Tylenol for a pain reliever, when you get serious pain all the time, doesn't help.*
>
> *You know, my only main concern is Medical. I met the measurements for a prosthetic and it's been two months and I've heard nothin'. My conclusion is that they were lyin' to me, so as of right now I'm refusing wound care. 'Cause they do nothing anyway, so I'm doin' it myself, mix a little salt into warm water…I said you guys should put me on dialysis so I can get rid of this fluid that could kill me. They only do what they have to do to keep you alive and that's it. They can't even get decent quality supplies. At times, they've run out of my medication. They tell you you need something to keep alive and they don't supply it. You know, with medical, some people want to do good and they weren't allowed. I'm just anxious to get out of here. The worst thing is trying to tell medical something and it's like talking to the wall. They're only allowed to do so much, even if it kills you. We cost 'em too much, I think that's why [I] can never get some of them things I need. Over here, there was one guy that died. Cause they didn't bring him to the hospital in time. He was sick. Everybody told them to bring him to the hospital. Like I said, I feel bad about stuff like that…You know, I was hoping I died. I was in such pain. And they weren't giving me anything. I'm ready to go anytime. I'd like to die quick. That's the way it is.*

Following Cat

At the time I met Cat, he was in his late-70s and nearly two decades into his second prison sentence. Convicted of a historical offence, Cat had started his second sentence relatively late in life. He was sentenced under Maine's determinate sentencing scheme and knew that unless he was granted the unicorn Clemency,[7] he would live the remainder of his life in the custody of the state. In all likelihood, his time would be spent in the five cell, seven bed infirmary in the state's maximum to medium security prison. Cat had been living with a number of serious health issues including heart failure, diabetes, glaucoma and atrial fibrillation. He was prone to bad falls and his legs, a deep purplish-black in colour with a white crust that gave the illusion of being mummified, required regular wound care. Cat's complex health needs warranted intensive observation and medical care; with a nurse assigned to the unit and a peer-caregiver program – and much to Cat's dismay – the infirmary was deemed the only viable housing option.

I lingered outside Cat's cell in the prison infirmary, listening intently to his conversation with one of the state's contracted physicians. "I want a regular diet," I overheard Cat tell the doctor.

"That looks like a regular diet," replied the doctor.

"It's not – I've had enough of this shit."

The doctor ignored him, "I'm here to look at your toe."

"Well I want a regular diet."

"It is a regular tray," the doctor replied as Cat began to unpack the contents of his tray, one over-cooked onion ring at a time. Cat showed the doctor his food and then reported that he ate an apple each night. Indeed, Cat had a collection of red gala apples surreptitiously acquired from other trays.

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[7] "Executive Clemency" refers to the constitutional power of the state Governor to grant a commutation of a sentence or a pardon for a criminal conviction.

“Where’d you get this tray?” the doctor asked incredulously.

“They gave it to me ‘cause mine ain’t got nothing.”

The doctor appeared to drop the issue of the tray, “You want me to take a look at your toe?” Cat conceded, asking if he should lie on his bed.

“You know I went a long time without fallin’?” Cat said, beginning to wiggle out of his heavy jean jacket. Two days earlier, another patient in the infirmary had found Cat on the floor of his cell wedged between the toilet and a wall. Cat had hit his head badly and his arm had a nasty gash and severe bruising.

“Did you break the skin?”

“Ya, you wanna take a look?” The doctor shook his head and informed Cat that he was still looking over his feet.

“You’ve got nice purple feet. I hear you had a good episode of A-fib [atrial fibrillation] this morning.”

“Yeah, happens often,” Cat said referring to the increasing zaps of his internal Defibrillator. “Three to four times a week, sometimes at night.”

“You hate going to the hospital don’t you?” the doctor then asked, Cat seemed genuinely confused by the doctor’s question. *Cat just told me the other day he likes the hospital because he gets pudding cups,* I scribbled down in my notebook.

“You don’t want to go to the hospital do you?” the doctor inquired again, though it seemed less like a question and more like the right answer was “no.”

Cat peered at him for a minute and thought about the question. "I want to go to Wyndham [MCC]," he informed the doctor about the medium security prison 90 miles away.

"Well we don't have any handicapped guys at Wyndham."

"Where are they?"

"We moved them out, we have an assisted living facility at Charleston," said the doctor, referring to a relatively new medical-unit of sorts in another prison several hours away. "We have 19 guys, they're not always very nice to each other, plus you need too much care for there anyway."

"He wants a regular diet," the doctor said to the nurse as she walked into Cat's cell.

"Not up to me doc," she replied.

"Have you seen what he's eating?"

The nurse looked over to the mound of onion rings, "He's got a mound of onion rings, like I said, not up to me, Doc."

The doctor and nurse emerged from Cat's cell, chatting as they made their way toward the attached medical clinic.

Cat realized he hadn't had a chance to address his other request. "'S'cuse me! S'cuse me!" Cat called down the hall after them. The doctor stopped, turning to look at Cat. "I'd like my cane back," Cat informed him.

"I'm not actually your doctor, you'll have to talk to Dr. Little," the doctor replied.

"That's the first time he's come to see me," Cat reported.

"The doctor?" I asked.

"Yah."

"When was the last time you saw a doctor?" I asked.

"Been a while. I mean they walk right by the door and don't come in," he replied.

I probed Cat, "Can you tell me a little more about that?"

"Don't know what else you want me to say," he shrugged, "Docs don't come around here much."

A few weeks later, Cat came down with pneumonia.

"I'll be fucking dead in the ground and they'll say 'Sorry, I don't have an order for that…He [doctor] can play all the fucking games he wants. I need some fucking oxygen." He began to cough and asked the nurse for the third time if he could have some oxygen.

"Can't do that Cat, don't have an order for more oxygen."

"Please, I need oxygen," he coughed a thick, juicy cough. "*Please*. Goddamnit. *Please*." His breath sounded strained.

The nurse walked around the desk and set her hand on Cat's head, "I'm sorry Cat, you know I need a doctor's order."

"I need a doctor's order," Cat said mocking her.

"I asked, Cat, they won't write you one," she informed him.

"I." *Cough.*

"Just." *Cough.*

"Wanna." *Cough.*

"Breathe." *Cough.*

Landon, a peer caregiver got down on one knee to talk to level himself to Cat's seated level. "Is there anything we can do to make you more comfortable?" Landon asked gently.

"Yeah, go get them to shoot me."

Cliff's Story

Cliff was in his mid-fifties and three years into his second prison sentence. He had previously spent 14 years in prison and had been living in the community before his most recent arrest. Our paths crossed when he was admitted to the prison infirmary after being diagnosed with cancer and becoming critically ill. I often heard the sounds of excruciating vomiting emanating from his cell. These were the only sounds I heard from him for many months as the radiation for his esophageal cancer had caused significant damage to his vocal cords. Exhausted from the cancer and his treatment, Cliff spent most of his days in bed. He was too weak to shower or socialize and emerged from his cell only a few times a week to weigh himself on the attached medical clinic's scale. He began to regain his voice near the end of my full-time fieldwork. One day after he came out for his regular weigh-in, he asked if I would join him in the yard. Cliff shared:

> *It's like I'm sitting in here deteriorating, it's like come on, do something. I sat in that cell Wednesday, Thursday, Friday and Saturday, hanging over my bed puking. Medical never came in `til Sunday. They said, "This,"* [he pointed to his saline IV] *"should have been done two days ago." I haven't been able to shower; it's been seven days. I don't know why they won't give me a sponge bath.*

> *Three weekends in a row, I was on my floor puking, diarrhea, they never came in and didn't take me to the hospital until I had a fever of 104…They want me to start swallowing so I can chew things, so they can send me the fuck out of here. Send me out into population at 110 pounds. It's been a fucking nightmare since I've been here. In May, I started to complain about pain in my ear. They said it was just a ball of wax. Then they said it was an infection, put me on antibiotics for ten days. Did nothing. So put me on stronger for another ten days. Nothing happened. Then more pain and shit in my ear, so they said infection spreading. Strong antibiotics and another ten days. 30 fucking days on antibiotics. Supposed to get sent out, heard nothing for 30 days. Doctor ordered more antibiotics for 14 days. Gave me eye drops, still have the box. That's negligence. Got sent to [hospital]. Two days later they said, "Got some bad news. You have a tumour located behind your ear… you're going to need radiation." I wanted to punch him in the mouth.*
>
> *30 days plus 30 days plus a month plus 14 days plus two more months of paperwork and x-rays. Five months. If they'd done the procedures, back-to-back, they would know by the end of September. Five months that tumour had a chance to grow and become malignant. And this here [infirmary], is a fucking nightmare. If these people were doing their job, knew what they were doing, I'd be outta here. They don't come and change IVs, they don't check in. They just look in in the [cell] window and do nothing. I was in room four on my hands and knees, diarrhea coming out of me. Throwing up. Tryin' to get to the toilet and no one comin' in. No one came in. No one. No one came to do anything about me. It's not right that nobody is checking on you. Hospice, they're doing the nurses' job. I'm screaming for help and I am covered in puke and my own shit. There was a time where I was incontinent, and I needed sheet for my bed, but there wasn't any. The laundry wasn't done or something, somethin' about it's not done on weekends. So it was either shit on my sheets or no sheets. You have any idea how fucking dehumanizing that is? Animals treated better than that.*
>
> *Anyways, they took my temperature and I had a fever of 104 so they finally decided to take me out [to the hospital]. Listen, the whole thing they're doing is the conservative procedure and they're doing it to save*

> *money. They're always trying to get you back here, anything to save a dollar.*
>
> *The politics behind it, it takes them away from being able to care for us as human. They're handcuffed by the policies of higher ups. Some people want to provide quality care and can't. Maybe they think we're all stupid, but I'm not some fucking dumbass. The provider has a different agenda. They're profit. Did you know that? I'll bet they tried to keep that hidden from you. Didn't they? Well, yeah, there's a profit to be made, that's for sure.*

Later, when Cliff returned to his cell, the officer turned to me, "Would be a real shame if they spent all that money on his chemo and then he died."

Discussion

Nikolai, Cat and Cliff's stories tell of lives lived in an environment that exacerbates health conditions (Ross, 2013) and of painful experiences as older adults in sites "not designed to care for the infirm" (Herbert, 2019, p. 66). Research indicates that older prisoners are at especially high risk for unmet health care needs or medical neglect, particularly given the complexities associated with chronic health conditions and ageing in correctional settings (Aday, 2003; Ahalt et al., 2013; Maschi et al., 2013; Novisky, 2018; Restum, 2005; Rikard & Rosenberg, 2007; Williams et al., 2012). Tina Maschi and colleagues (2012) reveal that, "Providing quality [physical] health and mental health care for older adults [in prison] has not been a priority for corrections and has been mostly neglected" (p. 444). The American Civil Liberties Union (ACLU) of Maine (2014), where my study was located, reported that out of 310 prisoners with serious unresolved health issues, 58 percent were over the age of 50.

Smoyer, Madera and Blankenship (2019) found that, "Participants reported excruciating experiences during incarceration related to untreated medical problems, including…chronic health issues" some "untreated in prison and worsened due to lack of care" (p. 224). Similar accounts of poor treatment permeate the narratives of nearly all of the older men I encountered; most often reported inadequate access to care or roadblocks to getting appropriate medical equipment or medications and understood these as contributing to a decline in their health. Nikolai, Cat and Cliff's concerns about their respective treatments and medications are consistent with the results of other studies that have identified significant rates of inappropriate prescriptions (Williams et al., 2010), or barriers to medication provision following entry to prison, such as changes or delays in medications (Sullivan et al., 2016).

Nikolai and Cliff's narratives also illuminate another theme that emerged through analysis: a lack of continuity of care. This situation was often the result of missing documents or health care records and miscommunications between and among on-site staff, as well as with external care providers at hospitals and clinics. Delayed medical attention, as a manifestation of inadequate access to health care in prison, constitutes inhumane and degrading treatment (Trestman, Ferguson & Dickert, 2015), and results in increased subjective suffering or, most tragically, "early" death (Bretschneider & Elger, 2014).

Further, the prison health care system has been described by experts as "ethically delicate and conflict-prone" (Pont et al., 2018). As Nikolai and Cliff's words reveal, and as the scenes I witnessed between Cat and medical practitioners indicate, there are significant power dynamics at play between individuals in custody and the providers who oversee their care. Participants often confessed feeling their voices were ignored or silenced by health care providers and most felt this silencing directly compromised their health and well-being. Incarcerated persons have little control over their health care; they cannot choose their providers (Pont et al., 2018). As Pont and colleagues (2018) importantly note of correctional facilities, "[T]he relationship between health care providers and patients is not based on free will" (p. 472). Moreover, medical administrators determine the treatment and health care plans of people in prison, which impedes possibilities for self-determination and autonomy and makes older prisoners vulnerable to the decisions and actions of medical providers. This situation becomes especially concerning in light of research that reports the "dual loyalty" of correctional health care providers who may be "compelled to report to correctional—rather than health care—leadership in the facility. These military-like, hierarchical chains of command…can exert undue influence and interference by custody staff on health care professionals" (Pont et al., 2018, p. 473; see also Williams et al., 2011).

There is also significant controversy surrounding the outsourcing of correctional care to private companies (for example see Robbins, 1999). Pont et al. (2018) draw crucial attention to for-profit models of care, and make the critical point that, "Health care professionals employed and paid by for-profit companies are exposed to the same, if not greater challenges regarding professional independence" (p. 474). It is not surprising that most interlocutors' experiences were marked by dissatisfaction and deep frustration with medical care, which often shaped feelings of mistrust or suspicion (Aday & Krabill, 2006; Byock, 2002; Novisky, 2018; Sufrin, 2017) toward the prison's medical department and providers.

We know that older prisoners are more likely to present to custody with existing complex health issues or to develop such issues as a result of "toxic" prison environments (Lock, 2020), and consequently are the largest consumers of prison health care and "the most expensive subpopulation to incarcerate" (Nowotny et al., 2016, p. 938). I once overheard a medical administrator describe correctional health care as a "lucrative business." Similarly, Sufrin (2018) explains, "Correctional health care had also become a revenue-generating business" (p. 58). Nikolai and Cliff were all too aware, sharing the tragic understanding that should their lives cost too much (at the expense of the provider's profit) their medical care, and consequently, their lives, would not be maintained. Indeed, older adults are frequently represented in the literature as the greatest financial "burden" to prison systems and thus giving too much "care" can be costly for the for-profit provider (see for example Ahalt et al., 2013; Chiu, 2010). Sufrin (2019) explains:

> Whether a health condition counts as a serious medical need depends on the local administrator's assessment. Will not addressing that condition result in serious harm to the patient or—a common concern—a costly lawsuit for the prison? How much money and trouble will that medical care cost the prison? (pp. 36-37)

As Jefferson and Jalloh (2019) articulate, the intractable reality is that:

> Not intervening – either because of lack of equipment, water, medical supplies, skills or compassion – can be an expression of a punitive penal consciousness… To borrow the language of Elizabeth Povinelli (2008) (who has written poignantly on what she refers to as 'economies of abandonment') sick bodies may not be being killed, but they may, by

> default, be subject to a process of 'letting die'. Letting die or, slightly less radically, simply letting suffer allows the prisoner's body to do the prison's punitive work on its behalf. (p. 583)

The words of Nikolai and Cliff, as well as the vast number of lawsuits against the correctional health service providers across the U.S.[8] suggest that outsourced and for-profit correctional health care ostensibly meant to care for prisoners, may actually implement cost-cutting practices that are detrimental to the health and lives of people in prison (see also Sue, 2019; Venters, 2019). This devaluation and deliberate indifference not only constitutes "cruel and unusual punishment" (Justice Thurgood Marshall as cited in Sufrin, 2019) but has significant "consequences for health – both morbidity and, in extreme cases, mortality" (Ross, 2013, p. 67, emphasis in original; as cited in Jefferson & Jalloh, 2019).

Conclusion

The men in my fieldwork give a human voice to many of the concerns raised by current research into ageing and health care in U.S. prisons. Despite the legal mandate for the right to healthcare for prisoners across the U.S., interlocutors' narratives reveal they encountered, and suffered from, a lack of adequate medical care. Based on their lived experiences, the constitutional right to health care does not equate to access to medical care and correctional medical units are typically poorly equipped to provide appropriate care for older persons. In addition, the privatization of prison health care

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[8] A public document compiled 1395 lawsuits against the correction health service provider. See https://www.scribd.com/document/391528197/FINAL-Master-List-of-1395-CCS-Cases-4848-9407-7557

exacerbates the social inequalities in health and health care between incarcerated and non-incarcerated populations. Barriers to health care access, as identified throughout my ethnographic study, shed light on the vulnerabilities of incarcerated older adults, particularly those living with chronic and serious health issues. The failure to care may have "devastating health outcome[s]" (Venters, 2019, p. 4) and life-threatening consequences (Aday & Farney, 2014), therefore it is crucial to question to what extent neoliberal custodial health care fosters life or in effect disallows it to the point of death (Foucault, 1978; see Sue, 2019, pp. 184-186). For many of the older adults I encountered, like Nikolai, Cat, and Cliff, their lived experiences in prison profoundly influenced their well-founded belief that "it's cheaper if you die."

What could and should be done? Most importantly, the pressing calls for significant sentencing reform must be answered and include the abolishment of truth-in-sentencing schemes and the reinstatement of parole. Further, although medical, "geriatric", or compassionate parole/release is an option for older prisoners in many states, very few individuals are released under these policies (Bedard et al., 2016; Prost & Williams, 2020). These options are not designed to facilitate timely release (Dubler, 1998), due to highly restrictive eligibility criteria (Chiu, 2010), inaccessibility or lack of knowledge about the policies (Prost & Williams, 2020), the length of time for parole decisions, denied requests, or prisoners' own wishes. Systems and mechanisms for early release must be reformed to expand the scope of who is eligible to apply (see Holland et al., 2018), and should be streamlined to facilitate accessibility for incarcerated persons and their families, as well as more timely decision-making by custodial authorities.

Given the persistence of punitive attitudes throughout the criminal justice system, as well as generally poor conditions of care, efforts to reform early medical release policies should also be paralleled by significant efforts to improve correctional health care and the care of older incarcerated persons. Correctional health care services require experts in geriatric correctional health and care (Bedard et al., 2016; Williams et al., 2012); more specifically, correctional assisted living units or geriatric units should be directed or overseen by physicians or nurse practitioners with specialized knowledge in geriatrics and palliative care. Moreover, there is significant concern surrounding the outsourcing of correctional care to private companies (for example see Robbins, 1999). In order to alleviate concerns with current commodification of health care through for-profit medical providers, geriatricians and palliative care providers should be hired independent of contracted health care providers and "should be fully independent of prison administration" (World Health Organization [WHO], 2013). Collaborations with community-based organizations and local medical school placements offer two alternatives (see Reeves et al., 2014; Trestman et al., 2015). Peer-interventions, which engage incarcerated persons as care providers, are often cited as ideal models of care (see Bagnall et al., 2015; Cloyes et al., 2015; Maull, 1991; and Chapter Three of this thesis), and their development should also be considered. Correctional services should take seriously the possibilities of alternative health care delivery with collaborators whose profit margin is not determined by who lives and who dies.

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My Prison Cell

I live here cold and dying,
In this Stone Age prison cell;
Old age has faithfully crept in on me,
With no hope of getting well.

I live in fear of my self,
That dies within each day;
The sun is sinking beyond its shadow,
Then I must fade away.

I live in fear of dying,
For the things that I have done;
Darknesss follows me around,
'Til death has finally won.

I could never understand why,
The reason I was born;
My bones are aching from the chill,
My flesh is almost gone.

I used to watch the guards,
Peeking in upon me lying there;
Now my eyes are cold and dim,
I can't see them anywhere.

And yet, all is well within this hell,
With death approaching near;
My life will soon be over,
From the madness and the fear.

\- Gray

Three

Prison Hospice: Making and Escaping Life and Power in Prison

For submission to *Ethos: Journal of the Society of Psychological Anthropology*

Preamble

We all die in the middle of a story.
- Davis et al., 2016, p. 324

It was the second last Sunday of July. I sat at the wooden picnic table in the prison infirmary yard, the afternoon sun magnified against overpowering cement walls. Beside me Agelu, a peer caregiver[1] in the prison hospice program at the highest security prison in Maine, talked with the program's director, Kandyce, who was seated across from Agelu and I in the otherwise empty enclosure. On nearly any other day, Brady, a long time patient in the prison's infirmary, would have been with us, his wheelchair pulled up to the edge of the table, animatedly chatting with us. But Brady had died the day before, shortly before 4 p.m., after a lengthy journey with cancer.

At the time of his death, I had known Brady for nearly a year; we had encountered each other shortly after we both came to the prison – Brady to do his time and I to conduct my doctoral fieldwork. As we sat in the yard the day after Brady's death, his

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[1] I use the terms "hospice volunteer" and "caregiver" interchangeably throughout the article.

presence lingered. My heart broke for Agelu who had known Brady long before our paths ever crossed. The two men had shared a 35-year friendship that began as teens running the streets to escape the cruelty of young lives marked by abuse and abandonment, a friendship that continued through everyday struggles with substance use and the harshness of prison time, and, at the end, concluded with the intimate care of hospice, one caring and the other cared for.

Agelu shared his sadness and confusion at Brady's death, which had come on much more suddenly than even the most seasoned hospice volunteer could have anticipated. As a medical officer later described of Brady's death, "It was quick, he might as well have died from complications from a car accident. He just fell off a cliff. No one was expecting that, not like that, not that quick." Agelu and Mamba, a fellow caregiver, had spent the previous morning caring for Brady; I had joined them early in the day and the three of us spent the morning sitting by Brady's bedside. At 1 p.m., Agelu and Mamba had traded off with Mateo and Jayce, two other hospice caregivers assigned to the afternoon vigil shift, but before departing Agelu and a nurse had carefully examined Brady for the telling signs of imminent death. Agelu told Kandyce and I that he had thought he would see Brady one more time before he died. Though Brady was dying, Agelu knew well the distinctive signs of death's approach; the usual indications, he recalled, were not present in Brady's case. Agelu confessed that he was struggling with not having had the opportunity to say a final goodbye to his longtime friend and patient.[2] As Agelu expressed his grief at the things left unsaid, a tiny yellow butterfly appeared at his shoulder and began to dance in small circles between us. "Well would you look at that?" said Kandyce, "Do you think someone might be with us?" She looked to Agelu and gave him a smile. "Agelu, what would you say to Brady if he were here with us right now?" Agelu gave Kandyce a knowing smile and spoke candidly to the friend that flitted amongst us, saying a soft goodbye before he fluttered away.

Introduction

On the day Brady C. Robbins was taken into Maine State Police custody, the Georgetown Villager reported:[1]

> `A police officer spotted a Dodge truck on Route 705 about 8:30 a.m. with an expired inspection sticker and attempted to stop the vehicle near the intersection of Circle Street and Maple Road. The driver of the truck, however, sped off, crossed into Georgetown, and made a turn onto a dead-end street. Without an obvious path out, the driver made an initial attempt to run off, but then got back into the truck and drove out the way he came in. He stopped later of his own accord…He was charged with failure to stop, driving to endanger, violating conditions of his release, failure to provide insurance, operating after a suspension, and driving with an expired inspection sticker. No one was hurt during the chase.`

In the pages of his black-and-white prison-issued notebook, Brady penned a different story:

> *I was diagnosed with multiple myeloma cancer in August. The thought of no-cure cancer made me think my life was over and I was going to die. I*

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[2] Through their experiences with death, longtime caregivers like Agelu became experts at anticipating when death would come (Chapter Four). This expertise often helped to lessen their emotional response to the death of a patient (Coe, 2020). In her study with home care workers, medical anthropologist Cati Coe (2020) writes, "their own training and experiences, and their presence and familiarity with their patient, allowed them to anticipate the timing of death" (p. 101).

> *got out of the hospital and started methadone and injecting heroin and cocaine more heavily. It just didn't block all the bad happening in my life. I wasn't going to follow up on cancer treatment. Nothing mattered to me except staying high. I was addicted and at the same time I just gave up on life. Then the police came to a drug house and I was caught with stolen shoplifting property. I sat in jail for 110 days and got out, I still didn't go to my cancer treatments.*
>
> *About a year later I was ending it. Staying high was the only thing I cared about. On my way to get the lethal dose of heroin I got into a high-speed chase with the police. Eluding police and theft were the charges. This time I wasn't able to bail out, and I thought I would spend the rest of my life in prison. I was so stressed out and depressed. One day I prayed and asked God to heal me. The county jail wouldn't take me to the hospital for cancer treatment, so I started asking God to heal me. I went to court with the two felony charges and a misdemeanor. The state offered me two years for the two felonies, to run concurrently and dismiss the misdemeanor. God answered my prayer and gave me the two years I asked for. Plus I needed my medical. My body was telling me bad things.*
>
> *Leaving the county jail, I was taken to Maine Correctional Center, I told the medical staff about the cancer. It took a while to set up at a medical center where they discovered the cancer came back with a vengeance. Two days after my first doctor's visit when I was transferring myself from my wheelchair to [a makeshift] shower chair, I broke my leg and while trying to soften the fall, I broke my right arm. I broke it in A-pod and I just kept going with it broken. I was suffering, [my roommates] helped me get out of the bed. I took a shower every two days. It was difficult, I broke my arm when they called a code and my legs separated and I went to grab onto the rail and I had no strength in my hips. They were crackling and they never gave me a shower chair, so I get my wheelchair in the shower. I never wore my shower shoes, I couldn't most of the time, but this time I did and it was when I fell.*

After this fall, Brady was hospitalized for several weeks and then transferred to the prison infirmary. This fateful fall set Brady and his caregivers on a yearlong path through which they negotiated the brutality of prison through intimate relational care as Brady moved through his terminal illness and eventual death.[3]

In this article, I examine the experiences of caring and being cared for in the context of a peer-centric prison hospice program. I share the story Brady told and relate the stories of his caregivers to consider the intersections and tensions between care, custody and personhood in prison. I locate my analysis in a state prison infirmary in Maine and within its sole peer-based prison hospice program. Through the entangled narrative of Brady and his caregivers, I suggest that, despite repressive structural constraints and dehumanizing institutional conditions, the intimate relationships that develop in the context of hospice care open up possibilities for making and remaking life and personhood at the end of life in prison for *both* patient and caregiver. More specifically, I contend that caring in prison hospice, and being a patient of that care, enables prisoners to experience aspects of the self and emotionality that stand in complete contradiction to normative representations and expectations of emotions and experiences of men's prisons (e.g., vulnerability vs. toughness, care for others vs. predation, relationality vs. isolation).[4] I contend that prison hospice thus emerges as a social and political site of resistance where hospice caregivers actively build a space of care and

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[3] Brady was one of more than 4,000 people who die in U.S. state and federal prisons each year. His death is part of a disturbing trend that reflects a steady rise in state prison deaths, despite a decrease in the number of people in state custody (Carson & Cowhig, 2020). Between 2006 to 2016, more than 53,000 people died of "natural" causes in state prisons, reflecting a 15 percent increase in prisoners' deaths. In 2013 approximately 3,800 people died in U.S. prisons (Bedard, Metzger & Williams, 2016), by 2016 more than 4,100 people died in state or federal custody (Carson & Cowhig, 2020).

[4] I do not draw comparisons between "community hospice" and "prison hospice" as such analysis is beyond the scope of this paper. However, it is worth mentioning that hospice is typically a gendered space and volunteers in the community are overwhelming women. As an example, at a two-day hospice retreat I attended in northern Maine, there were only a handful of men in attendance compared to dozens of women.

personhood at the figurative and literal margins. In doing so, hospice wrests some power over experience away from the prison apparatus, through cultivating death *and* life, and, I argue, presents a "nefarious" form of escape from disciplinary efforts over life (Foucault, 1978).

To make this argument, I draw on the work of Jefferson and colleagues (2018) who explore how life is lived in and across sites of confinement "by focusing on the tactics of everyday life and hope while being mindful of … ever-present forms of abjection." They propose the concept of "making life" to suggest, "The spectre of death – as a potentiality – does not in itself necessarily obfuscate life or hope totally" (p. 1). I also find inspiration in the anthropology of care literature, which represents care as an intersubjective and intimate reciprocal process that goes "beyond power dynamics" (Seaman, 2020, p. 32).[5] Though this work body of work focuses largely on traditional kin relations [e.g. mother-daughter (Taylor, 2008); spousal relationships (Kleinman, 2010), (Seaman, 2020)], in the absence of normative forms of kin, hospice offers an alternative form of relatedness (Carsten, 2000) that is constituted by deeply (inter)personal connections. These frameworks, therefore, provide a useful orientation for my exploration of peer-to-peer caring in prison and for my argument that caring shapes personhood and sense of self (Kaufman & Morgan, 2005; Taylor, 2008) for the care receiver and the care giver (Kleinman, 2010; Taylor, 2008; Seaman, 2020) in prison. Yet as a "counterpoint to social death" (Seaman, 2020, p. 30) and as "subjective

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[5] Anthropologist Aaron Seaman's (2020) "intimacy of care" work also offers a lens through which intimacy may be invoked as an analytical category to shed light on particular relational dimensions of caregiving that go "beyond power dynamics and, in doing so, can open the possibility for other forms of relationality to become meaningful" (pp. 32-33).

liberation" (Jefferson, Turner & Jensen, 2018), hospice does not translate seamlessly into the repressive penal regime and the disciplinary institution inevitably seeks to exert control.

I illustrate my argument by first describing the Maine State Prison (MSP) hospice program and the caregivers' person-centered and humanistic approach to care, and describe the ways in which hospice reconstitutes death and life. I then move back to Brady's journey to show how hospice care creates possibilities for cultivating life and personhood at the end of life in custody. I show how hospice has the capacity to provide a space for creative resistance to the inhumanity and indignities of incarceration and from repression of freedom and autonomy. I follow this with a critical reflection on the consequence of making life, and escaping life, and the ways in which the carceral apparatus seeks to reassert control, depicted through the harsh events that followed in the wake of Brady's death.

Ethnographic Context

Critical interrogations about how prisoners experience hospice programs, as either receivers or providers of care, and the experiential worlds and textures of life inside prisons are best understood through an ethnographic sensibility (Rhodes, 2009). Moreover, I suggest that we might be able to learn more about the experience of terminal illness and dying in prison by tracing people over time and across space via their illness trajectory (see Sue, 2019, p. 5). This is where the ethnographic methods of anthropology, as the "science of intimacy" (Myers, 2015, p. 10) and deep investigation over time, can draw out some of the complexities of dying in prison. However, such explorations have largely remained outside of ethnographic possibility due to the opacity of prisons (Herbert, 2019; Rhodes, 2004) and especially prison medical units as impenetrable spaces for ethnographers (Novisky, 2019).[6]

Over the course of eleven months, I followed Brady through his end of life journey; his prison sentence aligned with my primary fieldwork timeline, and he would often tell those he introduced me to that we were "doing our time together." Brady was one of seven men who died in Maine State Prison (MSP) custody during the course of my two-year ethnographic study and one of only three who died in the care of peer hospice caregivers.[7] As I describe elsewhere (see Chapter Four) my path into prison worlds began after a call with Kandyce,[8] the peer hospice program director, during which she invited me to visit the prison with her. A few weeks later, after a complex series of negotiations and permissions, I found myself behind the walls of MSP and with the prison hospice class I would come to know well. For the next six months, I made regular trips to the field to foster relationships and trust with the men I hoped to engage in my doctoral research – a study of the contours of end of life and care in prison. By my third visit, I was staying with Kandyce in her home and my visits were growing longer and

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[6] Sanders and Stensland (2018) observed advance care planning discussions between people "preparing to die" in prison and prison staff, though as they acknowledge, their study provides only "a glimpse into [the dying] experience for inmates" (p. 235).

[7] Three men died in hospice care; three died at an outside hospital; and one man died alone on the floor of his infirmary cell.

[8] Given the small number of individuals who died, in order to protect anonymity and confidentiality of participants, the time period of data collection is not disclosed.

longer. Six months later, Kandyce graciously opened her home to me on a full-time basis as I began my two-year exploration into end of life and hospice care in prison.[9]

The Maine Department of Corrections (MDOC)[10] was surprisingly supportive of my ethnographic endeavour – I imagine in large part because of Kandyce's endorsement and the support of the prison's warden whom I had come to know in the course of my preliminary fieldwork. My primary fieldsite, the Maine State Prison, is the highest security prison in the state and houses approximately 1000 men who have been convicted and sentenced to nine months or more. MSP has the only prison infirmary in the state and the only prison hospice program; therefore I spent the bulk of my time at MSP and in its small five-cell, seven-bed infirmary. I met with prison administration early in my fieldwork to develop a research schedule and negotiate access. I was offered unescorted daily access and an ID badge and pass that would open the prison's various steel barriers, on the condition that I participate in the MDOC's weeklong training for medical staff and interns.[11] Initially I was permitted to visit the prison between 7 a.m. to 6 p.m. however, after Daniel (the reader will encounter Daniel in Chapter Four) was nearing death and placed on vigil status, administration granted me 24-hour access at the suggestion of a long-time administrator who felt this would allow me to more fully trace the contours of

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[9] The research was approved by the McMaster University Research Ethics Board and the Maine Department of Corrections Research Review Committee. Local permission was also obtained from the Maine Hospice Council and Maine State Prison Hospice Program and confirmed throughout the fieldwork process.

[10] Consistent with the work of other penal anthropologists, I do not name prison staff or administration unless they are a public figure or invoked as an authority (see Sue, 2019) or requested to be identified.

[11] Due to space constraints, I do not reflect on the training here other than to say that beyond the practicality of having a pass to enter the prison, participation in the training offered rich yet equally concerning insights.

dying and hospice care in prison. Though most of the administration was supportive during my work, fieldwork was not without myriad challenges. As a petite young woman, "researcher" and ethnographer no less, I was often regarded as highly suspect by staff due to the embedded and intimate nature (see Myers, 2015) of my research with men in prison. I invoked any number of strategies to mediate their concerns (e.g. sharing letters of information, explaining my study, carrying a copy of my approved research plan, at one point even carrying Neely Myers' ethnography), but learned over time that despite my best efforts, the questions laced with suspicion, extended waits in the prison lobby, "unavailable" interview rooms, and seemingly never-ending new "rules", would be an inevitable part of my research experience.[12]

Over the course of two years, including fourteen months of full-time fieldwork, I conducted thousands of hours of participant observation in several state prisons of different levels of custody.[13] I primarily observed prison medical spaces but extended my observation to other prison spaces including housing units (e.g. close custody and medium custody, Administrative Segregation, Intensive Mental Health Unit) and conducted observation from different vantage points including as an engaged participant observer in the units themselves and more distant and unobtrusive observation from the view of control rooms or "bubbles". I observed prison activities including weekly prison hospice classes, prison hospice conferences and workshops, memorial services held at the prison, and non-hospice related events (e.g. talent shows, prisoner barbecues). This

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[12] On the methodological challenges faced by prison ethnographers see for example Crewe, 2014; Rhodes, 2009; and Waldram, 1998, 2009.

[13] I visited and toured all of the state's prisons, except for one, which was unexpectedly closed in the middle of the night by the former state Governor.

allowed me to gain a more holistic understanding of the prison and correctional system in which people lived their lives. I locate this article within the prison infirmary, out of which the long-standing peer-centric prison hospice program operated. I now turn my attention to the hospice program.

Maine State Prison Hospice: Everyday Caring

> Love, dignity and care are words that are synonymous with the word hospice.
> - Martin, MSP caregiver

> [Hospice] is about humbling yourself to the point where you step through the door to do the work you've been trained to do. If you're like, 'I don't know if I can do this,' that's how I was. But this is like a glass floor to humility and I can't imagine myself not doing it now.
> - C.R.

The idea of a hospice in Maine prisons emerged more than two decades ago at the former Maine State Prison, now only a bulldozed site a few miles from the current prison. Pépé, a man in his 60s who had spent nearly half of his life behind bars, described death in the "old" prison in stark terms, "If you got sick, you knew you were on your own" and shared countless stories of horrific end of life conditions. Of one man's death, tragically not unusual at the time, Pépé recalled:

> He was sealed off, left by himself. Nobody had contact with him. He was left in his own puke and feces. Finally, one day, right before he died they let us go in there and drag him out. And he died right there a few days later. He died right where we dragged him, on the floor outside the cell.

The proposal for a hospice program behind MSP's walls emerged in direct response to the inhumane and degrading treatment of people dying in prison, and was the work of two remarkable women who persisted over many years to see the birth of a prison hospice program in their state.[14] Dr. Diane Schekty (2016), a former psychiatrist at the prison, writes: [15]

> While still on staff, I proposed a hospice training class for inmates similar to the program started at Angola Prison in Louisiana. I naively wrote a proposal that sat gathering dust on an administrator's desk and went nowhere. At the same time, Kandyce Powell, Executive Director of the Maine Hospice Council and Center for End of Life Care was advocating for a hospice program at the prison…Kandyce taught me the importance of tilling the soil so that our proposal might find fertile ground. We offered modified hospice training to staff; met with chaplains and medical and security staff, among whom turnover was high; and talked regularly with senior administrators. We learned all we could about the successful Angola Prison hospice program. We encountered many concerns, fears, and obstacles along the way, and felt as though we were trying to move mountains. But we persevered. (pp. 480-481)

In 2007, the first Maine State Prison hospice class took place and, in 2009, they began their work with their first patient. For the next nine years, Kandyce would facilitate

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[14] The National Prison Hospice Association (NPHA) and the Guiding Responsive Action for Corrections in End-of-Life (GRACE) Project respectively formed in the 1990s in reaction to poor – or non-existent – end of life care and services in prisons and jails. Each developed practices and policies to facilitate the development of hospice programs in prisons. These guidelines and policies prescribe the same goals and program elements found in community-based hospice programs that exist outside of prison, including managing prisoner care using Interdisciplinary Teams (IDTs) consisting of medical staff including social workers, physicians, nurses, correctional staff, spiritual staff, and volunteer staff from the community (Yampolskaya & Winston, 2003).

[15] A number of prisons in the U.S. have implemented similar peer-based models of palliative and/or hospice care, in which incarcerated people provide some level of formal care to people experiencing life-limiting illness in prison (Cloyes et al., 2017; Hoffman & Dickinson, 2011; Linder & Meyers, 2009; Yampolskaya & Winston, 2003). The availability and extent of these programs is overstated in much of the existing literature, which often refers to the "wide availability" of these programs in the U.S (e.g. Maull, 2005) or suggests that "many correctional facilities" are exploring such care (e.g. Bedard et al., 2016). By way of perspective, there are currently approximately 70 known programs in the U.S.'s nearly 5,000 prisons and jails.

weekly classes with the hospice volunteers each Wednesday morning (and sometimes afternoon) and dozens of men – and one woman – would receive end of life care from MSP hospice caregivers.[16]

At the core of the MSP hospice program are peer caregivers; it is one of approximately 70 known prison hospice programs in the U.S. that represent a formal structure in which incarcerated persons learn to provide palliative and end of life care in the prison setting. Until recently, the MSP hospice program was a collaborative program between the Maine Hospice Council and Center for End of Life Care (MHC) and the Maine Department of Corrections, and operated independently from the prison's market-based system and for-profit health care structures (e.g. the prison's for-profit health care provider which was responsible for ensuring proper medication administration but did not oversee the hospice program nor peer caregivers itself).

The program is formally referred to as a hospice program, but over time the program has evolved to provide not only end of life care in the immediacy of death (which hospice workers call vigil), but extends care work to all patients in the infirmary. Prison hospice caregivers take a holistic approach to palliative and hospice care providing hands-on care[17] with basic prison Activities of Daily Living (pADLs), emotional and

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[16] There is currently no prison hospice program for incarcerated women in Maine; one woman died in the care of hospice transferred to the men's prison shortly before her death. The woman was locked in a cell and a male hospice volunteer was permitted to sit outside of the secured cell. Kandyce rushed to the prison to sit vigil at the woman's bedside, however she died alone in the cell shortly before Kandyce arrived.

[17] The Prison Rape Elimination Act (PREA) does not include guidance on palliative or hospice care in the prison setting and by peer caregivers. The MDOC Hospice Policy created by the Maine Hospice Council and MDOC, is guided by PREA legislation therefore there are some impossibilities to "complete" bodily care provided by peer caregivers. As an example, peer caregivers do not participate in any perineal care (peri-care) which is completed by nursing staff and often under the supervision of an officer. In order to

spiritual support, and sitting vigil 24 hours a day with people who are dying so that "no man dies alone."[18] I am reminded here of the work of anthropologist Robert Desjarlais, who draws on the philosophers Emmanuel Levinas and Paul Ricoeur to suggest "that one of the ethical obligations of human beings is to not 'leave the other alone in the face of death'" (Levinas, 2002, p. 112; as quoted in Desjarlais, 2014, p. 104) and:

> Staying alongside a person in his last moments makes the passing a less solitary enterprise. Unaccompanied dying is a harsh, unwanted way to end a life, much as unaccompanied living is not really living. Through a 'gesture of accompaniment,' to use the words of Paul Ricoeur (2009, pp. 17–20), family and friends relate in compassionate ways to a vulnerable loved one. Through that care, a person might well be 'alone in dying, but he does not die alone.' (Ricoeur, 2009, p. 20; as quoted in Desjarlais, 2014, p. 105)

When practicing hospice care at the very end of a patient's life, the caregivers extend emotional care to patients' families and loved ones (Nebel, 2011). The MSP hospice program is especially novel as peer caregivers participate in a 110-hour training program (compared to the standard 40-hour training of other peer-centric prison hospice programs; see Cloyes et al., 2017). Hospice caregivers also complete a 40-hour Personal Support Specialist (PSS) certification; the MSP hospice program is the only such program in the U.S. that I am aware of that involves PSS state certification. The training programs are

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respect patient's privacy and follow PREA, I did not observe peri-care and stepped out of the room when a patient was being changed or showered. In the instance of hospice vigil, I often observed administration and security balance the dying person's needs against typical security protocol; interpersonal touch in the form of resting a hand on a patient's shoulder or hand was permitted as a gesture of comfort.

[18] In the U.S., the term "hospice" refers to a program or approach and not a place specifically; in the context of the prison there was a hospice program and two cells where hospice vigil took place but which doubled as "normal" infirmary cells when there was not a patient on vigil status.

facilitated by community hospice and palliative care experts, as well as current prison hospice caregivers who take on key teaching and mentorship roles.

Caregivers are not paid and they do not receive "good time" or credits for their work. Rather, bearing witness to deeply dehumanized lives and their deaths, seeing the other stripped to "bare life" (Agamben, 1998), as well as the knowledge that they too might die in prison were often noted by the caregivers as their motivation to become involved in hospice. Caregivers expressed empathy and a desire to mediate end of life experiences, a hope to usurp conditions of death (Foucault, 1978). Martin, a newer caregiver, explained:

> Considering just how neglectful and horrific the treatment was in the old prison, I hope to always be a beacon of love and compassion for these gentlemen, making [the dying men] feel valued. And by acting in a way that always elevates the standard of quality care, and by acting in a way that validates the worth of their humanity, I hope to possibly alleviate whatever existential or physical ailment they may have.

Martin's words also allude to the relational and affective approach to care. The MSP caregivers seek to provide deep (inter)personal and emotional support for patients, who may not have family or who are denied access to loved ones due to prison rules and policies. Scholars have suggested that the meaningful engagement of prisoners in processes of care facilitates more comprehensive and personalized end-of-life care than is otherwise possible using health care staff alone (e.g. Maull, 2005; Cloyes et al., 2017). In their study of a peer-involved prison hospice program in a southern U.S. prison, Cloyes and colleagues (2017) report, "The volunteer program, and its peer-centric structure, is noted by both inmates and staff as foundational to the daily function and sustainability of their prison hospice program" (pp. 2-3). Caregivers also seek to humanize the person in their care, beyond the "prisoner-patient" identities imposed on them, as the prison subject and medicalized object, and describe caring for patient regardless of social identities typically dictated by traditional prisoner codes (i.e. "convict code" and stigmatized identities that determine social status such as the low status assigned to people convicted of sexual crimes against children or women).

Peer caregivers are able to offer fellow prisoners a level of empathy that cannot be achieved by others regardless of intention or training (Evans, Herzog & Tillman, 2002, p. 556). Agelu expressed this:

> Everyday when I struggle, who do I go to? I go to my friends, my peers, guys who understand my suffering.

The MSP hospice approach is understood as a way of "stepping outside of yourself and stepping into [the patient]." Caregivers describe "presence" and actively "being with" someone as being at the centre of their approach; being with a dying person can be a caring, compassionate act (Robbins, 1999). As Agelu described to a class of new caregivers:

> *Presence.* You will learn it in this room and it will invade all facets of your life out of this room. Be present. When you're present, it completely transforms that interaction. It's very real and very powerful.

Russ (2005) describes the creation of presence as "the sacred work of hospice" through which the "the primary economies…of life force and feeling" are made possible (p. 134). There is a closeness or intimacy fostered through peer caring, which are typically minimized by staff.[19] Further, caregivers may mediate mistrust between correctional care providers and patients (as discussed in Chapter Four). The peer relationship is also understood in literatures to be "a prerequisite for a good death in any setting" (Dubler & Heymann, 1998, p. 356).

For the caregivers, however, hospice is not about a "good death," but rather, a good life. As Agelu once explained to me:

> When I first came into hospice, for me, it was about dying. 'I'm gonna help people die a good death.' But hospice is about living, helping somebody live their last days. It's not about death. It's about how to live at the end.

In "Dying Well: Peace and Responsibilities at the End of Life" physician Ira Byock (1997) explains of his work caring for dying people, "The term *good death* [emphasis in original] tends to blur the distinction between death – the state of nonliving – and the preceding time of living" (p. 32). Therefore, engaging peer caregivers in end of life care may help to mediate some of the barriers to "good" care (Bedard et al., 2016) and foster a more interpersonal and affective approach that is otherwise not possible.

In what follows, I return to the story of Brady and his caregivers. I suggest that it is the relationality and mutuality of caring that makes the hospice experience significant and creates possibilities for making and remaking life and personhood in the prison. I elucidate this below through a vignette from a Wednesday morning hospice class in which Brady's end of life and the Celebration of his life ceremony were the focus. I

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[19] I am reminded here of the training I participated in alongside medical staff and facilitated by correctional and medical providers in which we were regularly ordered to maintain strict boundaries between ourselves and "inmates" by not sharing any personal information, no "giving or taking" of goods, not to touch, etc.—to foster detachment and minimize closeness.

follow this with critical ethnographic reflections on the ways in which hospice may be understood as a scandalous escape from the disciplinary power of the carceral institution.

Sharing Brady's (Celebration of) Life

Figure 3. Brady's Grave

"I'd love to hear about how his service was," Mateo said as Kandyce and I settled into weekly prison hospice class alongside Brady's former caregivers. Kandyce recalled the three-hour drive along winding roads and heavy forest to the small cemetery in Brady's hometown, where she and I had attended an intimate graveside service for him.

"It was lovely, lovely that we had spent time with [his] family before," Kandyce said thoughtfully, reflecting on the time the caregivers, Kandyce and I had spent with Brady's loved ones in his infirmary cell in the days leading up to his death. Brady had not been able to see his family for the entire year he was incarcerated in the prison infirmary, however when it became clear he would not live much longer, prison administration allowed Brady's many family members to join the peer caregivers in his cell. Over the course of his five-day vigil, Brady's two "families" came together at his bedside, peer caregivers taking his blood kin into their care.

"We were invited to put two shovelfuls [of earth] into the little hole where his urn was…From start to finish it was such a personal service. Everyone was invited to tell stories. It gave me a sense of who Brady was. Some talked about the dark times. He was a very intelligent man, who had many talents and those were highlighted. His son was front and centre, struggling with issues with his dad. It was hard to put those years in perspective with his dad." Kandyce paused. "His family expressed their gratitude for you men. His niece read a piece Brady wrote about hospice," she added, referring to a beautifully written "testament" Brady had written about his caregivers shortly before his death:

> *Day-by-day I began to start getting stronger because of the help these men gave me. And by stronger, I mean physically, mentally and spiritually because people on the team prayed for me, they help me keep clean and they kept me exercising, they motivated me to get well. The hospice program has helped me with my illnesses in many ways. First, they gave me a great deal of moral support, they have encouraged me to get out of bed, by doing this I strengthened my body, they gave me the strength not to give us and encouraged me to listen to my doctors. I have also learned the value of being honest about how I am feeling about my illness… thanks to these guys I have never felt alone.*
>
> *These men take the time to come to the infirmary; they have sat by my side when I have been in horrible pain. One example was the day my hernia popped out and caused some of the worst pain I have ever had. One of the men on the team took his time to come back to the infirmary to sit with me and hold my hand until the ambulance arrived. In the times when I am unable to go out into population, someone will stay with me in the infirmary to do work with me…Hospice men have taught me that I am a good person who deserves good care; I am worthy of good care.*

"After his niece finished reading, she acknowledged Daina and [me]," Kandyce elaborated, telling the class that our presence represented the hospice group. "As I was stepping forward to make some remarks, there was a little yellow butterfly," she said referring to a butterfly that was a mirror to the one that visited us the day after Brady's death. "The butterfly fluttered circles around us," Kandyce added and turned to Agelu.

Agelu gave a slight nod and began to re-tell the story of the small yellow butterfly that had danced through the prison yard the day after Brady's death. "I was telling Kandyce and Daina about how I didn't get the chance to talk to Brady and right when that happened, a little yellow butterfly appeared and started passing between us. And you know, we talk about signs. And Kandyce said, 'You think somebody's with us? If you had the chance to talk to Brady again what would you say?' I said, 'Brady, this is what I would like to say to you.' I was getting the chance to say things to him that I didn't get to say before."

Kandyce smiled again, "It does something for the spirit when you all open yourself up. Here's this little butterfly in an unlikely spot, that grey yard, and for the same butterfly to be right there at Brady's Celebration, just before the heavens opened up," she mused about the rain that began to fall after the last shovel of dirt was laid. I paused from the notes I was rapidly jotting to look around the class; misty eyes reflected the emotions of the class. Kandyce asked the group how they were doing.

The class remained quiet. C.R. was the first to speak, "Pretty good…" his voice trailed off as tears began to fill his eyes. "It's almost with a sense of relief that he passed in here with us," Agelu interjected, noting C.R. struggling. Brady and C.R. had been nearly inseparable since he had first met Brady in the infirmary. The two grew up in the same town and shared various connections; C.R. had gone to school with Brady's niece and Brady had known C.R.'s dad. "I was worried about him getting out when he didn't have C.R., or Daina, or myself or Pépé," Agelu noted, "It's so much easier when you have the support. You don't want to see somebody die, but you don't want to see somebody suffering. I'm glad he got to be here with us."

C.R. agreed with Agelu and then spoke of the profound connections between the caregivers and their patients (Kleinman, 2010; 2012; Taylor, 2008).[20] "I still miss him dearly. I still have subtle reminders of him constantly. I still feel him with me. When I was in the pod and I'd see a wheelchair and I'd think he was there. One thing we used to talk about a lot was getting out and looking at the skies together and that night [the night he died], what a sky. It was beautiful. I've never had an opportunity to show my soul to somebody like I did with him and he showed me his soul and he deeply, deeply impacted me and I think he will for the rest of my life. I realized I'm not a big, hard Irishman I thought I was. I'm very, very sensitive. I'm emotional. I realized that I love…it's a process, a journey. We all grow together."

Jenks, one of the quieter volunteers, suddenly spoke, "The bonds that I have grown with men in their final months of life have been the most rewarding things that one can ever experience." These were sentiments I had heard often from the caregivers, also mirrored in the written reflections of hospice practitioners (see for example Byock, 1997; Callanan & Kelley, 2012) and anthropological literature (e.g., Kleinman, 2010).

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[20] Physician-anthropologist Arthur Kleinman (2012) contends that, "Caregiving is one of the foundational moral meanings and practices in human experience everywhere: it defines human value and resists crude reduction to counting and costing" (p. 1550). In his seminal works, Kleinman offers a lens through which caregiving can be understood as a transformative process, a practice of ethical self-cultivation.

"This has challenged me to reconsider what I thought I knew about hospice and life," Landon concurred with his friend; caring for Brady "[made] life worthwhile" (Taylor, 2008).[21]

C.R. moved the class' conversation back to Brady, reflecting on Brady's life. "That last year of his life was probably one of the best years of his life. I'm still grieving; I keep reading some of his stuff. This is a new side; I've been emotional in a different sense. The guy was having a terrible day, he had *twenty two* breaks in his pelvis on his last day," C.R. continued through his tears. "This guy inspired so many people and is an example for me in my life to just try and do a little better. I'd like to share something with all of you." C.R. reached for a black and white notebook marked with the word "WINGS" on its cover: Brady's journal. He flipped through a few pages and began to read:

> *I received my first experience meeting my hospice family when I was transferred here [to the] Infirmary. I met hospice while laying in bed. At the time, I was a little angry at God because I wanted to stay at Maine Medical Center [hospital]. One day, the hospice people making rounds came right in my room. I was amazed by their kindness. It uplifted my spirit to hear fellow inmates at the Maine State Prison explain how they were there for ME. When I started this traumatic recuperation process, hospice, not my doctors, not the hospital personnel or chemotherapy [was the] significant factor in my survival. Attempting this by myself is like peeling an onion to find the core. When you're finished, there's nothing left but peelings and your tears. But hospice, with hospice I was never alone. I am no longer the same and I am refreshed every morning with the breath of life that the hospice men bring when delivering my*

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[21] In their book "Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying" hospice nurses, Maggie Callanan and Patricia Kelley (1992) write, "What you learn from…dying people…you can carry forward into the rest of your life" (p. 18).

> *food or getting me ready to face the day. What a change this is. I am set free on the inside.*
>
> *The comfort of their spirit and arms around me, the sincere passion in their words and stories are as fulfilling as I've ever had the pleasure to feel. When my leg broke from the cancer in my bones, one of my first thoughts was 'Am I still being punished?' and an even harder throught quickly followed 'I don't want to die in prison.' Then I was diagnosed. I faced rods in my legs, arms, and then chemo, reconstructive surgery. During my struggles I was very alone. I had so many questions that I didn't know if I was asking the right questions. Though I felt all alone during my ordeal, I actually knew I was surrounded by other incarcerated men who were also dealing with difficult diagnoses, including cancer. So I said, why not start a support group so others don't have to walk this journey alone. Then the hospice men found me. In a place like prison, where privacy and outward strength are hard to find, this group is making a statement that doing it together is better than doing it alone. And that vulnerability and community can make prison time not only more bearable, but actually something beautiful.*
>
> *Hospice is a big part of me today. Without this powerful force in my daily activity, I would again fall into the depths of my disease and death. I am overwhelmed with gratitude for their presence in my life. I was knockin' on death's door and this hospice program brought me back to life. More than anything they are a family. I never feel isolated and alone. I want people to know that even though we are away from our families during this difficult time, God has provided a beautiful family for the incarcerated men here at MSP infirmary and institution. I never feel so free as when I'm with my hospice family.*

C.R. finished reading from Brady's journal. As he closed the notebook he added, "Thank you everybody, he cared about everybody in this room."

Mamba, who was with Brady shortly before he died, was sitting beside C.R. He reached his arm out and touched C.R.'s shoulder, offering a light squeeze of solidarity and comfort. "The amount of things he taught us about ourselves, I loved his friendship.

We celebrate life instead of mourning death," Mamba said to C.R., alluding to the mutuality and "compelling reciprocities [which] occurred within [the] caring care-giving relationships" (McLean & Trakas, 2010, p. 21; see also Kleinman, 2010).

Longtime volunteer Landon then spoke up, "What you said about synchronicity of events, fate, whatever you wanna call it, it puts your life in perspective and what's possible in perspective. The emotional anguish or little bit of pain I'm going through, what is that compared to what he experienced? He came into my life in a time that just made sense. He came into my life for a purpose. I'm grateful for a lot of things and Brady is right up there on the list."

Kandyce spoke next, offering her wisdom after more than 30 years of working with hospice patients and their families. "Often the greatest learning in life comes at the end of one's life, when there's no more time to play games."

Agelu who had been listening intently to his fellow caregivers, offered his reflections on Brady's life, "As young men, Brady was supporting cast, in the background, supporting other people. I think that's one of the greatest gifts Brady was given by this group. He wasn't the supporting cast. He *was* the story. The gift we gave him – his existence was affirmed."

Ethnographic Reflections

> We have room to act, to shape our stories, though as time goes on it is within narrower and narrower confines. A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to

refashion our institutions, our culture and our conversations in ways that transform the possibilities for the last chapters of everyone's lives.

- Atul Gawande, 2014, p. 243

Brady was arrested as he was on his way to buy a lethal dose of heroin; unable to meet cash bail Brady spent several months in the county jail unable to access necessary medical care including radiation and chemotherapy for the cancer that was slowly destroying his body. His words, which opened this chapter, speak to the precarity and normalized abandonment that mark the lives of many people who move through the U.S. incarceration system. Brady wrote of praying to God for a two-year prison sentence because he "needed [his] medical." Under a 1984 court ruling (Estelle v. Gamble) imprisoned people are constitutionally required to be provided access to health care; health care remained otherwise unavailable for Brady in the moral economy of the U.S. medical system (Ticktin, 2011; Biehl, 2010; Han, 2011, 2012).[22] For him, prison meant the possibility of cancer treatment and the possibility of sustained life, even if that meant living his life in prison. When Brady prayed for a prison sentence that would give him the otherwise unattainable access to care, what he could not have known at the time were the broken bones that would follow, nor the transfer to the state's prison infirmary. Neither could he have known about the relational possibilities that emerged from the unique prison hospice program at MSP, when prisoners like Agelu stepped in to cultivate the care Brady would otherwise not be afforded, or that would fail to actualize in the prison's privatized health care structure (see Chapter Two).

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[22] The legal precedent for biosocial inclusion is consolidated under longstanding structural violence (Biehl, 2010, p. 165) and care itself has become entwined in privatized neoliberal health care systems (see Lovell & Rhodes, 2014).

As Brady's story highlights, caring reconstitutes the relational world of both Brady and his caregivers, fostering new kinship relations, or "cultures of relatedness" (Carsten, 2000) within the prison setting. In the absence of spouses and blood kin, caregivers take on the role of this intimate sociality, mutuality and recognition that is embedded in their approach to care. Seaman (2020), drawing on Taylor's (2008) beautiful and moving piece "On Recognition, Caring, and Dementia", writes:

> A kind of counterpoint to social death, personhood accounts for our intrinsic sociality, the tenuousness of people in its absence, and the necessity to support the maintenance of that sociality, an obligation engendered within a web of relations. Personhood hinges, in part, upon one' s recognition by an other…Family members…engage in the relational work of recognizing and sustaining personhood. (pp. 32-33)

Recall Brady's words, "I am set free on the inside," words expressing his "liberated subjectivity" (Jefferson, Turner & Jensen, 2018). Brady's story brings into being new imaginaries of custodial life and care whereby prisoners create new possibilities and freedoms in terms of identities (Jefferson et al., 2018) and personhood. Weegels et al. (2020) suggest that "prisons are often just one site of confinement in people's lives…as Jefferson (2014) has argued, it is not only sites that confine; confinement can also be a feature of everyday practices and states of mind" (p. 4). Brady's compelling words illustrate how he came to *be* and be seen as a person, as more than an object of penal and "medical mastery" (Krakauer, 2007, p. 392) through the creative (Borneman, 1997) and intimate (Seaman, 2020) care work of peer caregivers. At the same time, hospice also constitutes a site of self-making for the caregivers themselves. There is a reciprocity to caring (McLean & Trakas, 2010) understood by caregivers as a "final gift", "immaterial and ephemeral", "life force and feeling" (Russ, 2005, 134). Arthur Kleinman (2010) points to the mutuality made possible through intimate care work; in caring for his wife Kleinman experienced a radical sense of self transformation. He became fully alive and came to a new understanding of what it means to be human. "What starts out as caregiving for others becomes caregiving for ourselves," he writes (p. 8).

Through entangled and intimate caring relations, Brady and his caregivers grew independently and together (Byock, 1997), opening up new ways of living and being – a willful escape from the disciplinary efforts over life exerted by the carceral system (Foucault, 1978). Caring in prison hospice, and being a recipient of peer care, enables prisoners to experience aspects of the self and emotions that stand in complete contradiction to narratives depicting prison as exclusively violent and dehumanizing, as well as contradicting normative representations and expectations of emotions and experiences of prisoners that permeate male-prison literature. As the words of Brady and his caregivers show, hospice is the antithesis of such representations and understandings.

In the closing section, I suggest that care emerges as a site of resistance to carceral power, resistance that prison representatives are often loath to allow. So while I've shared the narrative of love and caring as written by Brady and reflected on by caregivers, in the pages to come, I recall the moments of Brady's death. This part of the story pains me both because I miss Brady and also because his death was marked by particular institutional cruelty. What follows offers some insights into the ways in which the brutal modalities of the prison interrupted the "subversive" work of hospice.

Brady's Death

I'd like to bring the reader back to the opening scene, in which Agelu, Kandyce and I sat in the prison yard. In the moments after the little yellow butterfly flew off, Agelu, Kandyce and I unpacked distressing events that took place in the minutes after Brady's death. While Mateo, Jayce and I sat with Brady as his final breath left him, his family waited in the prison lobby or arrived shortly thereafter and was delayed; I was never able to determine what exactly happened, or the precise timing. I wasn't comfortable pressing his heartbroken family for clarification and staff were not forthcoming. Brady's family members were eventually escorted to the infirmary, confused and distraught. "We were out front and they wouldn't let us come in, why wouldn't they let us come in?" his sister cried as I held her. Brady's best friend C.R. was called to the infirmary, but only after I begged a nurse to call down to the pod. Brady's family and C.R. were given a few minutes to say their goodbyes and then the cell door was slammed shut, the tray door popped open. An officer was given a notebook and the order to "sit on the body", in other words, to maintain constant observation of Brady's body until an investigator arrived. In an unusual move, a Captain ordered me to leave, escorting me out of the infirmary alongside Brady's sisters, who were not yet ready to bid their farewells. The disgruntled Captain deposited us in the prison lobby, where we remained for some time as Brady's weeping sisters implored me for answers I did not know and could not give.

Agelu explained to Kandyce and me that after I had left, a harsh confrontation between himself and a prison administrator ensued. Agelu had returned to the prison infirmary after learning about Brady's death. He arrived to find Brady's cell secured, his body lying alone on the other side of the door. Agelu was advised that the cell would not be re-opened until the appropriate administrators had conducted their after-death investigation. He and the other caregivers present opted to wait in the yard until they were permitted into Brady's cell to wash his body and dress him for his exit from prison, as they had done with their patients before. Once officials had concluded their formal death work, however, an administrator informed the caregivers that they could not enter the cell. Agelu, already upset at not having anticipated Brady's death, shared with Kandyce and I that being further denied the ability to say a final goodbye compounded his sorrow. Caregivers are not permitted to attend outside funerals for their patients, and being denied the opportunity to express their grief through the ritual of preparing Brady's body, a ritual that had been granted many times before, was both confusing and cruel. Agelu questioned the administrators' decision and described a tense exchange that grew increasingly heated. "Dude started by calling Brady 'the body.' I was upset when he said we couldn't clean him up and put him in fresh clothes. We do that for all our patients when they pass, why not now?" Agelu recounted. "Kept going on about policy, he kept saying something about policy, then told us we couldn't go see 'it' in the 'crime scene.' I lost it, called him an asshole."

Several days later, at Kandyce's request, a meeting was held between the caregivers and administration to try to work through what had unfolded after Brady's death. She opened the meeting, "Hospice is, in part, about giving dignity to a person before their death and after, we take pride in dignity in death." The administrator who had engaged in the cold exchange with Agelu spoke first:

> There is a requirement to deal with the body. This is a prison, there's the logistical, operational piece. He passed at 3:45, we're going right into chow time and it's on a weekend, so staffing is certainly an issue, so the Captain has to keep things moving and focus on feeding 900 other men… Right now, I'm policy-driven. There are Post Mortem Operating Procedures, it's about security. We clearly have steps. It doesn't make room for hospice.

The administrator's words drew a clear distinction between the affective and relational approach of hospice care and the brutal modalities of the prison, highlighting the sharp contrast between caregiving as a humanizing endeavour, and the prison system's dehumanization of prisoners.

Through the entanglements of men like Brady and his caregivers, the intimate relations that develop in the context of hospice care open up possibilities for cultivating life in the face of death in prison for those engaged in caring engagements. This caring as resistance subtly wrests some power over experience away from the prison apparatus, presenting a form of escape from the disciplinary power of the institution. But, as the power-laden interaction and events that followed Brady's death illuminates, the repressive regime re-asserts its control over the temporary "liberation" afforded by hospice to deny caregivers the possibility of escape (Foucault, 1978) from the social and emotional conditions of confinement through the "scandalous" act of grieving and caring for the body of their patient and comrade. A tragic paradox thus emerges of a bureaucratic system re-asserting its control, by invoking crude "policies and procedures," even as prisoners sought to “free” themselves “on the inside” through the mutuality of hospice caring.

Conclusion

While the benefits of hospice for both patient and caregiver are clear and many, hospice undeniably exists *within* the chaotic and cruel world of prison. Hospice volunteers, like Agelu, C.R. and Mamba, give compassion and tenderness to those in their care, and, by so doing, constitute their own humanity and selfhood. Yet, the disciplinary apparatus seeks to return prisoners each day – and at times in their most vulnerable moments – to the harsh confines and rigid strictures of the system. Hospice can perhaps be seen as an oasis in the corner of a sterile and concrete prison yard. Volunteers and patients, not unlike the tiny yellow butterfly, emerge transformed from this cocoon. Yet the butterfly must still flutter its wings in the omnipresent reality that is the prison yard.

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The Art of Caring

Figure 4. "Love" by C.R.

Today I know in my heart I experience the greatest fulfillment not when I am getting something but when I am making a sincere contribution to the happiness of others or to the common good, or when I produce something unique and beautiful or something that signifies a labor of love. In prison I have found service work and art provide wonderful opportunities to spread love. Through service work and art I am able to be fully present in the moment and to experience true enlightenment by giving the most I can to that moment. Painting provides me the chance to express gratitude and experience peace in prison.

Art has become part of my meditative practice. I have learned peace is possible. In the midst of a tough life, inside of prison, while missing my family and people I love dearly, it is possible to experience peace and to relax. Each stroke of the brush, each blend of color, and every placement of mixed methods is a moment I can reflect on what is good about today. I think about who will be receiving the painting and how it may positively influence their day. Painting permits me to maintain a state of gratitude. By placing positive vibes into each painting and focusing on making someone's day, I believe every painting becomes an expression of love.

I recently had an opportunity to create art for a very close friend of mine who lived in the prison's infirmary who was dying of cancer. My friend shared with me that the art provided color and warmth in a room that was very dark and plain. He told me it made him feel positive vibes and helped him with his pain. When he died in July his family presented the art at his graveside. I have learned when we put love into what we are doing, especially art, we can change people's realities and make even a sick and dying person feel peace. Every piece of my art is now dedicated to my friend Brady.

- C.R.

Four

Touching Life, Death and Dis/connection in a State Prison Infirmary

In press. Under licence. (February 2021). In Herrity, K, Schmidt, B., Warr, J. (eds).
Sensory Penalities: Exploring the Senses in Spaces of Punishment and Social Control.
UK: Emerald Publishing.

I encountered Daniel[1] at a men's state prison tucked away on the rocky Maine coast.[2] It was late summer; I sat in the prison infirmary yard with several of the men currently housed in the acute-care medical unit for a myriad of health issues. Surrounded by 20-foot cement walls and an open ceiling of sky, we soaked up the sun as it beat down on us. In a world of grey stone and uniform blues, an uncharacteristic pop of colour caught my eye; an assaulting orange jumpsuit overwhelmed the thin frame of the man who lingered in the open doorway. For weeks I had wondered who was confined to the dark shadows of the infirmary's cell no 5. I carefully looked over its occupant. In his first visit to the "outside", the man in orange continued to stand silently several feet away, squinting as though blinded by the sunshine. His hair was long and dishevelled, hiding a handsome

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[1] Pseudonyms and nicknames may be used to protect the identities of participants. Some participants are identified by name at their request.

[2] In order to protect the identity of participants, the time period of data collection is not disclosed. Fieldwork took place over two years, including fourteen consecutive months of participant observation in several state prisons.

but drawn face. Gingerly holding a plastic meal tray, he approached the group, and without speaking, took a seat beside me at the wooden picnic table – the only piece of furniture in the yard. He popped the opaque lid off the meal tray. Using a plastic fork, he poked through his "veggie" tray, picking up an unwieldy mass of over-processed cheese. Tossing it back into the tray, he looked over to me. "Hi, I'm Daniel," he said and lifted his hand in a small wave. As we began to make the small talk of strangers, I found myself transfixed by the shimmer of his greasy hair under the summer sun. An airy current brushed across us; the scent of unwashed human flesh filled my nostrils, the potent odour of punishment mingling with the refreshing coastal air. The brightness of the yard faded further as my gaze fixed on his hands, dried, cracked, and faintly yellow. Daniel snapped the cover back onto the meal tray. "Well, see you around," he said, shrugging his shoulders. I watched as he disappeared back into the dim depths of the infirmary. *SLAM! Click.* The sounds of Daniel being closed into the margins by heavy steel that sealed him away from us.

Introduction

> And so sensuous scholarship is ultimately a mixing of head and heart. It is an opening of one's being to the world – a welcoming. Such embodied hospitality is the secret of the great scholars, painters, poets, and filmmakers whose images and words resensualize us.
>
> - Paul Stoller, 1997, p. xviii

The United States has the highest rate of incarceration in the world (Fazel & Baillargeon, 2011), a direct consequence of "tough on crime" policies which have led to longer average prison sentences (Caverley, 2006; Hoffman & Dickinson, 2011) and a significant increase in the number of individuals serving life sentences without the possibility of parole (Nellis, 2010). While levels of incarceration in the U.S. have stabilized, the punitive criminal justice agenda that unfolded over the last four decades has led to perilous consequences, including an epidemic of deaths in American prisons.

Each year, thousands of imprisoned persons die from “natural” causes (Hoffman & Dickinson, 2011). Prisoners[3] are more likely to experience illness (Maruschak & Berzofsky, 2015) and “early” death (Kouyoumdjian et al., 2015; Venters, 2019; William, 2007), as they are more prone to chronic health conditions and infectious diseases, which have a higher prevalence in incarcerated than in non-incarcerated communities (Plugge et al., 2014; Mumola, 2007). This is the result of substance use history, poverty, and inadequate access to health care services, both before and during incarceration (Hoffman & Dickinson, 2011; Williams et al., 2012). Studies also indicate that unhealthy lifestyles and poor access to health care may speed the ageing process, and research suggests that the psychological and biological health status of an “older” prisoner may be more similar to that of someone who is ten to fifteen years older in the outside community (Aday, 2003; Maschi, Viola & Sun, 2013). This has contributed, in part, to a rapidly rising number of older persons in prison and is further compounded by changing population demographics (i.e. the baby boomer cohort) (Bedard, Metzger & Williams, 2016; Caverley, 2006), as well as an increase in later-in-life convictions for historical sex offences. The number of adults aged 55 years and older incarcerated in a US state prison increased from three percent in 1993 to ten percent by 2013, and the median age of

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[3] This decision to use the term “prisoner” was determined in an advisory meeting with interlocutors.

incarcerated adults rose from 30 to 36 years old (Carson & Sabol, 2016). Given the rise in the number of older persons in prison, the complex health profiles of prisoners, and generally poor access to appropriate care, it is not surprising that the number of people dying in custody is also rising.

This chapter is based on my larger doctoral study examining the end of life journeys of incarcerated men, as well as the experiences of the prisoners who care for them. In this piece of "sensory scholarship" (Stoller, 1997)[4], I draw on "sensory data and impressions to make sense" of the penal worlds in which I found myself (Atkinson, Delamont & Housley, 2008, p. 179). In what follows, I present an intentionally thickly descriptive (Geertz, 1973) account of my experiences as a subjective sensory explorer engaged "bodily in and with" (Blake, 2011, p. 3) Daniel's end of life in the prison infirmary. This is a heartfelt and humble attempt to contribute to "thickly-textured studies" (Howes, 2010) in the emerging field of sensory penology. As the other works in this collection illuminate, and as anthropologist Paul Stoller (1989) compellingly pens, "[C]onsidering the senses of taste, smell, and hearing as much as privileged sight will not only make ethnography more vivid and more accessible, but will render our accounts of others more faithful to the realities of the field" (ibid, p. 9). Thus, I dig deep into the depths of my field notes and research diaries to explore my sensorial experiences as an ethnographer immersed in the world of prison deathscapes.

First, I will share a brief description of my methodological journey into the medical spaces of contemporary prisons. I then return to Daniel, an interlocutor whose

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[4] "Sensuous scholarship" was invoked by Paul Stoller (1997) to denote the centrality of the ethnographer's embodied experience in their ethnographic work.

end of life I followed over several months. I introduce the sensorium of disciplinary segregation to present a densely descriptive account of the sights and imagined sensations of punishment. This section is short, abrupt, and may leave the reader reaching for more. My hands then take hold as I share a thickly-textured description of the intimate sensorium of Daniel's prison hospice cell. The two sections hold a mirror to the dissonant sensations of life, death, and dis/connection experienced in the rooms of the prison infirmary. Together they shed light on the contingency of relations and personhood, and paradoxically, the humanity and dignity that sensory recognition makes possible amidst a harsh penal regime. I conclude the chapter by reflecting on the ways in which engaging my sensorial subjectivity and particularly touch as a medium of inquiry (Blake, 2011) reconstituted my ethnographic practice.

Researching Dying and End of Life Care in Prison

Over the course of two years I spent thousands of hours in state prisons in Maine. My research journey began a year before I met Daniel, on a phone call with the director of a state prison hospice program, Kandyce. After speaking for about an hour, Kandyce asked if I would like to attend a hospice event to be held at the prison in a few weeks time. Unfortunately, the event was not approved. Instead, Kandyce invited me to join her in an educational class she held once a week with prison hospice volunteers. I jumped at the opportunity and, several weeks later, I pulled open the door to Maine State Prison – a maximum to medium security prison for men – for the first time. I conducted regular pre-field visits to foster relationships and build trust with my interlocutors and to learn more about the institution in which I hoped to conduct my study. Six months after my first steps behind barbed wire, I packed my car and made the thirteen-hour drive from the bustle of my lakeside Canadian city to a charming seaside town in Maine, moving in with Kandyce in order to immerse myself in the world of prison hospice.

U.S. prisons and jails have often been described as relatively impenetrable and marked by opacity (Fassin, 2017; Venters, 2019). However, after months of pre-fieldwork, and with the support of Kandyce and a progressive prison warden, I encountered comparatively few administrative hurdles – the Department of Corrections (DOC) was surprisingly open to having an ethnographer infiltrate its walls. A research schedule and research activities were negotiated in collaboration with prison administration. I participated in a weeklong training session for non-correctional staff and was provided with an ID badge that would allow me to pass through the secured doors of various state facilities. Site access initially involved unescorted daily immersion in the prison medical unit during the hours of 7 a.m. to 6 p.m. but evolved into 24-hour access, the result of an unanticipated suggestion made by a long-time administrator who felt open access would be necessary for me to more fully "capture" the experience of peer-based end of life care, and especially the hospice vigil. I was thus given the rare opportunity for an outsider to enter some of the most impenetrable corners of the penal world. The ability to come and go, and to spend extensive periods of time in the field, allowed me to study the everyday life of the prison and its care spaces, in a fluid and unstructured manner that mirrored the unpredictability and uncertainty of life and death. I observed various custodial settings, including close custody and medium custody housing units, administrative segregation, and educational classes, but largely focused my time in prison medical spaces, including acute-care clinics, a long-term assisted living unit and the prison infirmary where I first encountered Daniel. In addition to observation, I conducted unstructured interviews with prisoners in these various housing units, peer caregivers, correctional security and medical staff, as well as palliative and hospice care experts. This methodological account is, admittedly, overly simplistic, and fieldwork was not without myriad and complex challenges. However, the description of the prison ethnographer's "dance" (Jefferson & Schmidt, 2019) would fill these pages – and more – and is thus left to be told in the pages of another piece.[5]

Serving Empty Time in Cell No. 5

> Death in all its guises stalks
> the wings of our prisons.
> - Steve, "Life After Death"

As summer turned to fall, I would only share one more moment in the yard with Daniel, when he would join us, once more, at the communal picnic table outside. In earlier weeks, Daniel had been suspected of attempting to bring contraband into the facility, "They said I tried to get an Apple watch in here," he explained. This infraction, of which prison security determined he was "guilty", had resulted in "D-time" – disciplinary time for an infraction. Daniel's precarious health status meant he could not serve his time in the prison's dedicated D-time pod. Therefore, he was dressed in disciplinary oranges to distinguish him from the light blues and greys of regular prison-

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[5] See Stanley (2018, May; 2020).

wear and moved to the infirmary's small segregation unit. Involuntarily removed from the textures and "rhythms of life" (Haney, 2003), Daniel was confined 23-24 hours a day to cell no. 5 and monitored under the intrusive lens of a security camera, a technological extension of the "all-seeing institutional eye" (Crewe et al., 2014, p. 58).[6]

The segregation cell was smaller than the four other cells in the prison's infirmary and the cell appeared to be an environment of marked deprivation. Unlike the other medical cells in this space, there was no window; cell no. 5 was devoid of any sunlight or view of the outdoors, denying Daniel any access to the "natural world" outside (Wener, 2012, p. 321).[7] The cell was also strikingly barren. The only furniture, a standard steel toilet, sink, and dated hospital bed. The cell was noticeably absent of sound; no chattering television voices, staticky local news stations, or the thump of music that bumped from the CD players in other cells, giving me the sense Daniel had little "acoustic agency" (Rice, 2016; Waller, 2018).[8]

During these long weeks, I observed as Daniel served empty time, each passing day a near mirror of the one before (Wahidin, 2006). The rest of the infirmary buzzed with life, yet a heavy haze seemed to hang over cell no. 5. In "routine acts of humanity

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[6] In the time period in which I conducted my research and in the time since, the Maine Department of Corrections has undergone a number of administrative changes. These have resulted in reforms to practices of segregation.

[7] See Wener (2012) for a discussion about some of the health risks associated with poor, or no access to, lighting, windows, and nature views.

[8] The sounds of prisons, such as music, provide a rich site of analysis for understanding the social and political worlds of prison(er)s; see Rice (2016); Waller (2018); and Herrity (2018; 2020). Waller (2018) suggests music's "sanctioned role in the day-to-day running" of the prison is to ensure wellbeing and compliance. The institution may confiscate technological possessions under certain conditions. In Daniel's case, such technologies were confiscated or not permitted as part of his D-time conditions, thereby becoming "mechanisms of carceral control" (ibid, pp.277-278).

the incarcerated show towards one another" (Venters, 2019, p. 6), his infirmary counterparts and peer caregivers called greetings to Daniel through the steel blockade, filled the small infirmary bookcase with new books for him – Daniel was a voracious reader – and shared messages from "population". I made daily visits to his darkened cell but my interactions with him were restricted to a small wave and an empathetic smile. I longed to linger at his cell and share in dialogue, but with strict policies and rules that mediated our interactions, I often passed by feeling helpless and complicit in his punishment. The invisible bands in my stomach knotted tighter and tighter as I imagined the "weight" of isolation baring down upon him (Crewe, Liebling & Hulley, 2014; King & McDermott, 1995). The stale air of the cell seemed to grow more potent, the cinder block walls heavier, each time I laid eyes on Daniel's still body, as he lay beneath the thin white hospital blanket. At times, Daniel would be staring blankly at the cell door, and, upon seeing me, he would slowly raise a hand in recognition; at other times I would see only a still figure curled inwards facing the white cinderblock wall, withdrawn within the confines of his isolation.

There was something so completely unsettling about an ill man locked away in a tiny cement room, severed from the sensations and relations of everyday life.[9] Daniel's disciplinary status was eventually lifted and he was permitted by prison authorities to move freely throughout the infirmary during regular recreation time or meals. However,

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[9] A number of studies highlight the detrimental impacts of isolation on the health and well-being of individuals; see Charleroy and Marland (2016), Cloud et al. (2015), and Guenther (2016), for example. Social deprivation through the inability to establish or maintain human connections "may be the most damaging consequence of prison isolation" (Wener, 2012, p.321) and can have detrimental effects on the health and well-being of prisoners (Cohen, 1998; Toch, 1992).

he continued to spend most of his days occupying the fringes of the infirmary, in cell no. 5.

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On a cool day, as summer moved into fall, I heard the low rumble of a cell door rolling open. Flip flops slowly scuffling across the linoleum floor cut through the unusual quiet of the infirmary. I raised my head from my notebook and was surprised to see Daniel outside the shadows of his cell. He appeared unsteady. With small, methodical slides, he shuffled fragile feet to the nurses' desk only a few steps away, and slumped over it, setting his hands on its laminate top. His body shook. Afraid his legs were about to crumple beneath him, I reached my arm out to steady him. He lifted his head slowly and his eyes met mine; I was jolted by the deep yellow that now tinted the whites of his eyes. Mary, the nurse on duty, rushed over to us and took hold of Daniel's other elbow. His head fell forward as he leaned further over the desk in an effort to steady himself. The sound of the nurse asking Daniel if he was okay seemed to echo from far away as I caught sight of small red circles that stained his worn white t-shirt. Haunted by my previous work in infectious diseases, my stomach wrenched as I realized what the blood spotting his shirt might mean. Mary helped Daniel back to his cell. When she returned, she rounded the desk and motioned for me to join her. In a whispered voice, I shared my concerns with her and she confided that she too worried about Daniel's well-being; he had been refusing his antiretroviral treatment for some time.

Shortly thereafter, amidst his declining health, Daniel was shackled and sent to a hospital located beyond the walls of the prison. Several days later doctors indicated that life-sustaining treatment was no longer a viable option and Daniel was transferred back to the infirmary to spend his final days in the care of fellow prisoners who were trained and state certified, through a peer-based prison hospice program, to provide hospice and palliative care.[10] Upon his return to the prison's infirmary, and after undergoing the humiliation of the policy-mandated strip search, Daniel was assigned a new cell, the "terminal cell". Both prison administration and medical administration had determined that he would be placed on hospice vigil and would be provided comfort care. The hospice program had a carefully crafted vigil rotation that ensured two peer caregivers were with Daniel at all times until he died. The caregivers expressed feeling a stake in Daniel's dignity at the end of his life; at the core of their work, a peer caregiver explained, is to "validate the worth of [a patient's] humanity" and to ensure they are provided the "dignity that they deserve." In marked contrast to earlier weeks that were characterized by strictly enforced boundaries and isolation, Daniel's life at the end would be marked by the human connection that he had been previously denied. In the weeks that would come, I would observe Daniel at the centre of a network of caring relations (Kleinman, 2012; Taylor, 2008).

Warm(ing) Hands and Hearts in the Prison "Death Room"

> [T]he same environmental conditions that shape the land also leave their mark on the skin. This is a distinctive feature of the skin for, while we may perceive aspects of the environment with all of our sensory organs, only the skin can manifest the marks of what

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[10] Peer caregivers participated in an extensive 150 hour training facilitated by the Maine Hospice Council and the Center for End of Life Care. 40 hours of this included Personal Support Specialist (PSS) training. Upon successful completion, peer caregivers received state certification as a PSS. For a discussion about the peer-based hospice program, see Stanley (2020).

it has perceived. The skin may be dried by the sun and roughened by the wind; it bears the scars and bruises of its scrapes and bumps and the imprint of what has pressed into its soft surface, it becomes warm through perceiving warmth and cold through experiencing coldness.

- David Howes, 2005, p. 33

As I pulled into the prison parking lot on Daniel's first day back from the hospital, I was eager to make my way through the five steel doors and two metal detectors that separated us. After passing through the various barriers, I opened the infirmary door using my DOC-issued pass and greeted the officer sitting at the small black desk. A few more steps and I rounded the long nurses' desk, crossing over the yellow tape used to demarcate "staff only zones". I set down my clear plastic lunch kit, given to me by the medical service provider contracted by the DOC, and removed my wool jacket. I approached Daniel's new cell with trepidation – I had not witnessed death or dying before. Unlike his previous cell on the margins of the infirmary, the "death room", as many referred to it, was located in the centre. The cell contained a window and private shower, a television mounted on the wall, as well as a state-of-the-art medical bed.

I could hear the vibrant thump of '90s pop music playing as I neared the open metal door and made eye contact with Pépé, a senior prison hospice volunteer. Before I could ask if I could enter, Pépé waved his thin arm, motioning for me to join them in Daniel's new cell. As I entered, Pépé approached Daniel's bedside. "Daina's here," he enthusiastically informed Daniel. Slowly, Daniel turned his head to look at me. His dark eyes, set into a face sunken by long illness, brightened with recognition and he reached out to me. I eased towards Daniel, Pépé nodding his approval and took a seat beside the bed, which hummed mechanically. I reached my hand out to meet his open palm. Daniel suddenly exclaimed in horror, "You're so cold!" His other hand crossed his body in an unconscious reaction and encased my frosty fingers. The heat from his fever warmed my cold hands.

As I recall Daniel slipping in and out of consciousness, the heavy medications coursing through his body, the words of French philosopher Michel Serres (2008) echo, "I embrace you: here and now our contingency creates nuance on nuance, mixture on mixture" (p. 28). As my hand warmed in Daniel's, I was struck by the significant shift in our relations from distant observation to intimate encounter, the tactile granting sensory recognition and the mutuality of a relationship uncomplicated by consciousness and future expectations (Buber, 1970).[11] Where raised hands once met stale air, they now enfolded human flesh.

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On a snowy December night, five weeks after this visit to Daniel, Kandyce and I prepared to leave the nearby minimum-security prison after our bi-weekly hospice class. An officer approached me. "You received a call from up the Hill," he said.[12] Having just left the prison a few hours before, I was surprised to hear the prison had called for me. We hurriedly made our way into the blustery cold and back up to the Hill.

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[11] The work of philosopher Martin Buber (1970) offers a way of understanding the relational processes and states that unfolded in the prison. Buber understood the *I* and *Thou* relationship as characterized by presence and mutuality, through which both participants in the relationship become wholly human. Buber (1970) writes, "It is in encounter that the creation reveals its formhood; it does not pour itself into the senses that are waiting but deigns to meet those that are reaching out," (p. 77).

[12] The maximum-medium security prison, where the infirmary was located, was located on a slight hill a few minutes from the minimum-security facility.

Adrenaline coursed through my body as we walked down the bleak white hallway that would take us to the medical clinic door – our passage to the infirmary.

With the prisoners locked into their cells for the night and most staff home for the evening, the eerie silence of the night was cut only by the sharp squeaks of my wet winter boots on the linoleum floor. I shivered; the chill of the air recalled the cruel purpose of the corridor: to bring people into the depths of locked doors. I sped up my steps, anxious to be in the more comfortable warmth of the hospice. Reaching the door, I quickly connected my ID badge to the security censor. The slider rumbled back allowing us to pass through.

We exchanged a few words of appreciation with the night shift officer, thanking him for his kind gesture of calling down the Hill. "Of course, of course," he said nodding as we moved with intention towards Daniel's cell. The sounds of our booted footsteps alerted ears trained to pick up even the most silent of sounds, a developed sonic sensitivity key in a place where "much can be heard that is not seen" (Rice, 2016, p. 111), and Pépé emerged from the unlocked cell. "We called ya!" he announced, ushering us into the darkened room. There had been a notable change in Daniel's breathing – a sign to a seasoned hospice volunteer that death would be arriving soon. Upon entering the hospice sensorium, my ears were met with the familiar sounds of the monitors and IV pump beeping away and the hum of the hospital bed. Daniel's favourite dance music played from the CD player, the scratched CD skipping every so often. I had grown accustomed to the rhythms of the prison hospice cell over the past few weeks and I felt the tension ease from my body. I was surprised when I saw Daniel's brother, who was also incarcerated in the prison, in the cell with the volunteers. It was unusual for him to be permitted here at this time of night and I was grateful for the kindness of the staff and administration in accommodating this final interaction.

Writing about the moments of Daniel's nearing death, the memories that return equally vividly are the moments of both levity and care that characterize the ways peer hospice care affirms the patient's existence. In the preceding weeks, Daniel's brother and peer caregivers had shared with me their favourite stories and memories of the gentle yet witty man whose impending death brought us together. We had shared many gleeful laughs as Daniel "vogued", wriggling in his bed to pop music, which had become as much part of the hospice sensorium as the vibrating of the medical bed. On one night, Daniel insisted on standing, a peer caregiver on each side holding him steady, and began to shake his hips from side to side, his mouth curling into a cheeky smile as all of us laughed and danced alongside him. Other days, I observed intently as the volunteers carried out acts of care that might in any other setting be regarded as "simple": they carefully wiped chocolate pudding from his chin; gently massaged cream onto his dry feet; and showed his brother how to sponge Daniel's mouth. Other times, we sat in silent presence, words seeming to lose meaning as the physiological process of death brutalized Daniel's body (Tornøe et al., 2014), giving comforting hands when the pain he was feeling was too great (Blake, 2011; Classen, 2005; Peloquin, 1989).[13]

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[13] In the instance of hospice vigil, interpersonal touch is permitted as a gesture of comfort. Tornøe et al., (2014) suggest that compassion and consolation may be "communicated through a caring touch [of] gentle hand[s]" (p. 3).

As my eyes adjusted to the greyness of the cell, I laid my hand on Daniel's arm to let him know I was present. My ears pricked at the sounds of a crackling deep within Daniel's chest. The "death rattle". His chest racked up and down, every breath seemed to be a painful struggle. I moved my hand to his concave shoulder. My hand moved up and down, in sync with his laboured breaths, feeling every crackle, pop and gurgle and every heavy *thumph* of his beating heart. I stayed like this for a moment, feeling the sensations of his dying body and intensely connected to the man whose bodily tempo let me know the end was near.[14]

After several hours, Daniel's breathing had not changed. With his feet still warm and free of the small purple pools indicative of mottling, Kandyce and I decided to make a quick trip back home – I had been at the prisons since dawn and it was nearing midnight.

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We arrived back in the infirmary in the early morning hours. Daniel's brother remained by his side, with two peer caregivers – Agelu and C.R. – who were assigned to the overnight vigil shift. Kandyce and I joined them at Daniel's bedside, the five of us encircling him. I sat in silence at the foot of his bed beside C.R., who was also experiencing a hospice death for the first time. I listened intently to Daniel's breathing, each breath fewer and further between. Daniel's brother quietly stepped out of the room.

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[14] Buber's (1970) *I and Thou* resonates; Buber understood human existence as fundamentally interpersonal with persons engaged in shifting relationships. There are two relations, according to Buber. The *I-It*, from which objects are more distantly encountered as something to be experienced or known. The *I-Thou* relationship extends beyond experience to unconscious encounter whereby being is not consciously mediated, a more "pure" relationship and mutual intimacy.

Kandyce and Agelu stood at Daniel's bedside; I sensed a natural intimacy as Agelu tenderly stroked Daniel's head with large hands that had experienced nearly a decade of death as a peer caregiver. An electric calm, an impenetrable tranquility came over the cell. With ears that I had learned to open in new ways, I caught Agelu's whispered words: "Enjoy the journey". As the moon glistened through the small window, Daniel's chest rose in a large breath. Froze. And then fell for the last time. An indescribable burst of energy shot through my body and C.R. exploded up from his chair beside me, breaking through the peacefulness that had filled the room only moments before. Streams of heavy tears began to pour from his eyes as he rushed out of the cell. "I hadn't felt my heart my whole life, my life was on stagnant water and that night the stagnant water was removed; there was a thump and it's been thumping ever since," he would later tell me.

I moved to stand at Daniel's bedside. C.R. rejoined us; Agelu, C.R. Kandyce and I enfolding Daniel. I fought the embodied impulse to reach over to C.R. and rest my hand on his arm in a simple empathetic gesture of comfort, yet which remained beyond the bounds of acceptability in the prison. This "necessary suppression" (Herrity, 2020) was part of the careful craft of the ethnographer, a precarious balancing act, even in the intimacy and immediacy of human death. Daniel's brother returned to the room, took a step and then stopped. His eyes moved from Daniel's still body to meet mine. Without speaking, but keeping my gaze connected to his, I gave a slow nod to confirm what he was silently asking, speaking not in sound, but in silence. Suddenly an officer entered the cell. With "time of death" confirmed, it was time to leave the cell, and Daniel. The cell was secured, the tiny tray slot opened to offer a small rectangular view into the death room, and Daniel's body laid alone in wait for the prison's investigator.

Conclusion

> Visiting with prison hospice volunteers and correctional staff has reminded me of William Golding's classic novel, *Lord of the Flies* … Penitentiaries are islands within our society, yet prison hospices are the opposite of Golding's chaotic island.
>
> - Ira Byock, 2002, pp. 112-113

> The boundaries of his world are drawn by his bodily experiences to which visits of the dead belong quite "naturally". Any assumption that the non-sensible exists must strike him as non-sense.
>
> - Buber, 1970, p. 71

My initial encounter with Daniel in the prison yard would prove to be the first in an intense journey he would invite me to share, an expedition through the extremes of punishment in disciplinary segregation to the humanity enacted in prison hospice. In allowing me to bear witness to this journey, and through our sensory encounters, a dissonance emerged, felt most acutely through prison policies that mediated the tactile boundaries of dis/connections. Howes (2005) suggests that, "While knowledge of the world may be said to come from many bodily channels, the sense of touch is a particularly diffuse and varied source of information" (p. 28). I came to cultivate an understanding of penal life and death in new and intimate ways. More precisely, the *feel* of Daniel's life and death illuminating brutality and beauty, indignity and intimacy, in a contemporary prison medical unit.

Daniel's D-time placement in the prison infirmary was rooted in the custodial need to care for his chronic illness. However, Daniel was subjected to additional layers of punishment such as shackles (Granse, 2003) and strip searches.[15] Further, there was an institutional ambivalence and indifference to his well-being, with care not extending beyond medical treatment of his existing health condition. As I have discussed elsewhere (see Stanley, 2018, 2020), what is framed as institutional "care" may take on the form of harm, thus illuminating "repression and compassion [as] profoundly linked" (Fassin, 2005, p. 381; see also Ticktin 2006). In prison, there is a fundamental tension as violence and dignity exist and interact together. Though Daniel was provided with the crucial medical treatment needed to sustain his physical life, he was intentionally deprived of the "everyday" textures of the prison sensorial and the "bodily presence of others" (Guenther, 2013).

In "Solitary Confinement: Social Death and Its Afterlives", Lisa Guenther (2013) explains, "[T]here is something about the absence of regular bodily contact with others, the absence of even the *possibility* of touching or being touched, that threatens to unhinge the subject" (p. xiii, emphasis original). Thus, cauterizing Daniel from social relations and tactile sensations was a callous denial of his personhood and humanity, possibly a "death-in-life" (Guenther, 2013), or social death experience (Cohen & Taylor, 1972). As former prisoner Five Omar Mualimm-ak shares of his time in isolation:

> There was no touch … The very essence of life, I came to learn during those seemingly endless days, is human contact, and the affirmation of

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[15] See "The Power of Touch" (Warr, 2020).

> existence that comes with it. Losing that contact, you lost your sense of identity. You become nothing. (Quoted in Venters, 2009, pp. 77-78).

Therefore, disciplinary policies and practices impose limits to tactile engagements, impeding possibilities of sensory recognition and damaging the personhood of prisoners. Under the harsh penal regime, the approach of physical death was the twisted catalyst needed to move Daniel into a zone in which the reconstitution of relational personhood could become a glimmering possibility.

As Blake, drawing on the work of Peloquin (1989) contends, "Touch can diminish the distance between people and can [thus] be used to engage our awareness of ourselves and others and the connection between us" (p. 3). The shared sensation of touch, of human connection, was my real entry point into Daniel's end of life experience, the point at which he truly invited me into his life and to become an engaged participant in his final curtain call. The mutuality and dialogue of our tactile encounters pushed my understandings of the relational possibilities of prison ethnography into new realms. As a participant observer in this peculiar prison deathscape in which any form of intimacy challenged prison expectations for relationality, boundaries were breached and closeness attained with interlocutors. Blake (2011, p.1) expresses a similar experience, writing:

> Although I was familiar with and in favour of calls for a subjective and bodily awareness in the field, I found myself ill-prepared for the large role that touch would come to play in my interactions with the children in the ward and how this would affect me … I became aware that I had in fact been holding onto a perception of myself as the detached observer and I became aware of this in the moment it became impossible to retain such a perception.

Annette Leibing and Athena McLean (2007) suggest that pushing against the borders of the generally perceivable and observable is crucial to not only illuminate new knowledge and understandings, but “because the shadow might directly trouble or ‘overshadow’ what lies in the light” (pp.1-2). Sensorial scholarship thus provides a way of conceptualizing and symbolizing relations, around which prisoners live their lives, die their deaths, and structure their realities.

As a prison hospice volunteer once shared, “When you learn to be truly present for someone in their last days of this life, you unlock a part of yourself, a part of the universe that was completely and utterly unknown to you previous to that moment.” Day after day, as I set my cold hand in Daniels’s feverish palms, I felt the physical manifestation of the deep emotional bond between the participant observer and her “subject”. When I walked out of the heavy prison doors on that fateful December day, the volunteer’s words resonated deeply with me. Perhaps the most important sense-making imparted to me through my sensorial engagement was what it truly means to be *present* as a prison ethnographer.

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In Memory

Gary Lawrence 1975
Basil Ward 1977
Walter Bishgo 1977
Stewart Macamber 1979
Donald Melvin 1979
Louis Lusser 1979
Albert Simoneau 1980
Chester Seymore 1981
Richard Iles 1981
Ronald Johnson 1982
Greg Naoum 1982
Hazzenttall 1983
John Farrell 1983
John Mulligan 1983
Joseph Morin 1984
Peter Haines 1985
Larry Howard 1985
Philip Adams 1985
Clayton LeFay 1985
Anthony Bell 1986
James Jones 1986
Roger Haller 1988
Chandler Littlefield 1988
Jeff Long 1988
Safet Likay 1988
Gary Penney 1988
Robert Inman 1989
Wayne Northrup 1989
Joseph Picard 1989
Larry Richardson 1990
James Falcone 1990
Washington Norwood 1991
Ray Provencher 1992
Steve Gilcash 1991
Ricardo Cruz 1992
Robert C. Smith 1993
Thomas Morton 1993
William Whitten 1994
John Michaud 1994
Ernest Markham 1994
Cyrus Caldwell 1994
Douglas Farley 1995
John Dalot 1995
Reginald Richards 1996
John Joubert 1996
James Brown 1996
Vincent Hayward 1997
James Powelsland 1997
Terry Kerrigan 1997
Joseph Veilleux 1997
Charles Warren 1997
Shawn McNevin 1997
Paul Lafferity 1998
Ron Pelletier 1998
Gary Rainey 1999
Gerald Kelley 1999
Joseph Lovell 1999
David Grierson 1999
James Thomas 2000
Albert Thireault 2000
Thomas Thurston 2000
Gerald Troiano 2000
Reginald Berube 2000
Wally Corsen 2000
Dennis Larson 2000
Dean A. Curtis 2001
William Stone 2002
Paul Atkinson 2991
Bernie Hooper 2001
Allen Sampson 2002
Steven W. Smith 2001
Adam Duprius 2002
Earl Losier 2004
David Nelson 2005
Charlton Gassett 2006
Vernald Strikfoot 2006
Ryan Rideout 2006
James Devine 2006
Dana Goodine 2006
Ronald Dube 2007
James Dolan 2008
Roy Abbott 2008
Sheldon Weinstein 2009
Maurice Hupper 2009
Victor Valdez 2009
Francis Gallant 2010
James Nadeau 2010
Lloyd F. Miller 2002
Robert Ingerson 2011
Shawn Corson 2011
Mary Hoskins 2011
Robert Storer 2012
Charlie Page 2012
Raymond Tucker 2012
Alan Powell 2013
Donald Lloyed 2013
Steve Gravel 2014
Phillip Kay 2014
Paul Gray 2014
Jerry Lydick 2014
Ronald Farrar 2014
Steve Holloway 2014
Edward Robinson Jr 2014
Peter Dunbar 2015
Donald Riley 2016
Ronald Brann 2016
Gary Raub 2016
Michael Young 2017
Dean Brown 2017
Albert Cochran 2017
Charles Pettigrow 2017
Henry Bishop 2017
Robert Forrest 2018
Gregory Leeman 2018
Jeremiah Young 2018
Darrell Crosby 2018
Andrew Leighton 2018
Christopher Nault 2018
Raymond Leavit 2019
Carl Dyer 2019
Paul Rivera 2019
David Sirois 2019
James Young 2019
Stephen Burton 2019
Robert Rossingnol 2019
Joseph Dumas 2019
Robert Howarth 2020
Edward Hackett 2020

Bob Haller was the first person who died when I came in. There are a lot of people after that name. We've got to keep them alive; I'm not convinced anyone else will.

- Pépé

Five

Conclusion

Six months after I finished fieldwork, I received an email from the administrator of our Anthropology Department:

> `Hi Daina,`
>
> `I received a voicemail on December 27th from a lady named Judy McIntyre from Moose River, Maine. She said that she's a nurse and one of her patients was Gray River and he told her that you communicated with him. She said that she would love to speak with you because Gray passed away and she wants to fulfill his last wishes. She has some letters and some other stuff that he wanted you to have. Here is her cell phone number: 207-***-****.`
>
> `Best regards,`
>
> `Nadia`

Many months later, I found myself standing on the wraparound porch of Judy's elegant Victorian home. She welcomed me in, embracing me in a kindred hug of two people brought together by the death of a dear friend. We sipped chilled white wine, as the embers from the fire crackled and popped. Gray's beloved guitar joined us, propped up on a beautiful wooden rocking chair. Catching me looking longingly at Gray's most prized possession, Judy smiled, "Gray used to love to play his guitar by the fire." For two years, nearly to the day of his death, I had followed Gray. We spent hundreds of hours together; me jotting notes as his raspy rumble shared the secrets of 50 years of hard "time". Eventually, when my research visa expired and I had to return home, Gray and I stayed in touch by letters and visits whenever I could.[1] I came to know Gray as a complex and remarkable man. He was stubborn, fierce, kind, and inquisitive. His life had led him to be suspicious of most people but, for some reason, he had trusted me.

In the months since learning about Gray's death and finding myself in Judy's living room, I wondered often about his death. I knew he did not fear death, his letters and poetry told me as much. But, unlike most of the men the reader has met in the previous pages, Gray did not die in a state prison, though as one of the last prisoners on Maine's now defunct parole system, he was forever entangled in the carceral web. Gray had once shared, "If I have to stay here until the day they carry my body out… I'm not gonna curse Him [God]. See, I can die here as well as I can die on the street. On the street the dogs might get me. At least in here they'll throw me in the ground." All the same, Gray had anticipated getting parole (for the seventh time) and spent his last months in prison carefully crafting a small cardboard sign and deciding the street corner on which he would hold it.[2]

---

[1] It broke my heart to leave the field and felt as though I was leaving people behind. I questioned the ethics of inserting myself into people's lives only to leave. I extended my fulltime fieldwork by four months and visited every six weeks or so for the year that followed. I was fortunate DOC administration granted me this additional time, but eventually the "study had to have an end." Letters became a critical source of connection.

[2] While not discussed in this dissertation, the re-entry and release experiences of older or ill prisoners present significant concern. Gray's release on parole was unique, but concerns about housing, resources, and continuity of care were not. Nikolai's "release planning" with his correctional case worker offers another example. Nikolai explained, "My kids, they won't answer the phone. I asked my cousin if I could live with them, pay room and board, they said 'no', don't want boarders. They're afraid they're going to have to take care of me. I can take care of myself most of the time. Can't live with my brother, no room

In the end, Gray died in community hospice care with Judy at his bedside. As Judy recalled Gray's last months, a great deal of which were spent in the warmth and comfort of her home, and her experience being with him as his heart stopped beating, tears I had long held onto began to fall. Judy quietly got up, leaving me alone with Gray's memory. She returned to the room with a notebook. "Gray wanted you to have these," she said handing me the thick notebook marked "*Prison Poetry*" in Gray's familiar scrawl. I learned that Judy had carefully distributed Gray's few belongings among the people he had cherished; she held onto Gray's artwork and the cardboard sign he'd once designed; a prison Captain was moved to tears at being entrusted with Gray's chess set; I received the gift of poetry.

Holding his poems in my hands reawakened Gray's words: "I like to live my poems and relate them to my life now, future, physical death, spiritual, that echoes through a man's soul and being." I opened the book and became lost in a lifetime captured in verse.

---

and can't stay down cellar, can't go up and down the stairs." He paused, then added, "I do got a Quonset hut I could stay in." "Heated? Electricity?" his caseworker asked. "No," he replied. "Insulated?" the caseworker probed. "No. Can be," Nikolai shrugged. "Running water?" implored his caseworker. "No," Nikolai said. In the end both Nikolai and Gray ended up in the same community Assisted Living Unit which Gray labeled "the death house". "These places aren't meant for us," he wrote in a letter a few months after he moved into the residence. Historical injustices and systemic inequalities often lead to a stressful and difficult re-entry experiences and may have detrimental effects on an individual's health and well-being, such as exacerbating existing health conditions. Studies also support that release from prison presents a high risk of death, especially within the first two weeks following release from custody. Perhaps predictably, both Gray and Nikolai died less than a year after release. When serious health conditions are involved, the continuity of healthcare becomes dire. While some correctional systems have collaborated with geriatric clinicians or have established geriatric or palliative-specific care teams, such crucial modalities are rare (see Williams & Albrides, 2007, for example).

Memories

Years ago, when I were young,
I walked through the fields of clover;
The birds were music to my ears,
As the white clouds above sailed over.

Along the dunes and sea shore,
I left footprints in the sand;
I followed by the dreams of youth,
And the day I became a man.

To hear the sea waves roaring,
As they hit the golden shore;
Will always live in memory,
In me forever more.

Those were the days of solitude,
With my face against the wind;
Will I ever find what I'm looking for, and-
The peace I seek within?
- Gray

As I left Judy's that day, I felt a sense of peace I had not felt in quite some time. Reflecting on it now, it was the first time I had allowed myself to open up to some of the heartbreak. It wasn't until I began to grieve for lives marred by injustice, for the loss of people I had grown to know and hold dear, and for those in the field I had to leave behind, that the words of this dissertation began to flow. I realized then that this dissertation had to be more than a recounting of research and studies, more than an analysis of findings and conclusions. I had been entrusted with the most personal and intimate of stories, this brought with it a responsibility that formed an integral part of this thesis.

Ethnography and Care at the End of Life in Prison

This dissertation has explored the experiences of men who are living with and dying from serious illness in prison, with a particular focus on the kinds of care they receive and the ways in which they experience that care. Based on ethnographic fieldwork conducted over fourteen months in men's state prisons in Maine, I sought to address three pressing questions: 1) how does the prison and market-based care shape the illness experiences of older prisoners and the trajectory of their lives; 2) how do prisoners experience and mediate dying in custody through relational peer-to-peer care; and 3) how might sensory ethnography elicit new ways of knowing and understanding life and death in prison? I probed these questions in three respective chapters, interlaced by illustrative interludes.

In the second chapter of the thesis, I outlined the ways in which privatized care influenced the experiences of older prisoners living with illness. Specifically, at the core of this chapter was the question, what does it mean when the lives of older prisoners collide with contracted for-profit medical care and how might their lives be constituted as unworthy of care? As the title of my second chapter reveals, amongst older prisoners and prisoners who are ill, there is tragic and pervasive narrative: "it's cheaper if you die." I drew out some of the applied stakes of my study, offering practical recommendations for corrections services and health care providers, including possibilities for peer-based caregiving.

In Chapter Three, I explored the experience of caring and being cared for in the context of a peer-centric prison hospice program. Through tracing Brady's journey, I discussed how hospice caring shapes and reshapes death and life in prison, wrenching power over experience away from the harsh carceral grip. I argued that peer hospice care constitutes a site of prisoner resistance to the custodial brutality and repression, but in doing so it represents a perverse form of escape from disciplinary efforts over life, and thus the penal apparatus and its actors endeavour to reassert control. This and the final chapter highlighted the ways in which control and care coexist and interact.

The final chapter of the thesis is inspired by sensory ethnography. It reflects an emerging body of carceral research that pushes the spirit of sensory anthropology into the field of criminology and the study of penality. I interrogated my sensorial subjectivity and tactility to explore the dissonant sensations of life, death, and relational disconnections and connections experienced in the Maine State Prison infirmary. I reflected on how the feel of Daniel's life and death in the disparate spaces of segregation and hospice offered new ways of understanding end of life in custody and the medical unit as a space of simultaneous brutality, beauty, indignity and intimacy.

To date, there remains limited anthropological research that examines the experiences of prison hospice patients and their caregivers in the United States and, to the best of my knowledge, this is the first anthropological ethnographic study of its kind. The dissertation also contributes broadly to anthropological understandings of prisons (e.g. Cunha, 2014; Fassin, 2017; Rhodes, 2001, 2004, 2009; Waldram, 2009) as well as emerging anthropological scholarship at the intersections of health and incarceration (e.g. Sue, 2019; Sufrin, 2017) and custody and care (Rhodes, 2004; Sufrin, 2017, 2019). To unpack the stakes in more detail, this dissertation lays out the dynamics of dying and care in prison and considers questions about how people experience the end of their lives in custody.

As a whole, the thesis sheds light on contours of care in prison, the precarity of relations and personhood, and points of friction between care and custody. In one sense, I approach ethnographic questions of penal health care through the lens of violence. I take inspiration Ticktin (2011), Biehl (2010) and Han (2012) whose various works emphasize the salience of a moral economy of care in contexts where people do not have access to regular health care or live in situations of uncertainty and crises. The legal precedent for biosocial inclusion is consolidated under longstanding structural violence (Biehl, 2010, p. 165) and care itself has become entwined in privatized neoliberal health care systems (see Lovell & Rhodes, 2014). Market-based penal health care is thus an extension of the violent carceral phenomena. In another sense, I attend to the ways in which prisoners negotiate illness and imprisonment through relational caring in a way that shapes and refashions penal power and life, drawing from the conceptual care work of Taylor (2008) and Seaman (2020). This thesis demonstrates different types of care and the interactions between them, and that punishment and compassion are not dichotomies but entwined and entangled in complex and intricate ways.

This focused attention on one state in the behemoth U.S. incarceration systems does not speak to the conditions throughout the country as a whole. The justice system in Maine is a confusing mix of repressive and progressive policies and practices that separates it from others. Maine has a comparatively small prison population (just over 1700 in 2020) and a small number of prisons (five, as DCF has since re-closed). There are no private prisons in the state. Maine also has one of the lowest incarceration rates in the country, which falls more than three times lower than the national average (147 per 100,000 adult residents compared to 492 per 100,000 residents). Maine's prisons also do not fit the narrative of the overcrowded "warehouse prison" (see for instance Irwin, 2005); all of its prisons currently sit "under capacity" (see Maine Department of Corrections, 2020), fewer people are being sent to prison, and the number of people being released is up (see Carson, 2015).[3] Maine is only one of two states in which all prisoners retain the right to vote; but this likely reflects the racial make-up of Maine's prisons. The majority of prisoners in Maine are white (81 percent), which "defuses the racial dimensions of felony disenfranchisement laws" intended to limit Black political power (Lewis, 2019). As noted in the introduction of this dissertation, Maine remains one of the few states that does not have parole and a restrictive "good time" scheme. Moreover, unlike most other prisoners in the U.S., who typically serve sentences of two years or more, in Maine any sentence over nine months warrants state prison time, and any person with three or more years on their sentence are ineligible for a minimum custody rating meaning they must be held in either maximum or medium security facilities. Consequently, many people are serving their sentences in some of the state's most restrictive prisons.

This thesis focuses only on the experiences of people who were living with a terminal or chronic illness and whose deaths were anticipated. There are certainly many

---

[3] Between 2013 to 2014, nearly 17 percent less people were admitted to prison, while the number of people released rose almost six percent over the same time period (Carson, 2015). The current MDOC administration has also made some effort over the past few years to release more people from its prisons (in order to channel the high cost of housing prisoners into its extremely limited programming budget).

other "kinds" of deaths in prison and those deaths demand to be examined. Dr. Homer Venters (2020) recently published "Life and Death in Rikers Island". I implore anyone who has generously spent time reading this dissertation to also read Venters' work, detailing the tragic and brutal deaths of people under the custody of the New York Correctional Service. He presents a compelling account of the deadly risks of incarceration. Venters also highlights many issues I witnessed or heard about, but out of concern for interlocutors (especially those who are still incarcerated) do not document in this dissertation. While this thesis cannot treat the full complexities of care nor its myriad forms in places of custody, it nonetheless offers a starting point for further examination and critical discussion about what constitutes care in prison and how it is lived by those in spaces of confinement.

Ways Forward

To quote Behar (1997), "[A]nthropology that doesn't break your heart just isn't worth doing anymore," she writes, concluding the "The Vulnerable Observer" (p. 177). The weight of "bearing witness" (Farmer, 2003) to life and death, casual cruelty and systemic injustice, inspire in me a commitment to social justice and applied work. To that end, in what follows, I discuss some ways forward.

In "The Experience of Dying in Prison" Nicole Pizzini (2013) writes, "In light of the fact that prison populations are growing at alarming rates, it is imperative for there to be a greater understanding of the experience of dying in correctional settings, particularly prison" (n.p.). There remains a significant lack of systemic solutions to the human crisis of dying in prison. The availability of hospice and/or palliative care programs in prisons is greatly overstated in the literature. With less than 80 known programs in more than 5000 custodial institutions, people are dying without access to appropriate care. In Chapter Two I offered some suggestions for correctional agencies. To briefly revisit these recommendations, I advocated for parallel efforts aimed at: 1) sentencing reform [e.g. the abolishment of determinate schemes and life-without-parole sentencing; increased (and accessible) systems and mechanisms for early release]; and 2) reinvention of what constitutes "correctional health care" in ways that fall outside of market-based models and independent of prison administration. In Chapters Three and Four, the dissertation opened up new imaginaries of care that include prisoners in the process to make humane life possible at the end in prison. At the heart of such programs are the prisoners, both those who are dying and those who provide care. What the caregivers and Kandyce accomplished for end-of-life care in Maine's prison system was remarkable. The program was a model for how prison programs could be run to include prisoners in the process in ways that are meaningful and matter to them, and there is a great deal that can be learned and applied from the hospice program in Maine.[4]

Peer-involved care moves in the direction of more "humane" custody (which has become a popular mantra among correctional services), but as Chavez (2015) implores,

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[4] State and correctional authorities depended on the program and the capacities of Maine Hospice Council and caregivers to implement and carry out more compassionate end-of-life care. Unfortunately in the time since my fieldwork, the relationship between the Maine Department of Corrections and the MHC has fragmented and the MDOC has taken over the hospice program. The reorientation and change in administration of the program signals an interventive shift in the conditions of confinement but not its repressive structure. Today, it stands as yet another program that has been absorbed into the system, though I remain hopeful that the program as it once was and the relationships it created will be restored.

"Even when hospice is 'successful' inside of prisons, this does not alter the fundamental problem of mass death – it merely shifts the discussion from challenging mass incarceration, toward the goal of providing 'humane' channels for death" (p. 6). It is crucial to "challenge the fundamental conundrum of mass death" as opposed to simply "alter[ing] its aesthetic and material surface" (Chavez, 2015, p. 3). Therefore, while we must work to reimagine end of life care for people in prison, we must simultaneously work to deconstruct the lethal legacy of mass incarceration.

Conclusion

> Loss, mourning, the longing for memory, the desire to enter into the world around you and having no idea how to do it, the fear of observing too coldly or too distractedly or too raggedly, the rage of cowardice, the insight that is always arriving late, as defiant hindsight, a sense of the utter uselessness of writing anything and yet the burning desire to write something, are the stopping places along the way. At the end of the voyage, if you are lucky, you catch a glimpse of a lighthouse, and you are grateful. Life, after all is bountiful.
>
> - Ruth Behar, 1997, p. 3

At the heart of this dissertation are the Maine State Prison hospice program and the caregivers who graciously invited me into their world. This study initially began as an exploration of their subjective experiences of caring in prison. But, tracing their care led me into the dark shadows of prison medical units and the largely hidden world of custodial health care. I observed day-after-day peer caregivers intervene in the everyday brutalities and dehumanization to foster life and personhood in custody; it was this story I felt compelled to tell in the pages of this dissertation.

This fieldwork was a profound time in my life. The experience of witnessing death and dying and being invited into a person's most vulnerable moments shifted both my ethnographic and human sensibilities. In many ways, and under the guiding and comforting wings of the hospice caregivers, I learned to become a “vulnerable observer” and to open myself up to death and care in custody. I am forever grateful to each person I encountered along this journey; you’ve all left a deep imprint on my heart.

Swanbird

I listen daily for the swan bird's song,
Each day it helps me move along.
How sweet to hear its melody,
And the lasting peace inside of me.

How sweet to hear the swan bird's song.
To say "farewell" as I move along.
Then at last my soul is free,
I know someday you'll follow me.

How sweet to hear the swan bird's song,
As she glides away on the quiet pond.
The sun is sinking lower now,
How sweet to hear the swan bird's song.

- Gray

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